

# Infected Blood Inquiry The Report

## **Response of Government**

- Document Destruction
- · Self Sufficiency Report
- · Lines to Take
- · Delay in Holding a Public Inquiry
- Accountability in the Absence of a Public Inquiry
- Scotland
- Northern Ireland and Wales
- The Government's Response to Calls for Compensation 2020-2024
- Commentary on the Government Response

7 of 7

20 May 2024 HC 569-VII

# Infected Blood Inquiry The Report

Presented to Parliament pursuant to section 26 of the Inquiries Act 2005.



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## **Contents**

7.1 Document Destruction	2
7.2 Self-Sufficiency Report	62
7.3 Lines to Take	105
7.4 Delay in Holding a Public Inquiry	130
7.5 Accountability in the Absence of a Public Inquiry	180
7.6 Scotland	198
7.7 Northern Ireland and Wales	249
7.8 The Government's Response to Calls for Compensation 2020-2024	261
7.9 Commentary on the Government Response	286

Contents 1

## 7.1 Document Destruction

This chapter examines evidence around the disappearance (and in some instances, destruction) of documents relevant to the HIV litigation; records of the Advisory Committee on the Virological Safety of Blood; and the Private Office papers of Lord David Owen.

#### **Key Dates**

**1988** Lord Owen's files record a note that his papers had been destroyed by the Department of Health as "*Normal procedure after 10 years*".

**1990 - 1991** relevant documents are identified as missing during the HIV litigation.

February - March 1993 registered GEB/1 files relating to ACVSB sent to the DRO.

**September 1994** registered file GEB/1 volume 4 is destroyed in advance of its review date.

**June 1995** Dr Rejman notifies Solicitor's Division that one of the ACVSB files "has apparently been destroyed."

May 1996 documents relating to the settled HIV litigation are identified as missing.

October 1997 - November 1998 remaining GEB/1 volumes are destroyed.

April 2000 report of the internal audit of missing ACVSB documents.

**March 2004** Department of Health informs Lord Owen that its review into self-sufficiency "does not address why papers from your Private Office at the time may have been destroyed."

April 2005 meeting between Nigel Crisp and Lord Jenkin to discuss missing papers.

#### **People**

**Lord Nigel Crisp** NHS Chief Executive and Permanent Secretary to the Department of Health (2000 - 2006)

**Justin Fenwick QC** counsel advising the Department of Health in HIV and Hepatitis C litigation

**Laurence George** internal auditor who carried out the investigation into the loss of the ACVSB papers under the supervision of William Burleigh, head of internal audit

**Anita James** junior solicitor (1981 - 1996) and head of civil litigation in the Department of Health's Solicitor's Division (1999 - 2005)

**Lord Patrick Jenkin** Secretary of State for Health and Social Services (1979 - 1981)

**Dr Jeremy Metters** Deputy Chief Medical Officer

**Lord David Owen** Minister of State for Health (1974 - 1976)

Dr Andrzei Reiman senior medical officer for haematology. Department of Health

#### **Abbreviations**

ACVSB Advisory Committee on the Virological Safety of Blood

**DRO** Departmental Records Office

**GEB** General Blood files

Three separate sets of documents have been lost or destroyed. They are files of documents relevant to the HIV litigation (some were lost prior to 1990, some after the litigation ended); the minutes and background papers of the Advisory Committee on the Virological Safety of Blood ("ACVSB") in particular from 1989-91 (probably two separate sets of the same documentation); and the Private Office papers of Lord David Owen. What took place when Lord Patrick Jenkin sought access to documents has to be considered for the light it may shed on these three losses of documentation.

It is not always clear from the contemporaneous materials which set of documents is being discussed and there was some confusion within the Department of Health when discussing which documents were missing and what had happened to them. Different sets of documents and the reasons for their disappearance were frequently discussed interchangeably.

Professor John Cash separately alleged that there had been documents which were destroyed but the Inquiry has been unable to identify any further information about this.<sup>2</sup>

Dr Archibald Prentice who was president of the British Society of Haematologists (2002-2004) and president of the Royal College of Pathologists (2011-2014), and who had treated people with haemophilia in Plymouth in the 1980s, also told the Inquiry about a visit from DHSS officials in the 1980s to Plymouth, where he was a consultant haematologist:

"I was visited in Plymouth by three Civil Servants or Lawyers representing the Department of Health & Social Security in the 1980s. They went through all of my papers and expressed surprise that our concerns in relation to blood supplies were kept well documented in the correspondence I had retained and the copies of papers from medical journals. I understood this was happening across England and Wales. My recollection is that they removed some papers which were never returned but I am not clear at this great remove. I do not recall receiving any written report from the Department of Health about that visit." 3

## Applicable principles and guidance for retention of documents

A distinction needs to be made between documents which were part of the departmental records, and documents which, though official, were held by senior civil servants (in particular by Dr Jeremy Metters, the Deputy Chief Medical Officer ("DCMO")), by ministers (in the present context Lord Owen and Lord Jenkin) and by the Department of Health. The days of typescript and carbon paper are no longer familiar. At the time most of the records in question were created they were in paper format. Such documents occupied considerable space. It was understandable, therefore, that there should be some system for providing for the destruction of some documents which were of lesser importance in order to make way

In addition to these sets of documents, there are multiple examples of individual documents (including submissions, briefings, minutes, and letters) that are missing – but there is no realistic prospect of being able to identify why such individual documents can no longer be located.

<sup>2</sup> Note of John Cash and Davies Arnold Cooper meeting 17 January 2000 p1 NHBT0036250 034

<sup>3</sup> Written Statements of Dr Archibald Prentice para 112 WITN5422001 and paras 2-5 WITN5422002

for more current documents, or more important ones, and to avoid exhausting the available storage space. However, documents which remained of importance or were likely to do so, would have to be kept in conditions in which they could easily be retrieved for further use or reference if need be.<sup>4</sup>

Thus in 1971 a Guide for Departmental Records Officers set out the importance of being able to provide "departmental officers with speedy access to papers, which requires that these are kept in a good physical state and stored in an orderly manner so that they can be readily traced." The departmental records officer was to ensure "that Reviews are systematically carried out, so as to reduce the bulk of records in his custody, while ensuring that no papers likely to be required for permanent preservation are destroyed." The guidance stated that one of the "fundamental requirements" is "that all papers created in, or received into, the Department that require registration are brought within the registry system."<sup>5</sup>

To deal with the removal of documents which were potentially no longer useful, the Guide provided that there should be two reviews. The first review of papers was to take place no later than five years after the last document in the file. At this first review stage, "the reviewer is deciding whether the record is likely to be required any longer for the department's use. He must constantly bear in mind that 'departmental purposes' include the possibility of the file being required as a precedent or as a guide to action if similar circumstances arise in the future, and he must guard against destroying papers simply because those activities of the department which they record have ceased."

A second review of papers was required 25 years after the files were opened to determine whether they should be retained for permanent preservation with "comparatively few files ... still ... needed for administrative use, and it will be possible, while first-hand knowledge of the business recorded by the files is still available, to look at them in perspective."

The Guide also recorded that papers in the private offices of ministers should be carefully considered to ensure that those which were public records were dealt with through the approved procedures, and that "In most Departments Private Office papers are duly registered, but a DRO must maintain close liaison with his Minister's private secretaries, to ensure the segregation of private correspondence from official papers so that when a Minister

<sup>4</sup> Including for the public record.

<sup>5</sup> Public Record Office A Guide for Departmental Record Officers 1971 p7 WITN0001013

Public Record Office A Guide for Departmental Record Officers 1971 p7 WITN0001013. The Guide noted "Though the date recommended for First Review is 5 years after the files have passed out of active use, strict uniformity is not essential."

Public Record Office A Guide for Departmental Record Officers 1971 p8 WITN0001013. It was perhaps optimistic to think that much first-hand knowledge of the business recorded by the files would still be available particularly within the more recent years of the Civil Service when civil servants have tended to move from one post to another with some frequency. The Guide did note: "It may be practicable to undertake a Second Review of certain series earlier than 25 years, and in some cases there are advantages in dealing with blocks of years together."

relinquishes office the disposal of his papers is in accordance with the recommendations of the Grigg Committee."8 No further detail was given.9

From 1994 the Department of Health's record management guidance was "For the Record", with a short leaflet for staff and longer guidance for records managers and reviewing officers. <sup>10</sup> However, some witnesses had no recollection of this guide, nor did they recall any training or induction process which dealt with records management. <sup>11</sup>

This 1994 guide for record managers and reviewing officers set out how to complete the front cover of the file. On it there was a box for completion: the "*Branch Review Decision box*". It had to be completed before the file was dispatched to the Departmental Records Office ("DRO").<sup>12</sup> An index slip or file docket also had to be completed and was stored separately from the file: "*There is no point in having a file if no one knows it exists or where it is.*"<sup>13</sup>

The 1994 guide says that "Officially, files are recommended for review two years after the date of the last action. In practice some branches do not have sufficient storage space to

- 8 Public Record Office A Guide for Departmental Record Officers 1971 p9 WITN0001013
- The Grigg Committee (1954) recommended as follows: "The most important of a Department's papers for which separate arrangements are normally made are those kept in the offices of the Minster and the Permanent Secretary ... It is general, but not universal, practice for Ministers' letters and minutes dealing with general policy matters to be enclosed within files which are registered under normal Departmental registration arrangements. We would not wish to prescribe any universal procedure for dealing with these various types of papers, but would point out that they should not be overlooked when a Department compiles its detailed reviewing procedure. Probably the most satisfactory method of dealing with any of the papers that are registered would be to bring them within the scope of the arrangements to be made for the reviewing of the Department's registered papers generally ... We recommend that Private Secretaries should work in close contact with the Departmental Record Officers over the arrangements to be made for the handling of their Minister's papers." Committee on Departmental Records Report July 1954 p34 WITN0001012. During the bovine spongiform encephalopathy ("BSE") Inquiry (March 1998 to October 2000) a number of former ministers who gave evidence to the BSE Inquiry were critical about the fact "the actual papers they had seen and written on when in office had not been preserved." Written Statement of Brendan Sheehy para 35 WITN0001015. The Department of Health's evidence to the BSE Inquiry was: "The submission received in the Ministers Private office is the 'original'. During the period covered by the [BSE] Inquiry there were no specific instructions to Private Office staff about which papers should have been kept for the permanent record and it has become clear that many of the original papers seen by Ministers have been destroyed. In practice, once the Minister's decision/comment has been communicated to the relevant officials, these papers were usually retained by the Private Office, in case they needed to refer to them again. Private Office papers were 'weeded' periodically, often during the Parliamentary recess, and it was at this stage that a decision would have been made about the need to return papers to the originating section." The Department of Health could not confirm that the original submissions would have been returned to officials for retention, and was now "looking at the arrangements for review, retention and archiving of these documents and associated working practices." Memo from Department of Health to BSE Inquiry February 1999 pp2-3 WITN0001017
- A guide for records managers and reviewing officers 8 March 1996 WITN0001002, Memo from Graham Hart to all Department of Health staff 16 May 1994 WITN6955036. His message stated that "As a start each member of staff needs to be aware of their responsibility and the accompanying leaflet 'For the Record' is being issued to you and all members of the Department."
- Though the training may not have been memorable, as the audit discussed later in this chapter suggested. Internal Audit Review: Hepatitis C Litigation April 2000 p7 NHBT0000193\_137
- A guide for records managers and reviewing officers 8 March 1996 p15 WITN0001002. In 1987, the Department of Health and Social Security DRO file store moved from London to Nelson, Lancashire. Until 1996, records management was undertaken by Department of Health officials. Hays, a private company, was then contracted to undertake all record management on behalf of the Department of Health. Written Statement of Brendan Sheehy paras 10-13 WITN0001001
- 13 A guide for records managers and reviewing officers 8 March 1996 p16, pp19-20 WITN0001002

hold files for this long."<sup>14</sup> It explains that the Branch Review Decision box "is used by the person reviewing the file with a view whether to destroy it, retain it for a short period or for a long period. Each registry decides with the DRO at what stage a branch will review files. If a branch reviewing officer considers a file should be kept, a minute is placed on the file giving brief reasons for the decision and the front cover filled in. The file should then be returned to the appropriate registry."<sup>15</sup> The guide records that a branch reviewing officer must be executive officer grade or above and the files must be sent to the branch reviewing officer by the registry officer to decide whether they are to be destroyed at first review or retained for second review. A decision to destroy at first review "is made when files have no further administrative value at all; or only a short to medium term continuing administrative need. If the file has no further administrative value, then it may be destroyed two years from the date of the last document. If it has limited administrative value, it may be spared destruction until any date between 2-15 years from the date of the last document."<sup>16</sup>

A document should have been marked to be retained for a second review where the document was "likely to be needed for long term administrative reasons; or have potential historical or research value."<sup>17</sup> This would be the case where the files held details of:

"the DH's [Department of Health] history, its organisation and procedures; the formulation of policy and legislation or, more selectively, its implementation and interpretation; notable events or persons not available elsewhere; major events, developments or trends in political, social or economic history; scientific technological and medical developments; ... statistical or quantitative research useful for demographic, medical, social or economic history." <sup>18</sup>

Documents marked for second review were then to be kept for 25 years.<sup>19</sup>

Thus a branch reviewing officer would make the decision, on those grounds, whether to mark a file for second review or whether it could be destroyed at an appropriate date between 2 and 15 years after the last action on the file.<sup>20</sup>

## **HIV** litigation files

#### Documents missing by the time of the HIV litigation (1990)

Disappearance of documents related to infected blood products first came to note during the course of the HIV litigation between 1989 and 1991. When the plaintiffs in that litigation presented a summary of their central complaints in June 1989 the first of these to be

- 14 A guide for records managers and reviewing officers 8 March 1996 p33 WITN0001002
- 15 A guide for records managers and reviewing officers 8 March 1996 p15 WITN0001002
- 16 A guide for records managers and reviewing officers 8 March 1996 p34 WITN0001002
- 17 A guide for records managers and reviewing officers 8 March 1996 p34 WITN0001002
- 18 A guide for records managers and reviewing officers 8 March 1996 p35 WITN0001002
- 19 A guide for records managers and reviewing officers 8 March 1996 p34 WITN0001002
- 20 See also Written Statement of Brendan Sheehy WITN0001015

mentioned was delay in achieving UK self-sufficiency in Factor 8 concentrate. The third was "using Factor VIII concentrate derived from bought blood as opposed to donated blood" — which might be seen as another way of addressing the same point.<sup>21</sup> Many of the documents relating to "self-sufficiency" were found missing in 1989 and shortly after.<sup>22</sup>

Less than 20 years had passed since 1970 before the HIV litigation began. Applying the approach indicated by the Guide for Departmental Records Officers (1971) much of the material was likely to be needed for long-term administrative reasons or have potential historical or research value including the formulation of policy and legislation or its implementation and interpretation. Anita James, then a junior solicitor assigned to deal with the litigation on behalf of the Department of Health, told the Inquiry that she understood that if papers were "particularly important, contained policy review or even very, very occasionally had historical importance, I'd put something like 25 years on for -- 20 years, 25 years for review, and then, again, destruction would be decided upon after that." Whether applying the 1971 Guide, or Anita James' understanding of the general principles, documents relating to self-sufficiency should not yet have reached second review. In short, they should have been accessible and recoverable. Yet many were not.

It is deeply regrettable, and of significant concern, that documents touching on a central thrust of the case for people with bleeding disorders who had been infected with HIV should have been so thin on the ground by 1990.

The process of what was then known as "discovery"<sup>24</sup> in legal cases was a process whereby each party was obliged to identify the documents which it had, or had had, in its custody, possession or power which were relevant to an issue or issues in the case. They had to do so by listing the documents they had, or had had, but could claim an immunity against discovery if it was contrary to the public interest to disclose the documents concerned.<sup>25</sup> At a conference with counsel on 18 May 1990 in relation to the HIV litigation, Andrew Collins QC, who was acting for the Department of Health, is recorded as saying "we had not yet sorted out the documents on public interest immunity (PII). We must stop destruction on the date the litigation comes on. Hepatitis virtually nothing. Most of it has already been destructed [sic]."<sup>26</sup> Justin Fenwick QC, then the junior barrister in the litigation, stated in his written evidence to the Inquiry that "as written it makes little sense to me." He stated that both he and Andrew Collins QC "would have been well aware of the duty to preserve documents and we are likely to have advised that all documents which still existed and

<sup>21</sup> Letter from Dr Andrzej Rejman to Dr Harold Gunson 24 August 1990 p22 NHBT0000086\_012. If there had been self-sufficiency there would have been no need to import concentrate made from plasma which had been bought: there would have been enough made from locally sourced plasma from voluntary donors.

<sup>22</sup> As set out below.

<sup>23</sup> Anita James Transcript 13 September 2022 pp10-11 INQY1000239

<sup>24</sup> Now known as "disclosure".

<sup>25</sup> Public interest immunity, or "PII" for short.

<sup>26</sup> Emphasis added. Note of conference on public interest immunity 18 May 1990 DHSC0043223

which were relevant or potentially relevant must be preserved until the conclusion of the litigation and that routine document destruction policies should therefore be suspended."<sup>27</sup>

Even at that point, the stage of discovery during the HIV litigation, it seemed that documents were missing. A minute on 23 May 1990 recorded that an official had searched their files for documents relevant to the litigation but had been unable to find "copies of [Public Expenditure Survey] bids from 1975 to 1986 and the history of their success or otherwise. I understand that many if not all of these papers have been destroyed."<sup>28</sup>

After a meeting with counsel on 5 June 1990, a note was made recording that "Dr Williams<sup>29</sup> suggested checking minutes of the Hepatitis Advisory Board held in DHSS, and of which he was a member. [I have checked this out with administrators who believe that all these minutes have been destroyed]."<sup>30</sup>

Another minute on 29 August 1990 recorded that the original search of the database had made it known that a relevant file "existed even though it did not appear on the database or on the file checking system. Despite extensive searches ... the file never materialised and so it was assumed that it had been destroyed: it was therefore not declared" during the discovery process. The memo stated that it had recently been found together with another "previously unknown file". The law at the time required a party automatically to give discovery of all documents which "are or have been in their 'possession, custody or power' relating to matters in question in the proceedings." This included giving discovery of documents which might only lead to a train of enquiry enabling a party to advance their own case or damage their opponent's case. It is unwise to read too much into a minute to the effect that a document which was known to have been in existence was "not declared." It should have been declared, in a list of those documents which had been but no longer were in the possession, custody or power of the defendant, if it was not.

The "dearth"<sup>33</sup> of relevant documentation made the piecing together of the factual narrative and formulating the defence more challenging for counsel. Justin Fenwick QC recalled "I do know that we were disappointed by how comparatively little material there was and consistently asked for further searches".<sup>34</sup>

The departmental officials who attended consultations with counsel would have been left in little doubt that the documentation was disappointingly limited. They would have understood this was probably because relevant documents had been destroyed. They would also have

8

<sup>27</sup> He was on the verge of "taking silk" to become a QC: he was a very senior barrister. Written Statement of Justin Fenwick QC para 18.3 WITN7067001

<sup>28</sup> Memo from J Wheeler to John Canavan 23 May 1990 DHSC0046951\_015

A hepatologist instructed by the Department of Health as an expert witness.

<sup>30</sup> Note on meeting held on 5 June 1990 MHRA0017575

<sup>31</sup> Memo from R K Alder to Dr Jefferys 29 August 1990 DHSC0003963 064

<sup>32</sup> Rules of the Supreme Court 1965, SI 1965 No 1776, Order 24(2).

The word is that of Justin Fenwick QC. Written Statement of Justin Fenwick QC para 18.4 WITN7067001

Written Statement of Justin Fenwick QC para 18.5 WITN7067001

been aware that both counsel had considerable experience in acting for government and government bodies, and their reaction suggested not only disappointment but that the lack of documents stood out unfavourably as particularly unusual in their experience.

It was reasonably to be expected that care would be taken to preserve such documents as remained for use in the litigation, and other documents in the field of blood policy which might be needed to address ongoing campaigns by the Haemophilia Society and other groups who felt they had been failed by those people and bodies responsible for their treatment. Indeed, not long after the HIV litigation ended, it appears that civil servants in the Department of Health and lawyers in the Solicitor's Division were aware that what had happened in relation to infected blood remained controversial and could well lead to further litigation.<sup>35</sup>

#### After the HIV litigation: initially, all the files for the litigation still available

When the HIV litigation was settled, it was a term of the settlement agreement that all the documents that had been given to the plaintiffs by any defendant should be returned or destroyed within 28 days of acceptance of settlement.<sup>36</sup> However, at the end of the litigation, some solicitors' firms acting for the plaintiffs held on to documents to use them for the HIV transfusion litigation which remained afoot. Initially, there does not appear to have been much concern within the Department of Health about this,<sup>37</sup> but subsequently some concern was expressed about retaining control over who had access to the documents and possible leaks to the media.<sup>36</sup> The Central Blood Laboratories Authority was more concerned and objected to the provision of their documents from one solicitors' firm to another in what they viewed to be a contravention of the settlement agreement.<sup>39</sup> The plaintiffs solicitors' use of documents also expanded to include mooted hepatitis litigation.<sup>40</sup> Subsequently a court order was made allowing the use of documents in the hepatitis litigation where those documents had been received from the Department of Health but not from the Central Blood Laboratories Authority.<sup>41</sup> That is why at a later point in time, documents had been kept by, and could be retrieved from, solicitors for the plaintiffs.<sup>42</sup>

So far as HIV litigation files held by the Department of Health are concerned, as at 7 December 1992 it was believed that the files were still intact and available should they be required – in a handwritten note on a memo discussing the Arms to Iraq Inquiry, Dr Andrzej Rejman

- In a draft minute to the Permanent Secretary, Anita James (who drafted it, albeit it is expressed as if she were a third person) wrote: "At a time in the mid nineteen nineties when the Department thought it was going to be a major party in litigation, counsel, Justin Fenwick QC advised us to be prepared."

  Draft briefing from Marilynne Morgan to Chris Kelly 3 March 2000 p2 WITN5426205, Written Statement of Anita James para 4.91 WITN5426001
- 36 HIV Haemophilia Litigation: The Main Settlement Agreement 26 April 1991 p20 DHSC0001942
- 37 Memo from Ronald Powell to John Canavan 15 October 1991 DHSC0002900\_002, Letter from John Canavan to Ronald Powell 15 May 1991 DHSC0038940
- 38 Letter from John Canavan to Ronald Powell 23 October 1991 DHSC0003640 046
- 39 Letter from Angela Robertson to Dr Richard Lane 30 October 1991 BPLL0016045 066
- Telephone attendance note 4 December 1991 CBLA0000068\_009. The fact that litigation in respect of hepatitis was likely was no secret.
- 41 HIV Haemophiliac Litigation 11 December 1991 DHSC0002656 001
- 42 Written Statement of Carol Grayson paras 122-123, paras 153-154 WITN1055004

asked John Canavan and Ronald Powell to "ensure that any papers we have in respect of the PII disclosures are kept secure and not destroyed." 43

However, some of these HIV litigation files have since gone missing. It is unclear precisely when this occurred. The facts which relate to this are set out later in this chapter, after looking, first, at the one area where it is known for certain that files (relating to infected blood but not centrally to HIV) actually were destroyed since this may shed light on what may have caused the loss of the HIV litigation files. The immediate cause of the destruction of these other files was that someone within the Department of Health had asked that this should happen. It concerns files most centrally relating to Hepatitis C, and in particular screening for it.

## Minutes and background papers of the Advisory Committee on the Virological Safety of Blood ("ACVSB") found to be missing in 1995

When a class action in respect of Hepatitis C was mooted there was substantial publicity about the issue, and various responses were planned by the Government, the extent and adequacy of which are addressed elsewhere in this report.<sup>44</sup> An early question was whether the number of people "who might have been saved from infection" could be estimated and it was for this reason the ACVSB papers were asked to be turned up.<sup>45</sup> (ACVSB papers were confidential, and so would not have had a wide circulation when first produced: it might be thought that this was all the more reason to take care to retain them in a manner accessible to the Department of Health should it need them).

On 10 February 1995, Roger Scofield noted that "Having got the major part of the response package moving, we now need to address the issue of negligence." He sought to set in place a process of discovery of relevant papers and records in order to ascertain whether there had been negligence. The need for a chronology of events, supported by the "key papers" including the ACVSB records, was identified as an early action both in preparation for the anticipated legal disclosure exercise and to assist in identifying the numbers of people who might have not have been infected if there had been an earlier screening or

<sup>43</sup> Memo from Dr Robert Hangartner to Dr John Reed 7 December 1992 DHSC0017883. Dr Rejman was a senior medical officer for haematology in the Department of Health and the Medical Secretary to the ACVSB. Written Statement of Dr Andrzej Rejman 26 March 2021 para 8 WITN4486001. John Canavan was head of the section responsible for blood policy and the administrative secretary to the ACVSB. Written Statement of John Canavan para 1.22 WITN7115001. Ronald Powell was a solicitor for the Department of Health. Lord Justice Scott's Inquiry was into the Export of Defence Equipment and Dual-Use Goods to Iraq and Related Prosecutions, part of which examined (and criticised) the Government's use of public interest immunity in litigation.

The possibility of litigation under the Consumer Protection Act 1987 and European law to similar effect was foreseen in 1988 by Professor Cash and the SNBTS regional transfusion directors. Testing Blood Donors for Non-A, Non-B Hepatitis: Irrational Perhaps But Inescapable 4 July 1987 PRSE0001444

<sup>45</sup> Memo from Roger Scofield to T Kelly 7 February 1995 WITN5426003. The ACVSB first met in April 1989.

Memo from Roger Scofield to Charles Blake 10 February 1995 p2 WITN4486008. Roger Scofield oversaw the blood policy team after a reorganisation in 1992. Written Statement of John Canavan para 1.11 WITN7115001

testing date.<sup>47</sup> Roger Scofield identified the need to look for papers "which either relate to possible claims for negligence (judged from the perspective of the recipient and not from our own) and also for papers which, if exposed in public, might be used to ridicule the way in which the service is managed or decisions on safety are taken."<sup>48</sup>

Dr Rejman was apparently unhappy about the work that was involved in making disclosure of documents. He sent several memos expressing concerns about the length of time the discovery work would take and his reluctance to do it without a formal instruction from Dr Metters, the DCMO.<sup>49</sup> Dr Metters gave that instruction.<sup>50</sup>

On 19 May 1995 Dr Rejman confirmed to Anita James that he had gone through all of his files and was "now part way through the official files held by Mr Burrage" relating to the period of 1989-1991.<sup>51</sup> No mention was made of having identified that any documents had been destroyed at that stage.

However, on 7 June 1995, Dr Rejman wrote to Anita James and stated "I have gone through all my files and have gone through the files made available to me by Mr Burrage, GEB<sup>52</sup> vols 1-14. Unfortunately, vol 4 for part of 1989 has apparently been destroyed. Mr Burrage has asked for the individuals responsible to write to him formally confirming this."<sup>53</sup>

It is somewhat unclear whether Dr Rejman was looking at the registered files GEB/1 volumes 1-14 or whether they were copies kept by David Burrage separately. Dr Rejman's contemporaneous minute is difficult to reconcile with the DRO dockets for the files. These show that all the GEB/1 files had been sent to the DRO repository on 9 February 1993 (or perhaps 30 July 1993), other than volumes 16 and 17 which were sent there on 17 March 1993.<sup>54</sup> There is no reference to them being recalled by Dr Rejman in 1995 and the subsequent audit report in 2000 noted that an outstanding question was why they had not been recalled.<sup>55</sup> Dr Rejman states that he looked at the "official GEB file series"<sup>56</sup> and that "these volumes were held locally, and so the question of recalling them from the DRO did not arise."<sup>57</sup> In his oral evidence he recognised that the files had been sent to the DRO and

- 47 Memo from Anita James to Dr Rejman 31 March 1995 WITN4486010
- 48 Memo from Roger Scofield to Dr Rejman 12 April 1995 p3 DHSC0006352 081
- Written Statement of Dr Andrzej Rejman 26 March 2021 para 2 WITN4486001. Memo from Dr Rejman to Roger Scofield 13 April 1995 WITN5426015, Memo from Dr Rejman to Roger Scofield 13 April 1995 WITN5426016
- 50 Memo from Dr Metters to Dr Rejman 26 April 1995 WITN5426017
- Memo from Dr Rejman to Anita James 19 May 1995 WITN4486011. David Burrage was a higher executive officer in the blood policy team (1992-1995). Written Statement of David Burrage para 2.1, paras 4.2-4.4 WITN7149001
- 52 GEB refers to "General Blood". Written Statement of Lorraine Jackson para 3.3(I) WITN7193001
- 53 Memo from Dr Rejman to Anita James 7 June 1995 p1 DHSC0200022 002
- 54 Email and attachments from Steve Wells to Zubeda Seedat 13 July 2007 pp11-14 DHSC0014975 033
- 55 Internal Audit Review: Hepatitis C Litigation April 2000 p6 NHBT0000193 137
- Written Statement of Dr Andrzej Rejman 26 March 2021 para 29 WITN4486001, Dr Andrzej Rejman Transcript 11 May 2022 p183 INQY1000204
- 57 Written Statement of Dr Andrzej Rejman 26 March 2021 paras 30-31 WITN4486001

thought that perhaps David Burrage had had them recalled.<sup>58</sup> Dr Rejman did not know what steps David Burrage took to get the GEB/1 files and provide them to him.<sup>59</sup> Dr Rejman did not notice anything on the other files that alerted him to the fact that they had been labelled for destruction and his view was "I would have noticed anything obvious suggesting they were to be destroyed, as I understood their importance to discovery in the hepatitis C litigation."<sup>60</sup>

The request from David Burrage to individuals formally to confirm destruction of GEB/1 volume 4, and any response, has not been identified by the Inquiry. David Burrage was unable to recall who the individuals were whom he believed had been responsible for the destruction of the documents. Initials on some of the file dockets were JR. However, John Rutherford, who had been in the blood supply team, could not recall sending or being instructed to send the files for destruction; it is not his handwriting on the file dockets. Rather it appears that the JR initials may have been of the person at the DRO who confirmed the destruction of the documents. The information that David Burrage requested individuals to write to him was not provided to Laurence George for the internal audit that took place in 2000, and consequently David Burrage was not asked about it during that investigation.

In 1995 when the files were identified as missing, Anita James could not recall doing anything at that time to reconstruct the contents of those files. However, I note that Anita James was, at this time, a relatively junior solicitor, who would have been supervised by other more senior lawyers that the Inquiry did not have the benefit of hearing from. On 19 June 1995, Anita James provided an update to the Parliamentary Under-Secretary of State, Tom Sackville, and reported that Dr Rejman had "sent me a list of documents covering the three years [1989-1991]. They run into some 14 volumes." She was unable to recall for the Inquiry whether these 14 files were ever provided to her. However, the evidence before the Inquiry suggests that in June 1995 Dr Rejman sent over two lists. The first, on 7 June, contained a list compiled by him during the previous five weeks, some 50 pages long, of Hepatitis C litigation documents from 1989-91 in relation to blood transfusion. These contained various

- 59 Dr Andrzej Rejman Transcript 11 May 2022 p188 INQY1000204
- 60 Written Statement of Dr Andrzej Rejman 26 March 2021 para 32 WITN4486001
- Written Statement of David Burrage para 9.5 WITN7149001

- Laurence George was a higher executive officer in the Internal Audits Department, Department of Health. His report is dated April 2000, albeit with a correction identified in March 2007. Internal Audit Review: Hepatitis C Litigation April 2000 NHBT0000193\_137, Correction to Internal Audit Report March 2007 DHSC0046961 071
- Written Statement of Laurence George para 3.71 WITN6963001
- Anita James Transcript 13 September 2022 p34 INQY1000239
- 66 Memo from Anita James to Andy Hollebon 19 June 1995 WITN4486017
- Written Statement of Anita James para 2.27 WITN5426001

Dr Andrzej Rejman Transcript 11 May 2022 pp186-188 INQY1000204. There is an apparent contradiction in this, because documents would not need to be recalled if they were held locally: and if held locally, could not have been recalled unless they were copies. It is possibly a failure of recollection after some 25 years.

Written Statement of John Rutherford paras 3.22-3.23 WITN7224001. John Rutherford was a higher executive officer in the blood policy team (1991-1993). Written Statement of John Rutherford para 2.2, paras 3.1-3.8 WITN7224001

ACVSB papers.<sup>68</sup> The second consisted of papers extracted from the HIV litigation papers, rather than the papers in their entirety.<sup>69</sup>

Advice in the litigation was sought but nothing further appears to have happened in relation to the missing ACVSB minutes until October 1996. Anita James accepts that when she was told that GEB/1 volume 4 had been destroyed, "we should have insisted that files were better looked after" and that she, David Burrage and Dr Rejman should have made "sure that anybody involved in the management of those files understood that they were important, and even if they didn't know the contents of the files themselves, that they were important and that they should be kept and have a long, first of all, review date."<sup>70</sup>

In May 1996, Anita James moved departments and handed over to Ruth McEwen.<sup>71</sup> Initially, Ruth McEwen sought to find the missing ACVSB files. However, on 1 October 1996 Margaret Jackson-Roberts, a senior executive officer, told her that she had spoken to David Burrage "who asserts that when he left CA-OPU<sup>72</sup> a year or so ago all relevant files were located together in one filing cabinet. So if any is now missing he cannot account for either why that should be or the possible location."<sup>73</sup> She told Ruth McEwen that she would get her part-time executive officer to start searching for the files.

Even then, the registered files were not recalled from the DRO. If they had been it would have been discovered that registered file GEB/1 volume 4 had already been destroyed on 29 September 1994,<sup>74</sup> before the date that had been set for its branch review on 19 July 1995.<sup>75</sup> The other GEB/1 files had undergone branch review on dates between December 1994 and April 1997 but were not destroyed until between October 1997 and November 1998.<sup>76</sup> Therefore if the files had been recalled in September 1997, or earlier, the short document destruction dates could have been identified; and the latest files to be destroyed would not have been.

- 68 Memo from Dr Rejman to Anita James 7 June 1995 DHSC0200022\_002, Hepatitis C Litigation Documents 1989-1991 Blood Transfusion 7 June 1995 WITN4486015
- 69 Memo from Dr Rejman to Anita James 23 June 1995 WITN5426022
- 70 Anita James Transcript 13 September 2022 pp42-44 INQY1000239
- 71 Memo from Anita James to Ruth McEwen 18 March 1996 WITN5426072. She gave as reasons that she was "facing significant issues at work ... Both in terms of workload and bullying by the manager." Anita James Transcript 13 September 2022 p56 INQY1000239, Written Statement of Anita James paras 6.41-6.44 WITN5426001. No further details were asked of her, but this should be borne in mind to her advantage when considering criticisms that are made later in this chapter about her performance.
- 72 Corporate Affairs Operational Policy Unit which included the blood policy team.
- Margaret Jackson-Roberts was a senior executive officer. Email from Margaret Jackson-Roberts to Ruth McEwen 1 October 1996 WITN5426333
- 74 List of the Department of Health's deleted and destroyed forms p3 DHSC0200022\_007
- 75 Email and attachments from Steve Wells to Zubeda Seedat 13 July 2007 DHSC0014975 033
- Email from Annette Greenwood to Laurence George 31 March 2000 WITN6955044, List of the Department of Health's deleted and destroyed forms p1, pp3-6, pp9-12 DHSC0200022\_007. On looking carefully at the copies of the file dockets, what could be read as November 1996 is probably November 1998. The first reference quotes the range from November 1996 to March 1998, but David Burrage in his statement reads the dates as the Inquiry does; however, it is right to mention this possible discrepancy. It makes the failure to take earlier action to recall the files more regrettable still if the dates are read as the Inquiry thinks is more likely.

It is also plain, from what follows, that until his retirement in August 1999 Dr Metters, who had chaired the ACVSB, had kept substantial records. He was said to be meticulous.<sup>77</sup> Those of his records that related to the ACVSB were destroyed shortly after his retirement.<sup>78</sup> It thus followed that neither the minutes nor, perhaps more importantly, submissions, papers and surrounding correspondence were recovered. They were no longer available to plug the gap(s) in the registered files. If those gaps had been identified at that stage, as they probably would have been if the files had been recalled earlier, Dr Metters' files would probably have still been available to fill them. Yet in little more than three months not only were registered files relating to proceedings before the ACVSB found to be missing but so too were what were probably complete copies of those files. Whether this was a surprising and unfortunate coincidence, or something more sinister, is discussed below.

Charles Lister in his evidence said that the documents "shouldn't have been marked for destruction at all, so the dates are almost irrelevant. But yes, it makes no sense that they were marked for destruction at any stage."<sup>79</sup>

In short, file GEB/1 volume 4 should not have been destroyed at all. But in any event it should not have been destroyed in advance of its review date. The instruction to destroy it overrode the earlier instruction to review. None of the other files should have been destroyed either.

On 17 November 1999, the Department of Health were notified of a draft application for third party disclosure of documents by the claimants in the Hepatitis C litigation<sup>80</sup> and decided to agree to voluntary disclosure.<sup>81</sup>

This led to further work to identify documents and particularly the ACVSB minutes. Anita James (who by now had returned in a more senior role as head of civil litigation)<sup>82</sup> wrote a minute to Dr Metters on 23 November 1999 stating that the Department of Health planned to consent to the application for third party disclosure. She said that "I do not have skeletons in my cupboards just old files. One has come back to haunt me – Hepatitis C … I understand from Yvonne de Sampayo that she has no records on the subject beyond 1997. I wondered if

14

<sup>77</sup> Written Statement of Yvonne de Sampayo 5 September 2022 para 33 WITN7194001

The circumstances of the disappearance of these files have given rise to at least two very different recollections, which are examined further below.

<sup>79</sup> Charles Lister was head of the blood policy team from 1998-2003. Charles Lister Transcript 8 June 2022 p140 INQY1000212

Legal application notice to the High Court of Justice Queen's Bench Division regarding the Hepatitis Litigation 17 November 1999 WITN5426122, Draft court order in the case of *A and Others v National Blood Authority* 15 November 1999 WITN5426123. Third party disclosure is a process whereby documents can be asked for from a person or body who is not themselves a party to the litigation. The Department of Health was not a direct litigant in the case relating to hepatitis brought against the National Blood Authority, though obviously ultimately responsible for what had taken place in the screening of blood for non-A non-B Hepatitis and then Hepatitis C.

<sup>81</sup> Email from Anita James to Charles Lister 22 November 1999 WITN5426131, Email from Anita James to Charles Lister 23 November 1999 WITN5426134

<sup>82</sup> Although Anita James had returned to a more senior role, it remains the case that she would have been supervised by others who were more senior than her. However, the Inquiry has only heard from her from the Solicitor's Division.

you, by chance, had kept any records yourself."83 The evidence before the Inquiry suggests that this should read "before 1997."84

She no doubt asked him this because he had been chair of the ACVSB, and the proceedings of that Committee were confidential, so it must have seemed likely he would have kept copies. She also stated in her testimony that she had visited his office during her earlier stint at the Department of Health, and had seen that he was careful about keeping documents: she recalled seeing the ACVSB minutes then.<sup>85</sup> This is likely to have been in 1994, since that was the date she later put in her instructions to counsel.<sup>86</sup>

On 25 November 1999 Dr Metters responded to Anita James stating that all of his papers had been passed on to his successor, Dr Patricia Troop, when he retired as DCMO. He gave a further reason for his keeping the documents: that he had "retained more papers on this subject than on most topics" because "legal action against the Department on Hepatitis C had long been regarded as a possibility".<sup>87</sup> He suggested that Dr Mike McGovern should have inherited a set of the Committee papers,<sup>88</sup> and that Dr Rejman might also be asked for retained papers "as he too anticipated future legal action."

Anita James faxed Charles Lister on 29 November 1999 reporting that "Dr Metters says he left all his papers with his successor. It would appear that they have been shredded because they represented an inconvenience. If you can replicate them I [won't] hold a post mortem." The reference to the papers representing an "inconvenience" was expanded on in Anita James' instructions to counsel and is addressed below.

On 1 December 1999 Charles Lister reported that he had found volumes 1-4 and volume 6. He thought there was therefore at least one volume missing (volume 5) and identified gaps in the papers from June 1988 to April 1989 as well as papers missing from 1990/1991. He agreed to recall files from storage and see whether there was a basement at Eileen House where documents might have been stored. A manuscript list of documents that had been

- 83 Memo from Anita James to Dr Metters 23 November 1999 WITN5426133. Yvonne de Sampayo was Senior Personal Secretary to Dr Metters. Written Statement of Yvonne de Sampayo 5 September 2022 para 1 WITN7194001
- 84 Email from Anita James to Charles Lister 23 November 1999 WITN5426134
- Anita James Transcript 13 September 2022 pp68-69 INQY1000239
- Justin Fenwick QC Instructions to Counsel to advise in the matter of Hepatitis C Litigation 3 March 2000 p2 DHSC0046972\_131
- 87 If he felt this, and Dr Rejman did too, it may be inferred that others in the Department of Health were of the same view, or at least knew of theirs.
- Dr McGovern was medical secretary to the Advisory Committee on Microbiological Safety of Blood for Tissues for Transplantation, the successor committee to the ACVSB. As head of the blood policy team, Charles Lister initially reported to him before a restructuring. Written Statement of Charles Lister 19 May 2022 para 1.9 WITN4505002, Written Statement of Dr Andrzej Rejman 26 March 2021 para 8 WITN4486001
- 89 Email chain between Anita James and Charles Lister 25 November 1999 p1 MHRA0024553. This confirms the view expressed by Anita James (see text above) that those in the Department of Health were well aware of the likelihood of litigation for some time in advance of it commencing.
- 90 Memo from Anita James to Charles Lister 25 November 1991 WITN5426139
- 91 Memo from Charles Lister to Anita James 1 December 1999 WITN5426140
- 92 Memo from Anita James to Charles Lister 8 December 1999 WITN5426144

prepared in 1997 was used to identify the files that needed to be recalled. Anita James informed Charles Lister's team that they need only find those files on the list from the blood section and did not need "At the moment" to ask the file registry to search for all files that might be relevant.<sup>93</sup>

Charles Lister provided Anita James with the papers he had found but she identified further gaps in them and asked him to retrieve the registered files.<sup>94</sup> On 19 January 2000 she wrote to Charles Lister and Dr McGovern arranging for the ACVSB papers they had found to be copied and sent to the solicitors for the claimants in the Hepatitis C litigation. She noted that:

"Of the rest I clearly have what comes down to given the dates we have MED's papers and three ring binders of John Canavan's old branch papers. In Dr Rejman's 'personal' papers I have found two minutes which ominously do not appear elsewhere. There are obviously some gaps. We know Dr Metters' files have gone and I think he had a lot more than just the minutes of the Committee meetings. There must be some Finance Division papers and briefings to ministers. What I find surprising is the fact that we had ring binder after ring binder on HIV but there is so little on HVC [sic]. I wonder why this is?" 95

There was discussion between Charles Lister and Anita James about the thoroughness of the exercise required but Charles Lister cannot recall what was discussed.<sup>96</sup>

Anita James confirmed in evidence to the Inquiry that it did not appear that the registered files had been retrieved from the DRO at any time before January 2000 and there was no blanket request across the Department of Health to find any relevant files.<sup>97</sup>

When they received the documents from Anita James, the solicitors for the claimants wrote to her asking for specific documents that they had identified as missing. 98 Further efforts were made to find the missing documents, from sources including John Canavan, 99 Professor Arie Zuckerman (a member of the ACVSB), 100 Dr Angela Robinson (a member of the National Blood Authority), 101 Scottish National Blood Transfusion Service ("SNBTS"), 102 the Scottish

<sup>93</sup> Email from Gwen Skinner to Anita James 13 January 2000 WITN5426157, Email from Anita James to Gwen Skinner 13 January 2000 WITN5426158

<sup>94</sup> Email from Anita James to Charles Lister 6 January 2000 WITN5426155

<sup>95</sup> Email from Anita James to Charles Lister and Dr McGovern 19 January 2000 WITN5426160

<sup>96</sup> Email from Anita James to Charles Lister 19 January 2000 WITN5426161, Written Statement of Charles Lister 19 May 2022 para 2.13 WITN4505389

<sup>97</sup> Anita James Transcript 13 September 2022 pp79-81 INQY1000239

<sup>98</sup> Letter from Deas Mallen Souter Solicitors to Anita James 27 January 2000 WITN5426171

<sup>99</sup> Email from Anita James to John Canavan 21 January 2000 WITN5426164

<sup>100</sup> Email chain between Charles Lister and Anita James 28 February 2000 DHSC0046972 133

<sup>101</sup> Email from Charles Lister to Anita James 25 February 2000 WITN5426198

<sup>102</sup> Email correspondence between Charles Lister and Brenda Pheely 3 March 2000 WITN5426202

Government,<sup>103</sup> and Dr Robert Perry,<sup>104</sup> but not everything was found.<sup>105</sup> A handwritten note indicates that the Welsh Office was also contacted but the documents they had held had been destroyed.<sup>106</sup> In a response to the claimants' solicitors, the apparent destruction of the documents was described as "unusual and unsatisfactory."<sup>107</sup>

Anita James sought advice from Justin Fenwick QC. In her written instructions to him she stated that she had seen ACVSB records in 1994 when the litigation was first mooted. The document suggests that these were documents held by Dr Metters but when she had sought to obtain them more recently, "Quite to the incredulity of Mrs James, Ms De Sampayo told her that she had destroyed the documents because the BSE disclosure procedure had caused her great difficulty. Dr Metters' records are therefore not available." She also noted that the registered files "have been destroyed some time ago ... It should be said that the Department is actively seeking some of the missing documents from other sources but the registered files are irreplaceable." 108

Yvonne de Sampayo states in her evidence to the Inquiry that she was:

"particularly shocked to see reference to the suggestion that I destroyed documents because I was fearful of a difficult disclosure process due to a supposed bad experience with the BSE inquiry's disclosure process. It is not in my character to speak about work in this way and I certainly would not destroy documents for this reason. I have always prided myself on doing things 'by the book' and carefully following any instructions given. In fact, ... I was not involved in the BSE disclosure process and would not therefore be in a position to pass comment on the difficulty of it." 109

She denied destroying any of Dr Metters' papers and said that they would have remained in the filing cabinets; it was not in her remit to make decisions about the retention of files.<sup>110</sup>

Dr Troop stated that Yvonne de Sampayo was her private secretary for five years and did not believe that she would have destroyed papers because a previous investigation had caused her difficulty. She recalled Yvonne de Sampayo clearing out papers when Dr Metters left but did not find it unusual as "she would have wanted to start afresh and make space for a new DCMO coming into the office."<sup>111</sup> This accords with a subsequent note Anita James wrote in

- Email chain between Charles Lister, Sandra Falconer and Anita James 2 March 2000 p2 DHSC0046972\_130, Email from Charles Lister to Brenda Pheely 3 March 2000 DHSC0046972\_128 and Email from Brenda Pheely to Charles Lister 6 March 2000 DHSC0046972\_117
- Director, Protein Fractionation Centre in Edinburgh, SNBTS and member of the ACVSB. Email chain between Charles Lister, Sandra Falconer and Anita James 2 March 2000 p1 DHSC0046972 130
- 105 Memo from Charles Lister to Anita James 3 March 2000 WITN6955043
- 106 Letter from Deas Mallen Souter Solicitors to Anita James 27 January 2000 WITN5426171
- 107 Letter from Anita James to Deas Mallen Souter Solicitors 6 March 2000 WITN6955033
- Justin Fenwick QC Instructions to Counsel to advise in the matter of Hepatitis C Litigation 3 March 2000 p3 DHSC0046972\_131
- 109 Written Statement of Yvonne de Sampayo 5 September 2022 para 27 WITN7194001
- 110 Written Statement of Yvonne de Sampayo 5 September 2022 para 29 WITN7194001
- 111 Written Statement of Dr Patricia Troop 12 September 2022 para 2.34 WITN7169001

her diary on 8 March 2000 when she sought a further explanation from Yvonne de Sampayo about Dr Metters' papers and her diary note records "ACBS after 2nd meeting. subsequent. Clearout when Dr Metters left given not registered files." 112

At this stage, I should comment that there is no corroboration of Anita James' description to counsel that "Ms De Sampayo told her that she had destroyed the documents because the BSE disclosure procedure had caused her great difficulty." When she gave oral evidence, Anita James could not recollect it actually being said to her. On the evidence, it did not happen. That fits with the probabilities – the evidence is that Yvonne de Sampayo had little directly to do with the BSE Inquiry; she was unlikely to have advanced it as an explanation; and it makes little sense as an explanation that difficulty in respect of an inquiry should mean that documents which may or may not be called for in respect of something completely different should be destroyed "just in case".

After obtaining advice from Justin Fenwick QC, on 3 March 2000 Charles Lister wrote to Dr Troop explaining the position:

"A discovery exercise was undertaken by the Department between 1995 and 1997. These documents have now been indexed and given to DMS. However, some important documents are missing, mostly papers and minutes of the ACVSB – MSBT's [Microbiological Safety of Blood and Tissue for Transplantation] earlier incarnation. We established a week ago that a number of the Department's registered files containing ACVSB papers were sent for destruction, apparently in 1993 (although the file store tell us that the actual destruction dates were between 1994 and 1998). This should not have happened and we have not yet got to the bottom of why this decision was taken." 113

He said that Justin Fenwick QC had advised that "we should undertake a low key internal investigation to try to establish why the files were destroyed. The aim would be to ensure that procedures are in place within the Department to ensure that files are not destroyed in future where litigation is contemplated and that, when files are destroyed, proper records are kept showing who authorised destruction and why."<sup>114</sup>

<sup>112</sup> Photograph of diary entry for 7 March 2000 WITN5426220

<sup>113</sup> Memo from Charles Lister to Dr Troop 3 March 2000 p1 DHSC0046972 126

<sup>114</sup> Memo from Charles Lister to Dr Troop 3 March 2000 p1 DHSC0046972\_126. As it happens, the auditor who undertook the investigation in his report described the purpose of the inquiry to be to establish what happened, identify the extent to which procedures had not been followed, and make recommendations to prevent such incidents from occurring again. Internal Audit Review: Hepatitis C Litigation April 2000 p3 NHBT0000193\_137. Though Justin Fenwick QC had advised that the inquiry should try to establish why the destruction occurred, the word "why" is conspicuous by its absence from the auditor's overall statement of understanding of what he was to do. It does, however, feature in his later text "there is little documentary evidence to establish exactly why volumes 4-17 of GEB 1, which contained the minutes and background papers to the ACVSB between May 1989 - Feb 1992, were destroyed. However, the original file dockets still exist, and the annotations on these provide a reasonable audit trail, so that we can, with some certainty, piece the story together." It may best be seen, therefore, that the focus of the investigation was more upon the mechanics of what had occurred than the reasons for it in the mind of the person or persons who decided on destruction.

On the same day as his memo, Charles Lister provided some further documents to Anita James, filling in a few more gaps. 115

An explanation for the loss of the documents was also given in the internal memo to the Permanent Secretary, Sir Christopher Kelly, dated 8 March 2000. The memo notes that Justin Fenwick QC was "rather incredulous about the matter." It states that "This does appear to be a one off case. Sol Litigation has handled three other major writ actions of this kind and will undoubtedly handle others. They have no experience of this kind of thing happening before. But equally we cannot be complacent". A handwritten annotation notes that the Permanent Secretary agreed with the advice of counsel to have a "quick investigation" with plans to hand it over to the Department of Health's internal audit team.<sup>116</sup>

Justin Fenwick QC explained in his evidence that he was not sure "incredulous" was the correct word:

"I mean, I can't remember it. I think I was probably absolutely furious. Having given advice on document retention, having spent, by this stage, over 15 years representing the Department of Health and the CSM, having gone through the problems of lack of documents in HIV, the idea that when we knew about litigation, and the same group of people were involved, they should have allowed documents to go missing was intensely frustrating ... So it's not incredulous that I didn't believe what they were saying, it was just that: how could this possibly have been allowed to happen?" 117

Anita James informed the claimants' solicitors about the loss of the documents. On 9 March 2000 Anita James wrote again to the claimants' solicitors and said:

"It is difficult for me to offer anything other than a fairly bald statement as to what happened and why at this stage. As you may know, all departmental documents are kept on registered files. Once these files are no longer current they are sent to remote storage. In the Department of Health's case this is at Nelson Lancashire. Before any documents go to Nelson, they are given a destruction or review date. I generally mark my files (bearing in mind they are generally completed cases) with a ten year destruction date. Policy files, I understand, generally have a twenty year destruction date. In the case of the registered files containing the minutes of the Advisory Committee on the Virological Safety of Blood (ACVSB) for reasons which we do not yet know they were given an early destruction date and destroyed, as I understand it between 1995 and 1997. We thought there were back up documents held by the Chairman of the ACVSB. However, when he retired in the summer of 1999 there was a clear out of his papers given that

<sup>115</sup> Email chain between Charles Lister and Anita James 28 February 2000 DHSC0046972 133

<sup>116</sup> Memo from Marilynne Morgan 8 March 2000 WITN6955032

<sup>117</sup> Justin Fenwick QC Transcript 9 June 2022 pp184-185 INQY1000213

they were not registered files. We are seriously contemplating making a more detailed investigation in the matter." 118

On 13 March 2000, it appears that Yvonne de Sampayo found some papers and provided them to Mark Gidden, who was covering for Anita James. They included documents that had not previously been disclosed. Justin Fenwick QC also returned some of his papers which included a "more complete" set of the ACVSB minutes.

The internal audit department undertook an investigation, carried out by Laurence George, to "focus on lessons for the future." Terms of Reference were drafted by Laurence George for William Burleigh, the head of the internal audit branch, and agreed by Dr Troop who emphasised to her staff that they were to cooperate with the investigation and that it would "not seek to apportion blame, rather help prevent such things happening again". In her written statement Dr Troop stated that the audit was not a witch hunt: "the key point is understanding what went wrong. Although this may involve identifying who made what decisions, the primary purpose is to understand and learn from this." Is

Justin Fenwick QC stated that when advising the Department of Health he had anticipated that the individuals would be identified and an explanation sought.<sup>124</sup> Laurence George understood that he was expected to complete the investigation very swiftly.<sup>125</sup>

In interviews for the audit investigation, Dr Troop suggested that some of the medical professionals involved were "not traditional civil servants and this may have an impact on file keeping standards" but also noted that Dr Metters recognised the importance of good document keeping and maintained good records. Yvonne de Sampayo said that she had been asked for the minutes as a longshot and had found some records and forwarded them on. Anita James in her interview mentions that Yvonne de Sampayo had destroyed Dr Metters' personal papers. There is no record that this was put to Yvonne de Sampayo

- 118 Letter from Anita James to Deas Mallen Souter Solicitors 9 March 2000 pp1-2 WITN5426222
- Handwritten notes by Yvonne de Sampayo 13 March 2000 WITN5426224, Memo on Hepatitis C litigation 15 March 2000 WITN5426235
- 120 Note to Anita James 22 March 2000 WITN5426239, Memo from Anita James to Charles Lister and Dr McGovern 5 April 2000 WITN5426244
- 121 Email from William Burleigh to Sammy Foster 13 March 2000 WITN6955029. Laurence George was an internal auditor in the Department of Health who was relatively junior and worked under the supervision of William Burleigh. Written Statement of Laurence George 24 August 2022 para 2.3, para 3.20 WITN6963001
- Written Statement of Laurence George 24 August 2022 para 3.22 WITN6963001, Terms of Reference Internal Audit Review WITN6955028, Email from Bill Burleigh to Dr Troop 20 March 2000 WITN6955027, Terms of Reference for the Internal Audit Review WITN6955026, Fax from Laurence George to Anita James 24 March 2000 WITN6955025, Memo from Dr Troop to Dr McGovern and others 22 March 2000 WITN5426240
- 123 Written Statement of Dr Patricia Troop 12 September 2022 para 2.15 WITN7169001
- 124 Justin Fenwick QC Transcript 9 June 2022 p186 INQY1000213
- 125 Written Statement of Laurence George 24 August 2022 para 3.32 WITN6963001
- 126 Interview record 2 in Hepatitis C Litigation audit 23 March 2000 WITN6955051
- 127 Interview record 3 in Hepatitis C Litigation audit 23 March 2000 WITN6955052
- 128 Interview record 4 in Hepatitis C Litigation audit 23 March 2000 p2 WITN6955053. Anita James' interview was five days after Yvonne de Sampayo's interview. Anita James made no recorded

20

for her comment or explanation. The internal audit investigation also obtained further confirmation of the dates of destruction of the registered files by DRO.<sup>129</sup>

Despite counsel suggesting that Dr Metters be interviewed as part of the audit process, this did not happen, because he had left the Department of Health. <sup>130</sup> Dr Troop in her evidence to the Inquiry stated that she could not understand why he was not interviewed, nor recall the reasons for it but did not consider that the speed of the audit was the reason. <sup>131</sup> However, William Burleigh explained that the fact that they were his own copies of documents, rather than the registered files themselves was "enough to exclude him from investigation". <sup>132</sup> Dr Rejman was also not interviewed (as counsel had suggested he should be) because it was believed that he had left the Department of Health. William Burleigh accepted that it may have been helpful to have done so. <sup>133</sup>

Laurence George explained to the Inquiry that the individual who destroyed the papers was not spoken to because he was unable to establish who it was. His expectation would have been that departmental official records should have stood up to scrutiny without having to question staff who had left the Department of Health.<sup>134</sup>

The audit investigation final report reached the following conclusions:

"We concluded that an arbitrary and unjustified decision, most likely taken by an inexperienced member of staff, was responsible for the destruction of a series of files containing the minutes and background papers of the Advisory Committee on the Virological Safety of Blood (ACVSB).

We believe the destruction of these files would have been prevented had the person marking files for destruction, been aware of their importance." 135

Recommendations were made relating to improved induction and training procedures, updated record management guidance and changes to the level of authorising officer.<sup>136</sup>

#### The report stated:

"There is little documentary evidence to establish exactly why volumes 4-17 GEB 1, which contained the minutes and background papers to the ACVSB between

- suggestion that somehow problems with "discovery" for the BSE Inquiry had been the motivation for the destruction.
- 129 Email from Annette Greenwood to Laurence George 31 March 2000 WITN6955044
- 130 He became HM Inspector of Anatomy.
- Written Statement of Dr Patricia Troop 12 September 2022 para 2.8 WITN7169001. Laurence George understood that "it was not custom and practice to interview staff who had left the Department or retired." Written Statement of Laurence George para 3.66 WITN6963001
- Written Statement of William Burleigh 7 October 2022 para 3.13 WITN7305001. This perhaps misses the fact that two sets of what were probably the same documents, dealing with the same controversial area of dispute in the Hepatitis C claim, had both disappeared without any clear cause being established for the disappearance of either.
- 133 Written Statement of William Burleigh 7 October 2022 para 3.14 WITN7305001
- 134 Written Statement of Laurence George 24 August 2022 para 3.67 WITN6963001
- 135 Internal Audit Review: Hepatitis C Litigation April 2000 p4 NHBT0000193 137
- 136 Internal Audit Review: Hepatitis C Litigation April 2000 pp6-9 NHBT0000193 137

May 1989 - Feb 1992, were destroyed. However, the original file dockets still exist, and the annotations on these provide a reasonable audit trail so that we can, with some certainty, piece the story together ... [staff members'] memories of events up to 8 years ago were hazy at best, and added little to the evidence we had elsewhere.

From the dockets it seems clear that a two-stage process led to the destruction of the files:

- in February and March 1993 the files were closed, retained in the section, and marked for review 5 years from the date of the last document in each file. This part of the process followed normally accepted procedures;
- before any of the volumes reached their specified review date however, in July 1993 the files were marked for destruction and sent to DRO. Volume 4 for example, had been marked for review in July 1995.

This second decision effectively overrode the previous closure and review process. Marking the files for destruction was plainly wrong, and a bad decision was made worse by the short destruction dates assigned, which varied between  $1 - 4 \frac{1}{2}$  years. It was not possible to determine why different destruction dates were assigned." <sup>137</sup>

The audit report noted two outstanding questions. Firstly, why the ACVSB files that were available at the DRO were not recalled by Dr Rejman when he was collating relevant documents, instead of relying on other policy files. Secondly, why volumes 1-3 were treated differently with appropriately long review and destruction dates compared to files 4-17. The report noted that the destruction took place "at a time of major organisational change in the Department, i.e. the implementation of the FMR,<sup>138</sup> which resulted in two experienced members of staff leaving the relevant section." This, it states, "probably" resulted in either a delegation of responsibilities without proper instruction or assumption of responsibility without proper authorisation.<sup>139</sup>

By way of comment, the investigation was ineffectual in finding out what had actually happened. It started out at some disadvantage – it was held in 2000, relating to the reasons why files were marked for destruction in February and March 1993. However, the section was not a large department. It ought to have been relatively easy to identify the person responsible for the destruction of the documents, to ask them why the documents had been marked for destruction, and why destroyed files seemed to be focussed upon what was likely to be a central thrust of any litigation about Hepatitis C. It did not do so. It did not interview some of those counsel had expected should be interviewed, nor seek to ask each

22

<sup>137</sup> Internal Audit Review: Hepatitis C Litigation April 2000 p5 NHBT0000193 137

<sup>138</sup> The Functions and Manpower Review.

<sup>139</sup> Internal Audit Review: Hepatitis C Litigation April 2000 p5 NHBT0000193\_137. The draft report prepared by Laurence George was seen, reviewed and cleared by William Burleigh. Written Statement of William Burleigh para 6.2 WITN7305001

person who worked in the section at the time what had happened. The reason for this was probably that the audit department, asked to conduct the investigation, proceeded much as it would with an audit, to learn lessons for the future: to look at management and systems with a forward mindset, typically with an aim of strengthening the efficiency, reliability or safety of how a system operated. Rather than approach the investigation as a forensic one it saw its role as to identify any weaknesses in controls and to recommend how they could be corrected. A "witch-hunt" was to be avoided. However — whilst accepting that this last point has validity — it is difficult to see how the weaknesses in systems could be identified so as to prevent recurrence of what had happened without actually knowing what indeed had occurred, and to establish that it was critical to find out why the documents had been destroyed. The investigation did not focus on that, as it should have done.

In 2005 there was a Freedom of Information request for the destruction certificates of the documents. DRO staff provided information for the response and stated that they had certificates of destruction but that they doubted they would be useful because they only gave the weight of the papers collected and destroyed; there was no audit trail of the specific files that had been destroyed. Patricia Hewitt, Secretary of State for Health, responded to a letter from Charles Clarke MP which asked why an inexperienced member of staff had been allowed to make decisions to destroy important papers. Her response included the following:

"The plain answer is that we do not know enough about what happened to answer that question. Clearly, the papers should not have been destroyed. I am very sorry that they were.

When the records in question were destroyed, the general guidance on records management was broadly the same as it is today ... Decisions on retention and destruction of records should always be made by individuals with knowledge of the content and likely future importance of the records ...

Files marked for destruction would have been destroyed by the Departmental Record Office either two or five years after the date of the last paper on the file.

The appropriate decision for the records we are discussing would have been to retain the records for review after 25 years when a further decision would be made, whether to destroy or retain the files. After 25 years, we would only retain files if they had historical or continuing administrative value.

These particular records were destroyed between 1994 and 1998, in line with instructions written on the file by a member of the policy team when the records

<sup>140</sup> Written Statement of William Burleigh 7 October 2022 para 2.5 WITN7305001

Written Statement of Dr Patricia Troop 12 September 2022 para 2.15 WITN7169001. This is not a criticism of either Laurence George or William Burleigh: the DCMO commissioning the audit was "concerned about junior staff being blamed", hence a desire to avoid the pointing of the finger.

Email chain between Chris Gilson, Roseanne Pratt and Zubeda Seedat 16 December 2005 p2 DHSC0200107

<sup>143</sup> Letter from Charles Clarke to Patricia Hewitt 14 December 2005 DHSC6548565

were transferred to the archive three or four years before ... I do not believe we can go further in examining the causes of the mistake." 144

## Discovery in 1996 of the loss of files from the HIV litigation

There is no similar track record of written destruction dockets when it comes to the loss of HIV files, which is next to be considered. As described above, when the HIV litigation ended in a settlement the HIV litigation files (excluding of course those documents which had gone missing prior to the litigation) were thought to be intact and available: steps had been taken to remind officials that in particular documents in respect of the PII disclosures should be kept secure and not destroyed.

When in 1995 work was being undertaken in anticipation of Hepatitis C litigation Anita James did not think to look at the HIV litigation files and so had not sought to find them. She believed them to be held by a colleague in the Solicitor's Division, Ronald Powell.<sup>147</sup>

At that stage there was, as yet, no suggestion that some of the litigation files compiled for the HIV litigation had gone missing.

By the end of April 1996, the matter was being handled by Ruth McEwen. Dr Rejman provided Ruth McEwen with a list of the documents that had been disclosed in the HIV litigation, but was not confident whether it was the final version of the list that had been used.<sup>148</sup> Ruth McEwen and Dr Rejman discussed the discovery work that was needed and she told Dr Rejman that she believed that the Solicitor's Division had a "complete set of the files of HIV discovery."<sup>149</sup>

It was the next day that it came to light that some of the HIV litigation files had gone missing. This emerged when Ruth McEwen told Dr Rejman that "despite a locksmith breaking into a large number of filing cabinets in the basement at New Court<sup>150</sup> we have only been able to locate half of the HIV discovery documents. We have files 21-43 and 45 onwards. We

- 144 Letter from Patricia Hewitt to Charles Clarke MP 9 February 2006 WITN3996023
- 145 In the section of this chapter After the HIV litigation: initially, all the files for the litigation still available.
- Presumably documents for which PII had originally been claimed, but in respect of which the Court of Appeal had determined that save in respect of one class of documents relating to what was essentially a different topic that it had been properly open to the judge whose decision was under appeal to hold that the plaintiffs had shown that the documents "are 'very likely to contain material which would give substantial support to (the plaintiffs') contention on an issue which arises in the case and that without them (they) might be 'deprived of the means of ... proper presentation of their case" and should therefore be produced for inspection by the trial judge "to be decided by reference to the allegations in the pleadings and to the undisputed gravity and importance of the case", if this was indeed the case. Judgment Re HIV Haemophiliac Litigation 20 September 1990 p50 BPLL0016043\_025. The particular documents which should have been kept secure and not destroyed were therefore likely to be sensitive documents such as submissions and advice to ministers.
- 147 Anita James Transcript 13 September 2022 p49 INQY1000239
- On 29 April 1996. Memo from Dr Rejman to Ruth McEwen 29 April 1996 DHSC0011977. The list of documents contained 3,861 documents of which about 200 were considered to fall under PII. He objected to further extensive work being undertaken on discovery.
- 149 Memo from Dr Rejman to Ruth McEwen 1 May 1996 DHSC0006352 044
- 150 Where the Solicitor's Division was based.

24

are therefore missing files 1-21 and 44. I believe that the administrators have a copy of the discovery documents. Please could attempts to locate these files begin immediately." <sup>151</sup>

She was also unable to find two expert reports or the copies of publications that were attached to the statement of claim. She said that the files she held were copies and asked where the originals were.<sup>152</sup>

Dr Rejman replied on 3 May 1996 to say that they had files 1-30, both the originals and a duplicate set, and he thought that it was "*likely that the rest of the files are in a cabinet close by.*" The reply was annotated by Dr Metters asking "*Am I right in thinking that SOL have lost some of the original papers you sent them some months ago?*" to which Dr Rejman has noted "*Yes that is the case*". <sup>153</sup> Dr Rejman had indeed sent Anita James papers, most of which were extracts and thus not original files, in the previous June. <sup>154</sup> It is unclear whether Dr Metters was referring to these papers, or to the original HIV litigation files.

On the face of the documents which, between them, Dr Rejman and Ruth McEwen now had, it would appear that only file 44 had in fact been lost. However, in light of the volume of the documents that were subsequently found, it seems doubtful that the documents that were initially believed to have been lost were limited just to the contents of that one file alone. There appears to have been no comprehensive study into what was missing. Nor does there seem to have been any attempt to make an inventory of what was left. 156

Anita James recalls a phone conversation (on 5 June 1996 after she had moved departments) with Mark Wilson, a previous colleague, asking about missing HIV litigation files. Her notebook records the numbers of the missing files. Anita James could not recall doing anything further about the request asking about the files.<sup>157</sup>

On 27 June 1996 Ruth McEwen put the CA-OPU2<sup>158</sup> staff on notice that a significant discovery process would be required if claims in the Hepatitis C litigation proceeded. She advised that "some thought is given to locating the relevant files". <sup>159</sup> She wrote again on 29 July 1996 to clarify who was responsible for discovery work in CA-OPU2, <sup>160</sup> and Dr Rejman replied on 31 July 1996 continuing to object to further work being undertaken on discovery of documents because it was "wholly inappropriate and wasteful of resources ... until we [are] certain that something would come of the HCV haemophilia case." In that context, he

- 151 Memo from Ruth McEwen to Dr Reiman and Paul Pudlo 2 May 1996 DHSC0006352 048
- 152 Memo from Ruth McEwen to Dr Rejman and Paul Pudlo 2 May 1996 DHSC0006352 048
- 153 Memo from Dr Rejman to Ruth McEwen 3 May 1996 DHSC0006352 045
- Memo from Dr Rejman to Anita James 23 June 1995 WITN5426022. The extracts were from the claim, the defence, and from seven reports, together with another two reports in full.
- 155 Written Statement of William Vineall and Lorraine Jackson para 1.21 WITN7193052
- 156 This is a point made correctly by William Vineall and Lorraine Jackson. Written Statement of William Vineall and Lorraine Jackson para 1.21 WITN7193052
- Anita James Transcript 13 September 2022 pp57-60 INQY1000239, Photograph of notebook showing numbers of the missing files WITN5426092
- 158 Corporate Affairs Operational Policy Unit 2, which included the blood policy team.
- 159 Memo from Ruth McEwen to Dr Rejman 27 June 1996 DHSC0006348 068
- 160 Memo from Ruth McEwen to Dr Rejman 29 July 1996 DHSC0032238 008

said it was "extremely unlikely" that CA-OPU2 had any further discovery and that "The HIV discovery specifically included hepatitis and took many months to complete. I suggested to Mr Pudlo that he should contact Mr Burrage, who has left the Department regarding the location of the missing files of original documents. I do not know whether this was done. Anyway a set of copies was sent to SOL, Counsel and several sets to the plaintiffs." 161

The issue of the discovery of documents was picked up again in May 1997 following a conference with counsel. Justin Fenwick QC had been consulted about the Hepatitis C litigation and considered it was reasonable to use the HIV disclosure lists as a base for the disclosure exercise that was now required. Dr Rejman was to attend the solicitors' base in New Court to "prune the HIV discovery documents removing obviously irrelevant documents." 162

Ruth McEwen planned to create a second discovery list of "missing documents which cannot be located at CAOPU or SOLB4" and to ask one of the claimant firms to say whether they had copies of the documents missing from the Departmental files. The note shows that she thought that CA-OPU were likely to have a large number of relevant files which might include documents in addition to Dr Rejman's discovery. A reorganisation was due to take place in CA-OPU at the beginning of June but the head of the unit undertook to progress matters by trying to locate the files held and collect them at Eileen House. 163

Further work on discovery of documents appears to have been undertaken in June 1997 but a number of the files that were sought could not be found.<sup>164</sup>

The litigation proceeded without them. That is not the end of the story so far as the missing files are concerned: much of the loss was in due course recovered from copy documents, and from various sources, though by no means all. It is, however, an appropriate point at which to take stock.

### Commentary

The material before the Inquiry has been set out above at some length, because of its potential significance. It covers three periods during which particular losses of documents took place: before the HIV litigation began; when Hepatitis C litigation was in contemplation (the ACVSB documents); and the period after the HIV litigation concluded when files which had been in existence during that litigation disappeared.

<sup>161</sup> Memo from Dr Rejman to Ruth McEwen 31 July 1996 DHSC0004756\_027. There is a handwritten note on Dr Rejman's memo saying (in relation to the suggestion of contacting David Burrage) "*This was asked by MJR and he didn't know.*" An email from Margaret Jackson-Roberts records their conversation. Email from Margaret Jackson-Roberts to Ruth McEwen 1 October 1996 WITN5426333

<sup>162</sup> Memo from Ruth McEwen to Dr Rejman and Mr Guinness 12 May 1997 p1 DHSC0011944

<sup>163</sup> Memo from Ruth McEwen to Dr Rejman and Mr Guinness 12 May 1997 pp2-3 DHSC0011944

They were described as being a nil return. Chart showing files with a description relating to the discovery of Hepatitis C June 1997 DHSC0041813\_082, Chart showing files with a description relating to the discovery of Hepatitis C DHSC0041813\_085

There has never been a satisfactory explanation for any of these three losses. Though there is insufficient evidence to conclude that they are necessarily linked, 165 it is possible that at least the first two might be – since in each case what seems to have gone missing was documentation relating to the areas in which the government was most vulnerable to an adverse finding. 166

There has also been a search for an explanation as to what went wrong: what led to the loss in the first place. People have asked questions; an internal investigation was held. However, an explanation for what happened has been elusive – the closest has been the suggestion, in respect of the ACVSB documents, that it was the action of a junior member of staff who did not understand the significance of the documents with which they were dealing. The fact is that this was actually unknown.

The ACVSB documents are the one amongst the three sets of missing documents which are known to have been deliberately destroyed – that is, a decision was made (by someone) that that was to happen, and it did. The destruction was not an accident, nor the result of flood, fire or vermin. The immediate reason for destruction was human choice. Someone, for some reason, had chosen to have those documents destroyed. The reason is not apparent. It is not self-evident.

Though there must have been some reason for making this choice, no-one has identified what it was – for the very good reason that no-one knows who made it, so there is no-one to be asked about why they took that decision.<sup>167</sup>

I do not know what the reason was. Since there is common ground amongst those who gave evidence who were in a position to comment<sup>168</sup> that the documents should never have been destroyed it seems more likely that the reason was a bad one.<sup>169</sup> However I cannot on this basis alone say that the motive underlying it was to effect a cover-up.

In order to answer the Terms of Reference, which ask "whether there have been attempts to conceal details of what happened (whether by destroying documents [or in other ways])"<sup>170</sup> the Inquiry has to consider whether there is, on balance, sufficient evidence to show that the reason was to conceal the documents because they contained some details of what had

The fact that the disappearance has in each case no sufficient explanation is not in itself a reason to link them. The causes in each might be entirely distinct if only they were known.

<sup>166</sup> This is **not** to say that an adverse finding would have followed: many winning cases have areas of greatest vulnerability.

However, the fact that no-one has come forward to say they took the decision, and to give a reason, has to be taken into account.

<sup>168</sup> For example as described in this chapter Lord Nigel Crisp, Anita James, Justin Fenwick KC.

A "bad" reason in this sense might not be the same as having a bad motive for doing what was done. For instance, to clear files off the shelf to make space, without looking carefully enough at the contents, is bad because it is both careless and lazy; whereas destroying documents in order to cover up what they contain, or to make litigation in respect of infected blood more difficult for plaintiffs and pursuers to pursue, are blameworthy in a much more serious way. Neither ought to happen – and the decision in each case to send documents for destruction is a bad one – but the second is far worse because of the motive underlying it.

<sup>170</sup> Terms of Reference 9(a).

happened in respect of infected blood, whether there is sufficient material to show that there was some other reason, or whether there is simply insufficient evidence to show either.

I do not accept the conclusion of the audit report. It was fuelled by incomprehension<sup>171</sup> that anyone might have chosen to mark documents for destruction knowing of their contents; and since (it would seem, the section dealing with blood policy being a relatively small one) an experienced pair of hands would have known broadly what the document related to, it would have to be someone who had not had sufficient experience in the section yet to know better.

Though this is possible, the audit report contains a double speculation. The first is that it was "*likely*" that the decision was made by an inexperienced member of staff. Without knowing who it was, this is very difficult to say.<sup>172</sup> The second is that destruction would have been prevented if the person concerned had "been aware of their importance."<sup>173</sup> This makes an assumption about the approach of the person who decided on destruction: in effect, that they were careless, casual, and did not in fact look into the files – that they did not intend to destroy the files whilst knowing of their contents. This is not an assumption I can make without more evidence.

From the starting point, which is incontrovertible, that the documents should not have been destroyed,<sup>174</sup> and that no civil servant would think it proper procedure to dispose of files without having some idea of what they contained, the factors which tend to suggest that the reason for destruction was related to the content of the files are these:

- The documents in the destroyed files all cover ACVSB documentation. Each file follows
  on chronologically from the previous one, so that the files destroyed form an apparently
  complete series from the start of the ACVSB in 1989 until April 1992. There is no doubt
  that each file related to the ACVSB since this was written on each file docket.
- What happened was out of the ordinary. This was not just because of the way in which the files had been marked for destruction. It was recognised as unusual at the time – both in correspondence between Anita James and the solicitors acting for the

- 172 In general, relatively junior members of staff were responsible for keeping files, but that is not a sufficient reason for this conclusion.
- 173 Internal Audit Review: Hepatitis C Litigation April 2000 p4 NHBT0000193\_137
- 174 Charles Lister, head of the team, and Lord Nigel Crisp, NHS Chief Executive and Permanent Secretary both were clear on this. Charles Lister Transcript 8 June 2022 p140 INQY1000212, Written Statement of Lord Nigel Crisp para 31 WITN3996001. No doubt has been expressed in evidence; no suggestion has been made that someone looking at the contents of the documents might reasonably think they should have been destroyed.

The audit did not expressly consider alternative explanations. To her credit, Patricia Hewitt later, when responding to Charles Clarke, seemed less ready to ascribe the action to a junior member of staff, and left the issue open. Letter from Patricia Hewitt to Charles Clarke MP 9 February 2006 WITN3996023. The underlying assumption of the audit seems to have been that an established member of the policy team simply would not have sent the files for destruction, for no other reason than that an experienced person would not do it. This is not an assumption I can make. Speculation as to lack of experience was then built on with further speculation as to a lack of awareness: "We believe the destruction of these files would have been prevented had the person marking files for destruction been aware of their importance." There is no factual basis for thinking the person was unaware of this. No-one knows. I cannot assume this either.

claimants in the Hepatitis C litigation, and by counsel advising. It is illustrated by the fact that an investigation was started. The Solicitor's Division had dealt with three other major pieces of litigation in recent times, but there had been no similar loss of documentation.<sup>175</sup>

- Not only was destruction unusual, but attention had only recently been drawn to the
  need not to destroy documents relating to infected blood: when it was revealed that
  there was a surprising shortage of documentation concerning a major plank of the HIV
  litigation, Justin Fenwick QC said that he and Andrew Collins QC were likely to have
  advised on document retention, such that "when we knew about litigation, and the
  same group of people were involved, [that] they should have allowed documents to go
  missing was intensely frustrating."176
- There has been no suggestion that these documents were part of some more general clearout, for instance to make space in a section which was becoming cluttered; and in any event, all that was needed if a clearout was desired was to send the files to DRO, without also marking them for destruction.
- The documents were not just sent as one batch, on one occasion, but according to the records of the DRO some had been sent first on 9 February, then more on 17 March 1993.<sup>177</sup> This makes a one-off, unthinking decision seem less likely if the object was, for instance, to clear the shelves, where the ACVSB files could perhaps have formed one batch, why leave some? Would returning to dispose of more files not make one wonder if it was right to have disposed of the first?
- In the case of file GEB1/4 not only was the decision to destroy taken in advance of the review date, but so too the date set for destruction was set in advance of that date.<sup>178</sup>
- No one came forward to give any reason (whatever it was) for the destruction, when
  the internal audit took place but the audit was in 2000, so the events had taken
  place some seven years earlier; people may have moved on, or been unaware of
  the investigation.
- It is possible to see a pattern on three occasions, documents that might be useful
  to plaintiffs<sup>179</sup> in anticipated litigation went missing. But this may be no more than
  coincidence; and although the evidence is that loss of documents like this was highly
  unusual, the Inquiry does not have a full picture of all the documentation that was

<sup>175</sup> Letter from Anita James to Deas Mallen Souter Solicitors 9 March 2000 WITN5426222, Memo from Marilynne Morgan 8 March 2000 p3 WITN6955032, Anita James Transcript 13 September 2022 p122 INQY1000239

<sup>176</sup> Justin Fenwick QC Transcript 9 June 2022 p184 INQY1000213

<sup>177</sup> Email and attachments from Steve Wells to Zubeda Seedat 13 July 2007 pp11-14 DHSC0014975\_033. This has scans of the available dockets. One carries the date 17 March 1996, but this is probably a typographical mistake for 17 March 1993. Though curiously there are handwritten notes on all files, except one where it is crossed out, that say "Sent to DRO 30.7.93".

<sup>178</sup> Email and attachments from Steve Wells to Zubeda Seedat 13 July 2007 p5, p11 DHSC0014975 033

<sup>179</sup> Or in Scotland, pursuers.

retained or sent for destruction over the period, so this may be a coincidence which is seen to have significance purely because of hindsight.

#### On the other hand:

- It is difficult to see any personal advantage accruing to an individual from their selective destruction of records.
- There was ministerial agreement to replace the ACVSB with the Advisory Committee on the Microbiological Safety of Blood and Tissues on 9 February 1993, 180 the day the first files were marked for sending to the DRO for destruction: it is possible, therefore, that it might have been seen as no longer relevant to keep a series of files relating to a committee which was now defunct. However, there is no evidence of other files being removed for this reason; and anyone looking inside the files should immediately have realised that they should be retained since within the Department of Health there was a general awareness that infected blood and particularly Hepatitis C were live topics.
- Disposing of documents in order to conceal their contents is serious misconduct, and civil servants might be expected to be well aware of this. Though this does not necessarily mean that it never happens, it should not lightly be concluded that it did. However, the general legal proposition that the starting point should be that all the things a person is obliged to do should generally be presumed to have been done, in the absence of evidence sufficient to persuade to the opposite view, does not apply with the same force here. This is because it is the undisputed evidence here that the documents should not have been destroyed: in effect, that no-one acting properly would have arranged this.
- Closely coupled with this argument is the idea that it is counter-cultural for a civil servant to destroy documents when they should not do so. However as against this, the Department of Health had adopted the line that the treatment had been the best available treatment in the light of medical knowledge at the time; and this in turn led to a view that patients were unjustifiably complaining, and unjustly critical of delays when the Government had acted as swiftly as possible (another misplaced and uncritical assumption). It led inexorably to a view that the HIV litigation (and, no doubt, the Hepatitis C litigation that might follow) was unjustified. It led to being defensive especially when it came to the disclosure of some documents which might be interpreted adversely to the official departmental line.<sup>181</sup> This background context makes it less remarkable that a person might seek to dispose of material which (as they saw it) could be used to support an inconvenient and unjustified position.

The Minister for Health and Home Affairs, Lord Peter Fraser of Carmylle, confirmed his support in response to a letter from the Parliamentary Under-Secretary, Tom Sackville, of 21 January. Letter from Lord Fraser to Tom Sackville 9 February 1993 PRSE0000990. The Parliamentary Under-Secretary of State for Northern Ireland had given his agreement on 4 February 1993. Letter from The Earl of Arran to Tom Sackville 4 February 1993 DHNI0100028\_003

Memo from Roger Scofield to Dr Rejman 12 April 1995 p3 DHSC0006352\_081, Memo from Dr Rejman to Charles Blake 7 March 1995 p1 DHSC0004221\_039

**But** deliberately to destroy documents because their contents might be inconvenient would still be an action one might expect a civil servant to shrink from.

• Without being clear which individual was responsible, the Inquiry should not blame a person unknown within a small section, for this may tar all when only one justifies it.

It is not easy to reach a clear view given these particular points. There are however some matters which need to be ruled out as irrelevant to reaching it.

The question first is whether there is such evidence of "mess and muddle" that what happened is probably just the consequence of a chaotic system. 182

Anita James records in her written statement that file-keeping in SOLB4 within the Solicitor's Division was "haphazard. Files were kept in rooms. Papers were not put on registered files ... As a team under pressure ... our processes were just not as tight as they should have been." 183

However, though this may well have been the case, it is not only unlikely but reasonably certain that any such haphazard file-keeping was not the cause of the loss of the ACVSB documents.<sup>184</sup>

First, the destruction did not take place within the Solicitor's Division or the section but at the DRO, in consequence of explicit instructions from those responsible for the files.<sup>185</sup>

Second, the file dockets authorising destruction remain: they show that the files to which they related were sent from the section to the DRO.

Third, chaos is of its nature indiscriminate. "Mess and muddle" does not explain why it seems only to have been litigation in respect of infected blood and blood products that suffered from a significant loss of documentation.

As to this last point, Anita James did venture a suggestion in evidence as to the section: "people didn't understand the significance of what they were handling, the documents they were handling, and didn't give any thought in the -- to the possibility of litigation ... compounded by the fact that the Department had undergone extraordinary upheaval", 186 resulting in limited corporate memory of the issues. However, that does not meet the point. If people did not understand the significance of what they were handling, it would be expected that documents from several different areas would also have been marked for destruction:

It is right to acknowledge that the audit said "major organisational changes as a result of the Functions and Manpower Review (FMR), may have contributed directly to the poor decisions taken, through section reorganisation and the muddled allocation of responsibilities" (Internal Audit Review: Hepatitis C Litigation April 2000 p4 NHBT0000193\_137) but there would need to be more evidence to identify the nature of the "allocation of responsibilities" that led to the instructions for destruction considered in the text.

<sup>183</sup> Written Statement of Anita James para 6.39 WITN5426001

<sup>184</sup> Though it may help to explain why HIV litigation documents went missing.

This was not Anita James' direct area of responsibility. There is no evidence she had any hand in authorising destruction.

<sup>186</sup> Anita James Transcript 13 September 2022 p95 INQY1000239

yet no suggestion was made in oral evidence that files other than the ACVSB files were wrongly marked for destruction. The fact that it was only files in this area which are known to have been marked for destruction suggests it may have been something about those files that led to this – the common factor was their dealing with the viral safety of blood.<sup>187</sup>

#### Conclusion as to ACVSB files

Certainty is impossible. It is an uncomfortable conclusion that it is more likely than not that a civil servant chose to destroy the documents because they were **those** documents: but if that is what the evidence amounts to, it is the conclusion that must follow. Nonetheless, any conclusion (either way) is bound to be tentative, given the timescales and the inadequacies of the audit, which itself was hampered by being some years after the events which inspired it. The available evidence is incomplete. There is more I would wish to know. If prompt action had been taken when the loss was first discovered; if all those known to have been working in the section had been spoken to, I might have had the account of each of those people to consider. There might have been more information on what might have been other motives underlying the deliberate instruction to destroy the ACVSB files. I am deeply conscious that if further material had been available, either a different conclusion – or a stronger one to the same effect – could well have followed. But I have only the evidence set out above.

Balancing the factors I have mentioned, they incline me more towards the conclusion I have called "uncomfortable" than towards my thinking it was for some, unknown, "good" reason.

In short, it is on this basis more likely than not that the authorisation to destroy the files was because the documents contained material dealing with delays in the UK to the introduction of screening of blood donations for Hepatitis C, which was anticipated (or known) to be a live issue at the time. If this is right, it was a deliberate attempt to make the truth more difficult to reveal.

Though I cannot say who the person was who might have been at fault (if, given the difficulties now of establishing all the facts, anyone was), I am clear who it was not. It was not Anita James (though as shown by what follows, her inaction compounded matters by leading to delay and difficulty in re-assembling a set of documents which was probably near complete, and may have resulted in the permanent loss of some documentation); nor was it Charles Lister, who by comparison was proactive in attempting to trace missing documents, and joined the blood policy team in October 1998, by which time all the files were destroyed; 188 nor was it Lord Nigel Crisp, who dealt with matters within the scope given to him by the briefings he received from his officials, and did not join the Department of Health until November 2000, and whose involvement in matters relating to loss of documents is explored later in this chapter. 189 I am also clear that the fact that so many documents have been recovered

32

<sup>187</sup> For the ACVSB files, the other common factors are that (a) the team responsible for the files provided the secretariat function (January 1991 to September 1993) and (b) the files were the committee records.

<sup>188</sup> Written Statement of Charles Lister para 1.17 WITN4505002

<sup>189</sup> Written Statement of Lord Nigel Crisp para 18 WITN3996001

from a number of different sources makes it almost certain that it was not orchestrated "from the top" – if it had been, then it is likely it would have been much more effectively organised. There would most probably not have been an investigation. This Inquiry would not have seen all the documents it has.

I also note that Justin Fenwick QC said he "had no impression from any of the multiple officials with whom I met that they were being evasive and potentially inclined to destroy embarrassing documents." <sup>190</sup> I take this into account.

Though the balance of probability is as I suggest, and I must reject the explanation put forward by the internal audit review for the reasons given, I am unable to identify who it was.

By contrast, if the thesis is that an individual wanted to destroy the files because of what they thought the nature of their contents to be, then the pattern of behaviour shown by the facts fits better. They are likely to have been conscious they were doing wrong. Destroying them in the office would risk detection. At the DRO the destruction happened out of the office, at the hand of a third party, unseen by the section.

#### Commentary on the loss of HIV litigation documents and Dr Metters' files

This finding does however have an impact on the other two main areas of documentary loss – before the HIV litigation reached discovery phase and after it concluded – and makes me uneasy about the fate of Dr Metters' copy files of those that were destroyed at the DRO. The next part of this chapter examines whether a more proactive approach might have prevented these losses.

## **Preventing the losses**

#### Context

190

As to the context, there are several deeply concerning aspects in relation to the keeping of documents related to infected blood and blood products. First, there is an uneasy similarity between events in 1989 when the class action in respect of HIV litigation was beginning, and the late 1990s when the class action in respect of Hepatitis C began. In each, documents relating to a central thrust of the plaintiffs' or claimants' case went missing. In the first, those relating to self-sufficiency were found to be missing in 1989 when the HIV litigation began; in the second, those relating to decisions of the ACVSB, the committee making central recommendations about the timing and nature of viral screening for Hepatitis C were destroyed. In each case someone in the Department of Health had identified the areas of their defence which were potentially the weakest: and they were why self-sufficiency was never achieved in respect of HIV; and why the UK introduced Hepatitis C screening some

Written Statement of Justin Fenwick QC para 18.5 WITN7067001

time after other developed nations had already done so. In particular, an issue in respect of the latter was why there were delays introducing screening from mid 1990 well into 1991. 191

This similarity may be mere coincidence. It is entirely understandable that viewed individually each loss of documentation from the Department of Health's control was "more likely to be a mistake and a negligent error than a deliberate one". This assumes however that they are to be viewed individually, and not each as part of a picture. One question is thus whether the similarity is no more than chance: simply a coincidence. Given the finding I have been compelled to make in respect of the ACVSB files this cannot be dismissed out of hand; nor can the possibility that the losses of Dr Metters' copy documents or those of the HIV litigation files are not mere chance.

#### Role of the Solicitor's Division

There is some evidence of poor document management within the Solicitor's Division. This is reviewed at some length below. This does not and cannot explain the loss of the ACVSB documents which were never held by the Solicitor's Division at any relevant time. Nor does it explain the loss of self-sufficiency documents prior to the HIV litigation reaching discovery stage which, as far as can be ascertained, were not held at the Solicitor's Division but within the sections responsible. However, it may help to explain why documents in respect of self-sufficiency became difficult to locate and/or became lost after the HIV litigation had concluded, and before the documents had been returned to the archives from which they had come.

As to the loss of documents after the HIV litigation is concerned, it is certainly possible that a lack of understanding by those in the Department of Health as to the principles and guidance applicable to document retention, coupled with limited staffing resources in a section which had a heavy workload involving a number of different aspects of blood policy to consider amongst other health issues, may have resulted in mistake and muddle. There was a lack of clarity about who had what documents more generally, and where they were, which adds to this picture. For instance, Dr Rejman's recollection is unclear as to whether files were recalled from the DRO or not; David Burrage had some files, but it is unclear if they were files which had been recalled from the DRO.<sup>194</sup> This seems unlikely, for there was no entry

Anita James identified a six-month period of particular vulnerability in her interview with Laurence George, and accepted in evidence that she had highlighted the Department of Health as being vulnerable for the period between 1989 and 1991: the very period during which the ACVSB was central to what was happening. Interview record 4 in Hepatitis C Litigation audit p1 WITN6955053, Anita James Transcript 13 September 2022 pp46-47 INQY1000239, Memo from Anita James to Ruth McEwen 18 March 1996 WITN5426072

Justin Fenwick QC Transcript 9 June 2022 pp189-190 INQY1000213. What he said in full was: "This sort of destruction requires an explanation. It is more likely to be a mistake and a negligent error than a deliberate one but, nonetheless, the fact that people who had been involved in the previous litigation had had their files destroyed was something which needed to be taken seriously."

They did not become subject to management in the Solicitor's Division until they were being assembled for disclosure in the usual course of litigation (when it is highly unlikely they would have been lost).

<sup>194</sup> Dr Andrzej Rejman Transcript 11 May 2022 pp186-196 INQY1000204, Written Statement of David Burrage paras 8-9 WITN7149001

in the DRO which corresponds with it – but the files he was using nonetheless were called "official" by Dr Rejman. <sup>195</sup> Dr Rejman had some files, Anita James held others, Yvonne de Sampayo was able to find some files, yet this still left documents missing. <sup>196</sup>

It may therefore have been too much to expect of a human system, relying on paper copies, to have been so well organised that all that had to be done to find all the files on a particular topic was to seek their recall from the DRO. A system organised to that extent would depend upon individuals scrupulously returning documents after use, inspection, or copying to the DRO. Life is not necessarily like that.

The Solicitor's Division would have handled the HIV litigation documents after the time of settlement. So far as her involvement in the later use of these documents was concerned, there was a general lack of careful control from Anita James. There are numerous examples of this. Thus, when Dr Rejman said to her in June 1995, in respect of the documents she was seeking in order for her to deal with hepatitis litigation, that "As agreed, I do not intend to go through the full discovery list which we prepared at the time" for the HIV litigation, she did not insist that he did. Yet she accepted that with the benefit of hindsight the discovery list for the HIV litigation was something which should have been gone through in full. 198

Though when Dr Rejman sent her a selection of documents for disclosure, she knew he was filleting and taking a whole raft of files out that he thought were irrelevant, Anita James did not recall asking, simply, for the files to be sent over from his workplace to hers. Asked why this was, she replied: "I just can't remember what was going through my mind at the time. I know this is sounding rather lame but I just can't remember very much at all about 1995, '96." 199

Nor could she remember why she was satisfied (as she says she was) that she was providing all the relevant documentation to counsel when their advice was being sought – despite the deficiencies in that documentation which later became very clear.<sup>200</sup>

She was not proactive in seeking documents, investigating why some seemed to be missing, and filling the gaps. She was sent a minute in August 1995 that mentioned possible destruction of important policy files.<sup>201</sup> Asked if that raised any concerns for her at the time

<sup>195</sup> Internal Audit Review: Hepatitis C Litigation April 2000 p6 NHBT0000193\_137, Memo from Dr Rejman to Anita James 19 May 1995 WITN4486011

Written Statement of Dr Andrzej Rejman para 23 WITN4486001, Memo from Dr Rejman to Anita James 23 June 1995 WITN5426022, Handwritten notes by Yvonne de Sampayo 13 March 2000 WITN5426224, Memo on Hepatitis C litigation 16 March 2000 WITN5426235

<sup>197</sup> Memo from Dr Rejman to Anita James 25 June 1995 WITN5426022

<sup>198</sup> Anita James Transcript 13 September 2022 pp35-36 INQY1000239

<sup>199</sup> Anita James Transcript 13 September 2022 p37 INQY1000239

<sup>200</sup> Anita James Transcript 13 September 2022 p37 INQY1000239

<sup>201</sup> The minute was from Leonard Levy in the blood policy team to Ann Towner and then Anita James, asking whether they could shed any light on why "An exception was that the £2,000 for persons not infected with HIV but at risk, eg wives, was only available to those who were pursuing litigation, ie had served a writ, before 13 December 1990" was made in respect of payments related to the Macfarlane Trust, adding: "Unfortunately, our policy files giving the reason for the distinction appear to have been destroyed." Ann Towner's reply to him included "are you sure that earlier files in that series have been destroyed? To my reading the dockets only indicate that they have been sent to DRO for destruction after 25 years, which would not of course be yet. Perhaps you would let me know if they have in fact

she replied "*I don't remember raising any concerns, no.*"<sup>202</sup> She did nothing to ascertain whether or not policy files had been destroyed, despite her recognition that infected blood and blood products remained a live issue. Then, having been told that file GEB/1 volume 4 had been destroyed, she took no steps to ensure that the policy team destroyed no other files. In testimony, she recognised she should have done so: "*obviously, we should have insisted that files were better looked after.*"<sup>203</sup>

When it emerged in early 2000 that files were missing she had "entirely forgotten that there had been a minute nearly five years earlier from Dr Rejman that had mentioned the destruction of the first of those folders."<sup>204</sup> This in itself is remarkable, in that the destruction of a file which had been highlighted at the time, against a background where it was a rare occurrence, had not been memorable. It suggests that Anita James was not much interested in the disappearance of what were probably relevant documents.

She said that "between us<sup>205</sup> we **should have** ensured that a clear message was delivered such that files should obviously be retained / marked for lengthier retention. While I cannot now say whether I did say anything to that effect at that time, I very much regret that between us we did not act so as [to] make sure that other files which had been marked for destruction were not in fact destroyed."<sup>206</sup> She had not retrieved HIV litigation files sitting in the Solicitor's Division earlier because "Oh, I had to find time to do everything, so whether I had considered it, I knew they were there ... So I knew they were all there but I just never thought to look at them."<sup>207</sup>

When counsel showed Anita James a memo from Dr Rejman to Ruth McEwen, who took over Anita James' role in 1996, saying in part "I would urge you most strongly to try to locate the reports from Dr Perry and Dr Williams which I sent to Anita James in June 1995 ... I contacted her a few days later to ask for a return of the originals. This was promised but did not happen", she was unable to say anything about the apparent loss of those reports, the second of which was regarded by Dr Rejman as being of particular significance. She did not know how they came to be mislaid; and had no recall of receiving them in the first place.<sup>208</sup>

The minute from Dr Rejman went on to suggest that the Solicitor's Division should still have publications which were listed and attached to the main statement of claim – but they, too,

already been destroyed. We may need to think of reconstructing papers eg from what Dr Rejman and others hold." Memo from Leonard Levy to Ann Towner and Anita James 21 August 1995 WITN5426039, Memo from Ann Towner to Leonard Levy 24 August 1995 WITN5426040

<sup>202</sup> Anita James Transcript 13 September 2022 p41 INQY1000239

<sup>203</sup> Anita James Transcript 13 September 2022 p42 INQY1000239

<sup>204</sup> Written Statement of Anita James para 6.32 WITN5426001

<sup>205</sup> She meant herself, Dr Rejman, and David Burrage, though it should be recognised that David Burrage was considerably the junior.

<sup>206</sup> Emphasis in the original. Written Statement of Anita James para 6.32 WITN5426001

<sup>207</sup> Anita James Transcript 13 September 2022 p49 INQY1000239

<sup>208</sup> Memo from Dr Rejman to Ruth McEwen 3 May 1996 WITN5426084, Anita James Transcript 13 September 2022 pp53-55 INQY1000239

were apparently not available. Anita James was asked if she had any recollection of what happened to them and said "No, I'm sorry. I don't." 209

When it came to the papers which Dr Metters had kept (until their destruction) as DCMO Anita James was asked why he had not been approached "much earlier, when the GEB file was identified as missing?". Her response was "I don't know."<sup>210</sup>

Asked if she took any steps to address the information she had been given that papers kept by Dr Metters had been shredded, she said she had not done so in 1999 because "Things hadn't come to a head." Then asked "what would have been a trigger for you to investigate?" she responded "I'm not sure that ... it was for me to investigate, because she – that is Yvonne de Sampayo – was Dr Troop's responsibility and not mine. And if she had done anything wrong, it would have been for her to sort things out. And I didn't go to Dr Troop, if that's what's being asked. But no, I just didn't think I wanted to make a fuss about it with her."<sup>211</sup>

When, on 2 December 1999, Anita James was copied into a message suggesting that the Solicitor's Division held a copy of the committee papers of the ACVSB she could not remember what she did about it, and said that she did not, at that stage, authorise a thorough search of the documents which might be held by the Solicitor's Division.<sup>212</sup> When she was asked from within the Department of Health for "what we need to do in the discovery of files/papers for the HCV litigation" in the light of the fact that the manuscript list of files drawn up in 1997 was "only part of a longer list, and we have not been able to trace the remainder", Anita James responded "If I can be put in a position to explain why the files are missing and it is for a good reason I can argue that it would be disproportionate to pursue the matter further. At the moment just concentrate on the list you have."<sup>213</sup> It is not entirely clear what she meant by this. However, at that stage, Anita James had not yet told the solicitors acting for the claimants that the files were missing.<sup>214</sup>

Asked if she thought whether a more systematic assessment perhaps at an earlier stage might have helped<sup>215</sup> more documents to be found, the following exchange took place:

- 209 Anita James Transcript 13 September 2022 p55 INQY1000239
- 210 Anita James Transcript 13 September 2022 p66 INQY1000239
- Anita James Transcript 13 September 2022 p74 INQY1000239. The approach of "not wanting to cause a fuss", ie to duck rather than confront an issue, is a curious one for solicitors engaged in litigation: but it typifies the responses which Anita James made in her evidence.
- 212 Email from Dr McGovern to Charles Lister and Anita James 2 December 1999 WITN5426141, Anita James Transcript 13 September 2022 pp75-76 INQY1000239
- Email from Gwen Skinner to Anita James 13 January 2000 WITN5426157, Email from Anita James to Gwen Skinner 13 January 2000 WITN5426158
- 214 Anita James Transcript 13 September 2022 pp78-80, pp99-100 INQY1000239
- Her evidence was that neither she nor any member of her team had sat down and done a systematic assessment of where the missing files might be. Anita James Transcript 13 September 2022 p80 INQY1000239. However, when the same matter was revisited a minute or two later she explained that she and Charles Lister were "working it out". Anita James Transcript 13 September 2022 p81 INQY1000239

- "A. I fear not.
- Q. Why do you say that?
- A. Passage of time.
- Q. And with the passage of time what would you be concerned has happened?
- A. That people who had been involved, their memories had faded." 216

That (describing the position as it was in 2000) is exactly why action should have been taken earlier than it was.

Why did this not happen? First it should be noted that she was new to litigation in 1993 and worked under the supervision of Charles Blake who headed the division in which she worked. Whilst this chapter is critical of her actions she would have been one of a number of solicitors in the Solicitor's Division at that time and she is the only lawyer from whom the Inquiry has been able to hear. At that earlier stage, shortly before she left the Department of Health in 1996, it is plain that Anita James faced a number of problems as well as an intense workload. She left the Department of Health in 1996 amongst other things because of issues with her manager until late 1995 (which she described in her written statement as behaviour and bullying which "even for the time was very questionable and certainly by today's standards was bullying and clearly inappropriate"), his sudden departure leading to her stepping into his role and having to organise his "massively disorganised" files, arrange staff cuts, and draft a branch plan, before then being succeeded by a new appointee (without prior notice to her) leaving her feeling unsupported and undermined. At the time she was "having to endure a working environment which by today's standards would be viewed as entirely unacceptable" such that she recalled "finding it difficult even simply to go to work."217 A consequence is, as I find, that she was not as concerned about the loss of documents as in happier circumstances she might have been, and should have been. The result was, too, that she preferred to duck rather than confront issues concerning document retention when they arose.<sup>218</sup>

#### Consequence if proactive steps had been taken

If Anita James or the Department of Health more generally had been proactive in June 1995 when Dr Rejman informed her that GEB/1 volume 4 was missing,<sup>219</sup> this would have had three consequences. First – probably – the only ACVSB file to have been destroyed at DRO would have been GEB/1 volume 4. The other 13 files would probably have been recalled, and would have survived. Second, if this had not happened, the Department of Health would have been able to obtain the duplicate files held by Dr Metters before he retired, and after

<sup>216</sup> Anita James Transcript 13 September 2022 pp80-81, p87 INQY1000239

<sup>217</sup> Written Statement of Anita James paras 6.42-6.43 WITN5426001

<sup>218</sup> It may also be that whilst she has done her best in evidence to recall events which happened over 20 years ago she is remembering a time which she has been trying to forget ever since.

<sup>219</sup> Memo from Dr Rejman to Anita James 7 June 1995 p1 DHSC0200022\_002, Anita James Transcript 13 September 2022 p34 INQY1000239. Dr Rejman's memo was copied to others, including Charles Blake (who was senior to Anita James in the Solicitor's Division) and to Dr Metters, the Deputy CMO.

which they became lost. Third, it would have lent emphasis to the blood policy section that there was a real need to safeguard files relating to infected blood and blood products, and this in itself would not have made the climate as conducive as it was to the actions of the person responsible for assigning some of them to destruction.

Apart from this lack of proactivity, other aspects were muddled. The investigation was ineffectual, for reasons set out above. Together with the ineffectual nature of the investigation, the heavy workload in the section, and the repeated need for one person to ask another what documents they had to see how complete a set they had between them, there can be little confidence that document retention and recall would have been rigorously managed either in the section or in the Solicitor's Division.

These points might tend to suggest that "muddle and mistake" were the cause of the destruction of the HIV files. They might suggest that mismanagement, and a failure to take a grip of the issue of missing documentation when it first became a live issue (and it should have been addressed at that stage) were the cause of losses of further documents, since those losses would have been avoided if action had taken place more quickly. That might lead to a conclusion that the similarity between the loss in respect of central issues in the HIV litigation and central issues in the Hepatitis C litigation was purely coincidental.

Taking the context, and the role of the Solicitor's Department, into account in the context just described, I am satisfied that the cause of some loss of documentation (the ACVSB files) was not simply marking the registered files for destruction. It was also a failure to recall documents from the DRO before destruction happened (in all cases but GEB/1 volume 4, where it would have come too late to "save" the file). The failure to recall was a failure by Anita James, and probably Dr Rejman.<sup>220</sup> I am not persuaded that the loss of documents (other than the ACVSB files) after that was mere mischance (though there is no sufficient evidence to conclude it was deliberate): the failures described above should not have happened, and contributed to or caused it. However in weighing the degree of blame to attach for these failures it should be borne in mind that the section was under pressure, coping with the changes from the Functions and Manpower Review, facing having to deal with the demands of significant litigation, and with the solicitor involved having in addition to cope with the issues arising in respect of her work environment of which she spoke of in evidence and are mentioned above.

### Evidence of context

The picture of some muddle and mistake, lack of clarity as to who had which documents, and a failure to take steps to preserve documents after it first became apparent some were apparently missing, are only part of the picture.

The audit investigation posed the question why Dr Rejman did not seek the recall of the files but gave no answer, noting that he had retired. Internal Audit Review: Hepatitis C Litigation April 2000 p6 NHBT0000193\_137. As a senior medical officer, Dr Rejman was not immediately responsible for records management but he was more senior than David Burrage who had provided the files to him. Written Statement of Dr Andrzej Rejman para 29 WITN4486001, Dr Andrzej Rejman Transcript 11 May 2022 pp186-197 INQY1000204

Other aspects deserve highlighting. Thus, at the time the losses of documentation came to light, the Government was steadfastly resisting compensation for having suffered HIV and then Hepatitis C infections caused by NHS treatment. A repeated refrain was that patients had had the best available treatment in the light of medical knowledge at the time. Throughout the 1990s suggestions that people who had suffered Hepatitis C infection should receive support, let alone compensation, were strongly resisted on the basis that this would, in effect, be a first step to introducing no fault compensation. Any such scheme would simply be unaffordable. The chapters of this Report considering the "line to take" and how calls for a public inquiry were met show that those working in the Department of Health took a defensive approach.

There are signs – which are examined elsewhere in this Report – that those working in the Department of Health were also generally dismissive of the claims being made that self-sufficiency should have been achieved, and that if it had been would probably have saved lives. (The report *Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991* is one example of this, where the desire to stick by what had been the narrative of "best treatment" and "no failures" may have affected the extent to which facts or documents which did not fit it were expressed).<sup>221</sup>

Individuals had views which echoed this. The evidence suggests that within the Department of Health, amongst those who dealt with blood policy and administration, there was a defensive attitude towards allegations that deaths, HIV and hepatitis had been wrongfully caused. Though civil servants may have their own views it is almost inevitable that there will be some discussion in the workplace. Where there is a consistent view, expressed by robust personalities, it may become difficult for others to avoid dropping into line, and broadly adopting a similar approach. Charles Lister put it like this in evidence:

"I think in situations where a decision is taken, like a set of lines to take, those lines to take get used again and again, nobody particularly questions them, a debate happens in the Commons, and we use the same lines to take, there is a risk that you don't question -- you stop questioning that. I think as well, you know, from everything I heard, from the point of joining the blood team to when I left, was the view that everything was done as soon as it could be done, that was something that everyone believed. I didn't challenge it. So that's what I mean as well. There's that risk that, if enough people believe something, it becomes quite difficult to say 'Actually, maybe that's not the case. Maybe we should look at this differently'." 222

<sup>221</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991 2006 DHSC0200111. See the chapters on the Self-Sufficiency Report and Scotland.

He concluded this part of evidence by adding: "I'm not saying that happened, but I think there is always that risk.

Q. So do you think that decision making in the Department on both of these issues that we've been looking at this morning, the HCV payment scheme and the public inquiry, were affected by groupthink or the collective mindset?

A. I think the point I make in my second witness statement when I refer to this is that, looking back on this, I asked myself whether I could have, you know, done anything differently, and I said I wasn't

This can become what was described, several times, in evidence to the Inquiry as developing "groupthink".<sup>223</sup> It amounts to a closing of ranks around a position, whether or not that position is adequately justified.

From the evidence the Inquiry has received, Dr Rejman was one of those who commented with "pretty strong medical views." He was asked by counsel to comment on a sentence in Charles Dobson's submission about the HIV litigation that "at every stage it [the Government] has acted as swiftly as possible to minimise the risk of infecting haemophiliacs with AIDS in the light of the best expert opinion available at the time." When counsel pointed out that this was expressing a matter of fact, and asked if there had been any formal review of the facts to justify this, he said there had been none. He made no secret about his reluctance to be involved in the details of disclosure without being instructed — expressing this on separate occasions to Roger Scofield, and required formal instruction from Dr Metters. He made no secret about his reluctance to be involved in the details of disclosure without being instructed — expressing this on separate occasions to Roger Scofield, and required formal instruction from Dr Metters. He made no secret about his reluctance to be involved in the details of disclosure without being instructed — expressing this on separate occasions to Roger Scofield, and required formal instruction from Dr Metters. He made no secret about his reluctance to be involved in the details of disclosure without being instructed — expressing this on separate occasions to Roger Scofield, and required formal instruction from Dr Metters. He made no secret about his reluctance to be involved in the details of disclosure without being instructed — expressing this on separate occasions to Roger Scofield.

He expressed his disagreement with counsel's advice as to whether blood products fell within the Consumer Protection Act;<sup>229</sup> and (although his role was principally to provide medical input) freely expressed his views on essentially non-medical matters, arguing (for instance) that claims were overstated or certain categories of claimant should not be compensated.<sup>230</sup> He seems to have been relatively free with his views: Anita James described him as "a bit

honestly sure that I could have done. And I think that's where I am still at, that, although we might have all felt that we were right about this, that, you know, there wasn't a case to answer, that there wasn't a case for compensation, that there wasn't a case for a public inquiry, I'm not sure that I was in a position, you know, as a middle-ranking civil servant, with views taken by many more senior people and by ministers, to challenge that, even if it had occurred to me to do that." Charles Lister Transcript 8 June 2022 pp78-79 INQY1000212

- See for example Written Statement of Charles Lister para 4.93 WITN4505389 and paras 2.96-2.98 WITN4505002, as well as the testimony cited in the text.
- Justin Fenwick QC Transcript 9 June 2022 p12 INQY1000213
- 225 Memo from Charles Dobson to Alan Davey 26 June 1989 p3 MHRA0017681, Dr Andrzej Rejman Transcript 10 May 2022 pp98-101 INQY1000203
- 226 Memo from Dr Rejman to Roger Scofield 13 April 1995 WITN5426015, Memo from Dr Rejman to Roger Scofield 13 April 1995 WITN5426016, Memo from Dr Metters to Dr Rejman 26 April 1995 WITN5426017
- The disclosure was not of Government documents, but minutes of UKHCDO meetings, for use in Irish litigation. Letter from Brian Colvin to Dr Rejman 27 February 1995 WITN5426007
- 228 Memo from Dr Rejman to Charles Blake 7 March 1995 DHSC0004221\_039
- 229 Memo from Anita James to Dr Rejman 26 September 1995 WITN5426047, Memo from Dr Rejman to Anita James 28 September 1995 DHSC0006352 007
- One particularly striking example, in the context of discussing a proposed compromise of the HIV litigation, in respect of sexual partners suffering secondary infection, reads "What guarantee is there that an individual will not put herself at risk and subsequently become infected and then claim a sum in the future? Among the ISCs [ie individual statements of claim] that I have read, there are several cases where wives have put themselves at risk against the express advice of their medical attendants. How would one deal with such individuals? It would be easier to state that there is a cut off point after which time no additional infected intimates are accepted." Memo from Dr Rejman to John Canavan 10 November 1990 p2 DHSC0046962 061

of a law unto himself in the sense that he wasn't a great respecter of lawyers, but then, you know, that goes with the territory."<sup>231</sup>

Richard Gutowski, who was a long-serving member of the Medicines Division, expressed concern about reaching a settlement in the HIV litigation: he was responsible for providing the Medicines Control Agency's comments that fed into Charles Dobson's submission about the HIV litigation: "Officials would accordingly advise strongly against an out of court settlement in the HIV/haemophiliacs litigation." He said "I should just stress that it's not my opinions being expressed here: it's the opinion of Medicines Division in its role as the Licensing Authority and also the Committee on Safety of Medicines." When pressed, he acknowledged that this would also have been his own view at the time. 233

The view within the Department of Health that the treatment had been the best that could be given called out for justification, but that was none other than a misplaced and uncritical assumption. This assumption in turn led to a view that patients were unjustifiably complaining, and unjustly complaining of delays when the Government had acted as swiftly as possible (another misplaced and uncritical assumption). It led inexorably to a view that the HIV litigation (and, no doubt, the Hepatitis C litigation that followed) was unjustified. The onerous demands on time and resources that litigation imposed because of the need to disclose documents probably fuelled these views further. It led to being defensive especially when it came to the disclosure of some documents which might be interpreted adversely to the official departmental line.<sup>234</sup> It is reflected in advice to ministers.<sup>235</sup>

Over time a climate had come to exist which could have formed a backdrop to the actions of a person who chose to remove documents. Once destroyed, the documents could no longer be disclosed, could no longer be a potential embarrassment to the government, and the position of the government would be less open to attack. Pressures of work would be eased. The sense that there was lack of rigour in safeguarding documents would have made it easier to choose to sideline some documents without any real risk of detection. It would also have tended to contribute to a feeling that proactive steps to recover missing documents were not a priority.

If the climate had been one in which it had been felt that there was significant justification for complaints about treatment, about the implementation of the self-sufficiency policy, or about delays in taking steps to protect the public, this would have given pause for more thought about whether the tentative conclusion that an individual had marked documents for destruction because of their contents was correct. In the light of the general climate

**Document Destruction** 

Asked, at the end of her evidence, to explain what she meant, she said "I don't mean he was rude or anything like that, but he had his own views about things, quite rightly, and he didn't necessarily take to what we were saying to him." Anita James Transcript 13 September 2022 p29, p116 INQY1000239

<sup>232</sup> Fax from Richard Gutowski to Mike Arthur p3 WITN5292078, Written Statement of Richard Gutowski paras 8.5, 8.6 WITN5292001

<sup>233</sup> Richard Gutowski Transcript 10 June 2022 pp8-9 INQY1000214

Memo from Roger Scofield to Dr Rejman p3 DHSC0006352\_081, Memo from Dr Rejman to Charles Blake p1 DHSC0004221\_039

<sup>235</sup> See the chapters on Lines to Take and Delay in Holding a Public Inquiry.

revealed by evidence touching on the context within which that action occurred, this was not the general view. No such pause is needed.

I must make it absolutely clear that it would be unfair – very unfair – for any reader of this Report to assume that because I have mentioned names in respect to strong views which influenced the culture in the Department this makes it more likely that those individuals have been the agents of any wrongful conduct. The two issues are separate.

# Further questions raised in the 2000s about the missing files

The need to have the fullest information available about infected blood, and hence the need for adequate documentation, continued to surface in a number of contexts after the Hepatitis C litigation concluded.

Concerns continued to be expressed by campaigners, MPs and the press to the Government about what had happened in the past. To meet these a number of reports were drawn up both in relation to the UK and Scotland.<sup>236</sup> At Westminster these in particular were a report, to be compiled from Department of Health records, published as *Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991* in 2006.<sup>237</sup> It was followed by a specific project to review the documentation which remained available, to which Linda Page was assigned (the "Page Review").<sup>238</sup> In addition the Department of Health needed to be able to interact with an inquiry chaired by Lord Archer of Sandwell (the "Archer Inquiry")<sup>239</sup> in 2009, and to respond to requests made from time to time under the Freedom of Information Act 2000.

All of these required that there be access to the fullest documentation available. Accordingly, a range of people in the 2000s looked for documents. Their searches threw up a somewhat muddled picture: but what remained clear was that though many documents or copies were turned up, piecemeal, some remained stubbornly unavailable: they had irretrievably and inexplicably gone missing.

When the Self-Sufficiency Report was being written, after 2002, the issue of the loss of HIV litigation files came to the fore. On 10 June 2003, Charles Lister explained to Zubeda Seedat that:

"Unfortunately, none of the key submissions to Ministers about self sufficiency from the 70s/early 80s appear to have survived. Our search of relevant surviving files from the time failed to find any. One explanation for this is that papers marked for public interest immunity during the discovery process on the HIV

<sup>236</sup> For Scotland, see the chapter on Scotland.

<sup>237</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991 2006 DHSC0200111. See the chapter on the Self-Sufficiency Report.

<sup>238</sup> Review of Documentation Relating to the Safety of Blood Products 1970-1985 (Non A Non B Hepatitis) May 2007 PRSE0000642. See the chapter on *Delay in Holding a Public Inquiry*.

<sup>239</sup> Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 ARCH0000001

Litigation have since been destroyed in a clear out by SOL (there is an email from Anita James to me confirming this). This would have happened at some time in the mid 90s." <sup>240</sup>

However for two reasons this does not fully explain the loss of files. First, Dr Rejman had said that his administrative colleagues had the **originals** of files 1-30 (and a duplicate set) so it is unclear why they did not have the originals of the remaining files.<sup>241</sup> The Solicitor's Division only had copies in any event so what had resulted seems very odd. The Solicitor's Division had lost copies.<sup>242</sup> Dr Rejman did not have all the originals.<sup>243</sup> And everyone had lost file 44. Moreover, the explanation of a "*clear out*" given to Charles Lister by Anita James (he said) is not supported by any direct testimony from Anita James: she does not herself say that she participated in any "*clear out*", and she knew that counsel had advised strongly that documents be preserved.<sup>244</sup> Second, it does not recognise that many files relating to self-sufficiency never made it as far as having to be considered for public interest immunity: they went missing before the litigation began, as discussed above.<sup>245</sup>

In February 2005 further questions were raised about the documents in the context of a Freedom of Information request.<sup>246</sup> Zubeda Seedat prepared draft responses and a briefing paper dealing with the HIV litigation documents. She noted that:

"We have two cabinets of papers (about 60 folders) which we understand were sent to our solicitors at the time of the litigation. However, it is not clear which of these papers (if any) would have been made available to the plaintiff's lawyers during discovery.

We have also looked at a number of registered files to locate the papers. We have found a minute dated 6 September 1990 which refers to documents identified under the PII claim and which were sent to Sol. There is also a list of documents marked 'PII claim category 2' (vol 17). In addition, we have consulted with Sol Division. However, we have been unable to establish what happened to these documents.

It is also our understanding, having spoken to the previous head of the blood team that that [sic] an earlier search for some papers (about self sufficiency into

- 240 Email from Charles Lister to Zubeda Seedat 10 June 2003 p1 DHSC0020720\_081. The same explanation was given in a minute from his successor Richard Gutowski on 15 December 2003. Memo from Richard Gutowski to Tony Sampson 15 December 2003 pp1-2 LDOW0000350. Zubeda Seedat was a higher executive officer in Charles Lister's blood policy team. Written Statement of Zubeda Seedat para 5.6 WITN4912001
- 241 Memo from Dr Rejman to Ruth McEwen 3 May 1996 DHSC0006352 045
- 242 Memo from Ruth McEwen to Dr Rejman and Paul Pudlo 2 May 1996 DHSC0006352\_048
- 243 Memo from Dr Rejman to Ruth McEwen 3 May 1996 DHSC0006352 045
- One question is whether there may be a confusion in Anita James' mind between a clear out in the Solicitor's Division and a clear out in Dr Metters' office. Although the documents are different, since one set relates to submissions on self-sufficiency and the other on arrangements to screen for Hepatitis C, Anita James did show some confusion between the two on at least another occasion: see the text on the next page discussing her response to Zubeda Seedat on 22 February 2005.
- 245 In the section of this chapter on *Documents missing by the time of the HIV litigation (1990)*.
- 246 Email from Michelle Lucas to Andrew Faulkner 2 February 2005 WITN6887002

blood products) from the 70's/early 80's could not be found. One explanation for this is that papers marked for public interest immunity during the discovery process on the HIV litigation have been destroyed in error at some time in the mid 1990's." <sup>247</sup>

(By way of comment, none of this seems to have been alert to the fact that much of the documentation relating to self-sufficiency had never been available for the HIV litigation in the first place, as counsel were complaining at the time).

In response to an earlier request, Anita James responded that:

"It was during a look for papers in the Hepatitis C case which did not involve the Department of Health that it was discovered that the papers had been destroyed. Charles Lister and I came to that conclusion and we had an audit done ... Also I would say 'by a junior official at the Department of health who no longer works there' (He took early retirement to look after his smallholding)." <sup>248</sup>

However, this email appears to confuse the position of the HIV litigation documents and the ACVSB minutes.

Anita James told the Inquiry that, at the time, she believed the person she was referring to as having retired to his smallholding was David Burrage but was now aware that she was mistaken given that Dr Rejman had told her on 7 June 1995 that David Burrage had asked the individuals responsible for setting the destruction dates to write to him.<sup>249</sup>

Further advice was sought from the Solicitor's Division about the Freedom of Information request, and the possibility of further searches of records in the Solicitor's Division, the archive at Nelson, the National Archives and the DRO was raised.<sup>250</sup>

Anita James responded on 5 April 2005 and said:

"My colleague Ronald Powell had conduct of the litigation all those years ago. Once the litigation was finished the files were sent to remote storage. About six years ago I looked for them in relation to another case we had and was unable to retrieve them because they had been destroyed. Department of Health records (as opposed to ours) were inadvertently destroyed in the early nineties as the HEO working in the branch had given them a ridiculously short destruction date ... There are no records." <sup>251</sup>

<sup>247</sup> Briefing paper on Freedom of Information Case 209 March 2005 pp3-4 DHSC0200049. The response from the Solicitor's Division is: Email from Mike Patrick to Zubeda Seedat 4 March 2005 DHSC0038529 056

<sup>248</sup> Email from Anita James to Zubeda Seedat 22 February 2005 DHSC0038529\_063, Briefing paper on Freedom of Information Case 209 DHSC0200044

<sup>249</sup> Written Statement of Anita James para 5.11 WITN5426001, Memo from Dr Rejman to Anita James 7 June 1995 DHSC0200022 002

<sup>250</sup> Email chain between Michelle Haywood, William Connon and others 29 March 2005 DHSC0200071

<sup>251</sup> Email from Anita James to Michelle Haywood 5 April 2005 p1 DHSC0038529 017

She explained to the Inquiry that she was referring to both the HIV litigation files and the ACVSB minutes in GEB/1.<sup>252</sup>

The account which follows is of a piecemeal, gradual, incomplete recovery of documents, some being originals, some being copies, from different sources and different places, over some time. It was a painstaking process. Eventually a large proportion of the documents that had been missing have been recovered.

When the work on the report by Linda Page, prepared by the Department of Health about documents relating to the safety of blood products in relation to Hepatitis C was being completed,<sup>253</sup> and at the same time there was a need to respond to various Freedom of Information requests, further documents were searched for.<sup>254</sup> In early 2006, documents held by the claimants' solicitors in the HIV litigation were returned.<sup>255</sup> These documents were copies of documents sent to the claimants' solicitors by the Department of Health, rather than the Department's original versions of the documents.<sup>256</sup>

The Scottish Executive independently decided to release documents which it was realised were not held by the Department of Health.<sup>257</sup>

Thereafter on 25 May 2006, it was agreed, following a meeting between officials, Caroline Flint and Lord Norman Warner:

"Destroyed documents: although not explicitly requested, I think it would be helpful to compile a definitive list of all the sets of documents which have been destroyed (there are two sets and we know more about one than the other), when they were destroyed (if we know), circumstances of destruction and likelihood of the documents which have just been found by the solicitors being copies of some [sic] the destroyed documents. We have this info but just need to pull it together in a crib sheet." <sup>258</sup>

- 252 Written Statement of Anita James para 5.16 WITN5426001
- The project objectives were: "Assess and report on documents relating to previous Government policy on the safe use of imported and domestic blood products during the period 1970 to 1985 when BPL commenced general issue of 8Y heat-treated factor VIII." Review of Documentation Regarding Government Policy in relation to the safety of Blood Products 12 June 2006 p4 DHSC5424612. The report was a year-long project from July 2006-July 2007 for which Linda Page had specifically been commissioned. Review of Documentation Relating to the Safety of Blood Products 1970-1985 (Non A Non B Hepatitis) 2007 PRSE0000642
- 254 Written Statement of Zubeda Seedat para 60 WITN4912001
- 255 Written Statement of Carol Grayson paras 122-123 WITN1055004, Email from Zubeda Seedat to Vicky Wyatt 19 May 2006 DHSC0015834, Hansard parliamentary question on Contaminated Blood Products: Hepatitis C 24 May 2006 DHSC0041304 052
- 256 Written Statement of Linda Page para 2.92 WITN7269001
- 257 Briefing on Blood Products Destruction of Records 11 May 2006 p2 DHSC5076111, The Observer Tainted blood victims allege official cover-up 23 April 2006 GFYF0000109
- 258 Email from William Connon to Gerard Hetherington 25 May 2006 pp3-4 DHSC0015812, Submission on Self Sufficiency in Blood Products 25 May 2006 p2 DHSC5106722. Caroline Flint was Parliamentary Under-Secretary (2005-2006) and then Minister of State for Public Health (5 May 2006 June 2007); Lord Norman Warner was Parliamentary Under-Secretary (2003-2005) and then Minister of State for Health (2005-2007).

Ministers also wanted an independent legal expert to review the documents that had been returned from claimants' solicitors to provide an initial analysis of what they contained, and this was done.<sup>259</sup>

On 27 July 2006, a meeting concerned with the review of documents by Linda Page noted that 47 lever arch files were located in Wellington House.<sup>260</sup> In handwriting it was added that a further eight files had been found in Wellington House, but overall "300 documents have been identified as missing from this series of files; 100 from 1973 - 1975 (1100 - 1199), 200 from 1985 (3600 - 3699 and 3900 - 3999). Seven of these documents are in the files returned to SOL."<sup>261</sup> 84 files at the DRO in Nelson had also been identified as "of potential interest."<sup>262</sup>

On 9 October 2006, William Connon explained that "This whole area is far from straightforward ... I am by no means certain that the 47 'files' were included in the self-sufficiency report and I am told they were not shown to Lord Jenkin either. The reason being that they are not actually registered files but folders of papers which were simply found in a cupboard in the office."<sup>263</sup> In a document dated the same day, the Wellington House files were described as having "always been in the possession of DH" but the 47 files "were not properly filed on registered departmental files" and the DRO files in Nelson were "recalled as part of the 'look back' exercise and a subsequent search for relevant files."<sup>264</sup>

In December 2006, William Connon told the Chief Medical Officer ("CMO") that 92 files at the DRO in Nelson had been identified as of "possible interest; these were scanned for content relating to NANB and ten files identified for further review."<sup>265</sup> He also noted that "Some documents previously thought destroyed or mislaid have been located. These are documents that were the subject of non-disclosure during the HIV litigation."<sup>266</sup>

The progress report of the Page Review for October 2006 - January 2007 recorded that additional documents had been identified in December 2006 and had now been placed in eight registered files: "These documents were located during a search of filing cabinets and were either loose, in box files or lever arch files. Two data cartridges were also found,

- Email from William Connon to Gerard Hetherington 25 May 2006 pp1-2, p4 DHSC0015812, Letter from Anne Mihailovic to Leigh-Ann Mulcahy 8 June 2006 DHSC0200127, Note from Leigh-Ann Mulcahy to Anne Mihailovic DHSC0004232 020
- 260 Review of Documentation Related to the Safety of Blood Products: Progress Report 26 June 14 July 2006 14 July 2006 p1 DHSC0004232\_066, Notes of Project Board meeting 27 July 2006 p1 DHSC0004232\_070
- 261 Review of Documentation Related to the Safety of Blood Products: Progress Report 26 June
   14 July 2006 14 p1 DHSC0004232\_066, Notes of Project Board meeting 27 July 2006 p1
  DHSC0004232\_070. The fact that the documents appear to have gone missing in three batches, each
  containing consecutively numbered documents, may suggest that the documents had been taken
  as batches from the files and not then returned except for the seven individual documents later
  obtained from solicitors.
- Notes of Project Board meeting 27 July 2006 p1 DHSC0004232\_070
- 263 Email from William Connon to Liz Woodeson 9 October 2006 p1 DHSC5154769. William Connon was head of blood policy (December 2004 November 2008). William Connon Chronology to the Infected Blood Inquiry 31 August 2022 para 1.1 WITN6887001
- 264 Memo from William Connon to Lord Warner 9 October 2006 p1 DHSC0200135
- 265 Memo from William Connon to CMO 4 December 2006 p4 DHSC5069877
- 266 Memo from William Connon to CMO 4 December 2006 p5 DHSC5069877

marked HIV Litigation 1989-1991. We do not have the technology to read these cartridges in house and ISD have arranged for the content to be accessed ... No further documents have been located."<sup>267</sup> Linda Page stated that one of the cartridges was readable but the other was corrupted.<sup>268</sup>

The action plan for January 2007 recorded that ten files of "recently located 'Wellington House' documents" were to be reviewed, along with 28 files from the DRO in Nelson.<sup>269</sup>

In July 2008 further files still were found. These were discovered:

"when reorganising the filing cabinets in Wel 517. We assume they were stored there by a previous inhabitant of Wel 517, perhaps since the 1989/90 Haemophilia litigation. They are not registered files, and are not very well organised. They contain documents from the time of the litigation, and documents from the 1970-1985 that have been removed or copied from the original files in order to be organised for discovery prior to the litigation." <sup>270</sup>

The significance of the files was noted because they included litigation documents and documents from 1970-1985 that were not in any other files. A further explanation was given that they had been found in "the hanging file system at the entrance of bay 517. It contains 41 folders of documents apparently compiled at the time of the HIV litigation (1989-90). Some of it is out of scope of our review and disclosure of documents (i.e., it is later than mid 1986)."<sup>271</sup> The plan was to inventory the papers and cross-check whether they had already been released or not. In addition, the documents that were found were filed into new registered files with the locations of the files being noted and the documents that were still missing.<sup>272</sup>

In September 2008, expert witness reports written for the Department of Health for the HIV litigation were also found.<sup>273</sup> The decision was taken in October 2008 not to release Professor Bloom's report because it was written in 1990 so it was outside the date range of papers that the Department of Health had committed to release.<sup>274</sup>

<sup>267</sup> Review of Documentation Related to the Safety of Blood Products: Progress Report 25 October 2006 - 3 January 2007 10 January 2007 p4 DHSC0046869

<sup>268</sup> Written Statement of Linda Page para 3.15 WITN7269001

<sup>269</sup> Review of Documentation Related to the Safety of Blood Products: Next Steps 1 January - 31 January 2007 3 January 2007 DHSC0103397\_004

<sup>270</sup> Email from Laura Kennedy to William Connon 16 July 2008 p2 DHSC5532594

<sup>271</sup> Email from Patrick Hennessy to William Connon 18 July 2008 p1 DHSC5533007

Email from Patrick Hennessy to William Connon 18 July 2008 pp1-2 DHSC5533007. See for example: Note from Patrick Hennessy and Charlotte Mirrielees to unknown 1 November 2010 DHSC0003581 001

<sup>273</sup> Email from Laura Kennedy to Patrick Hennessy 4 March 2009 p11 DHSC5562807

Email from Laura Kennedy to Veronica Fraser and Graham Kent 7 October 2008 p2 DHSC5545920, Email from Laura Kennedy to Veronica Fraser 24 September 2008 p2 DHSC5543979

In their joint written statement to this Inquiry, William Vineall<sup>275</sup> and Lorraine Jackson<sup>276</sup> identified the documents that had been found and those which remained outstanding. They acknowledged that to their knowledge, "there has never been a satisfactory explanation for why some of the HIV Disclosure files were permanently lost after the litigation ended."<sup>277</sup>

# Lord Jenkin's papers

On 14 December 2004 Lord Jenkin wrote to Lord Warner providing a copy of a request from a campaigner for him to provide a "so-called secret Westminster-funded report into haemophilia and hepatitis non-A non-B between 1979 and 1982".<sup>278</sup> In response, standard lines to take were used and Lord Jenkin understood from the letter that there were issues with the filing and record management systems.<sup>279</sup> He raised these concerns with the office of Sir Nigel Crisp (later Lord Crisp), who was both the Chief Executive of the NHS and Permanent Secretary at the Department of Health.<sup>280</sup>

A further letter was written by Lord Warner to Lord Jenkin dated 10 March 2005 "to correct the impression I may have given that we hold no records on the treatment of haemophilia patients, blood safety and related issues. The Department of Health has a Departmental Records Office (DRO) that holds closed files on these areas. These files have been subject to a branch review." <sup>281</sup> However, the background note that officials had prepared for Sir Nigel was also mistakenly sent with the letter. <sup>282</sup>

Lord Jenkin then requested a meeting with Sir Nigel because he believed that he was being denied access to papers that related to his time as Secretary of State and which he considered he was entitled to review under the Ministerial Code.<sup>283</sup>

On 24 March 2005 Lord Jenkin told the campaigner that he had an appointment with Sir Nigel and had asked him to make available all the files on contaminated blood and hepatitis from Lord Jenkin's time in office.<sup>284</sup>

A briefing was prepared by William Connon for Sir Nigel before his meeting with Lord Jenkin. It stated:

"We understand from colleagues that on a previous occasion, in 1999, Lord Jenkin wrote seeking access to policy papers, including unpublished research

- 275 Director of NHS Quality, Safety and Investigations, Department of Health and Social Care.
- 276 Director of Information Risk Management and Assurance, Department of Health and Social Care.
- 277 Written Statement of William Vineall and Lorraine Jackson para 1.40(g) WITN7193052
- 278 Letter from Lord Jenkin to Lord Warner 14 December 2004 p1 ARCH0003128. Lord Jenkin had been Secretary of State for Health and Social Services from May 1979 to September 1981. Lord Warner was the Parliamentary Under-Secretary at the Department of Health.
- 279 Letter from Lord Warner to Lord Jenkin 14 December 2004 p4 DHSC0200076
- 280 Now Lord Crisp. Email from Shaun Gallagher to Zubeda Seedat 9 February 2005 pp3-4 WITN3996006
- 281 Letter from Lord Warner to Lord Jenkins 10 March 2005 p1 ARCH0002570
- 282 Background Note from Blood Policy Team 28 February 2005 WITN3996007
- 283 Email from Norma McCarthy to Shaun Gallagher 16 March 2005 p2 WITN3996009
- 284 Letter from Lord Jenkin to Anon 24 March 2005 p8 MACK0000721

studies, that he had brought with him when he arrived at the DHSS in 1979. On that occasion, colleagues were unable to locate the documents. In fact, it is unlikely that they would have been retained, as they would not have been required either to support administrative needs or accountability." <sup>285</sup>

#### The lines to take included:

- "Many key papers from the 1970s and 1980s have been destroyed. During the HIV litigation in 1990 many papers from that period were recalled. We understand that papers were not adequately archived and were unfortunately destroyed in the early 1990s.
- We have been in touch with Departmental Records Office to check which files related to the treatment of haemophilia patients and blood safety are still in existence from the period between 1979-1989. We have obtained a list of some files from this period".<sup>286</sup>

The line to take continued that it would take too much staff resource to go through the files: "It would require significant staffing resource to go through these files to identify official papers that Lord Jenkin handled at the time."<sup>287</sup>

The meeting between Lord Jenkin and Sir Nigel took place on 13 April 2005.<sup>288</sup> Shaun Gallagher, private secretary to Sir Nigel, emailed Zubeda Seedat after the meeting noting what was agreed at the meeting, specifically that Lord Jenkin wanted to go through papers he would have seen at the time he was in office but that "He recognised that not all the papers would still exist; and that it would take some time and effort to identify the relevant files and find the appropriate papers."<sup>289</sup>

Lord Jenkin also wrote a note of the meeting to Carol Grayson, a campaigner, and said that the meeting had been "reasonably satisfactory" and that:

"Sir Nigel had with him the senior official who looks after the records for the Blood Policy Team at the Department of Health, Miss Zubeda Seedat. She produced a long list of files covering several pages of papers relating to the blood products policy over several years. These are files which exist in the Public Record Office, but so far nobody has begun to go through them to find out which of them might be relevant to the issue of contaminated blood leading to either HIV or Hepatitis C ... Sir Nigel went on to make the point that the initial use of the files was about HIV, but when compensation was paid to those who contracted HIV through contaminated blood products, it appears that most of the relevant files were then

<sup>285</sup> Memo from William Connon to Sir Nigel Crisp 11 April 2005 p2 DHSC0200075

<sup>286</sup> Memo from William Connon to Sir Nigel Crisp 11 April 2005 pp2-3 DHSC0200075

<sup>287</sup> Memo from William Connon to Sir Nigel Crisp 11 April 2005 p3 DHSC0200075

<sup>288</sup> Email from Norma McCarthy to Shaun Gallagher 16 March 2005 p1 WITN3996009

<sup>289</sup> Email from Shaun Gallagher to Zubeda Seedat 13 April 2005 p1 DHSC0200058

scrapped. At the time, Hepatitis C had not been identified as another potential risk. It may be, therefore, that some of the files I will want to see no longer exist." <sup>290</sup>

In his evidence to the Archer Inquiry, Lord Jenkin said that at the meeting with Sir Nigel, "Sir Nigel made it clear to me that all the files that bore upon the issue of contaminated blood products had been destroyed ... He then said that when this [HIV] litigation had been settled and the compensation paid, it was felt by the Department that there was no longer any point in retaining the files about contaminated blood and that they were accordingly destroyed."291 Lord Crisp in his evidence to this Inquiry had no recollection of the meeting but did not think that he would have said anything contradictory to the briefing that was given, otherwise this would have been picked up by his office afterwards.<sup>292</sup> He did not consider that there was any suggestion that "the destruction was the result of a deliberate decision in the sense of anyone knowingly acting outside Departmental policy. However, at least some of the destruction appears to have been deliberate in the sense of being the result of poor and unjustified decisions and/or bad archiving practice."293 In his oral evidence he gave three reasons why he did not believe that he said to Lord Jenkin that there had been a "deliberate cull" of documents: (1) he did not have any knowledge other than the briefing he had received; (2) it was not true because the Department of Health subsequently reconstructed most of the papers and (3) his officials would have raised it with him if he had gone beyond the lines to take.294

After the meeting, Zubeda Seedat worked to find relevant files, contacting the DRO in Nelson<sup>295</sup> and the National Archives.<sup>296</sup> Twenty files were found and were being assessed to see which may have come across Lord Jenkin's desk but it "does not look too hopeful".<sup>297</sup> Lord Jenkin was informed of the findings.<sup>298</sup>

Lord Jenkin attended the Department of Health on 13 September 2005 to view the files.<sup>299</sup> On the same day he emailed the campaigner who had prompted his interest and said that having been through the files "it is already clear that, after the finalisation of the HIV settlement, many of the most relevant files were no longer thought to be appropriate to be retained at the Public Records Office, and have accordingly been destroyed. Apparently, these include ALL the files that bear on the supply of contaminated blood products."<sup>300</sup>

On 19 October 2005, William Connon wrote to Lord Jenkin providing two sets of papers and said "As you know we requested all files relating to your period in office, dealing with

- 290 Letter from Lord Jenkin to Carol Grayson 14 April 2005 LDOW0000352
- 291 Written Statement of Lord Jenkin for the Archer Inquiry 20 April 2007 p2 ARCH0002968
- 292 Written Statement of Lord Nigel Crisp paras 36 and 55 WITN3996001
- 293 Written Statement of Lord Nigel Crisp para 69(4) WITN3996001
- 294 Lord Nigel Crisp Transcript 12 September 2022 pp89-90 INQY1000238
- 295 Email from Zubeda Seedat to Bill Proctor 15 April 2005 DHSC0046961 038
- 296 Action taken to retrieve papers 23 June 2005 DHSC0046961 036
- 297 Action taken to retrieve papers 23 June 2005 DHSC0046961\_036
- 298 Memo from Zubeda Seedat to Shaun Gallagher 19 April 2005 DHSC0200082
- 299 Email from Zubeda Seedat to William Connon 5 September 2009 DHSC0200087
- 300 Email from Lord Jenkin to Anon 13 September 2005 p2 MACK0000677 001

haemophilia patients who were infected with contaminated blood products. A number of files from the 1970's and 1980's have in fact been destroyed but we have made available to you all those which are currently held."<sup>301</sup>

On 25 October 2005, Lord Jenkin wrote to Sir Nigel raising his concerns about how few files were available to him: "However, as you indicated at the outset, all the files which would have borne upon the subject of contaminated blood products no longer exist. I have to say I find this extremely surprising given that the Government must have known that there were many further cases of people suffering from contaminated blood, notably haemophiliacs, some of whom have contracted various forms of Hepatitis." Lord Jenkin requested to discuss this with Sir Nigel because "They represent, by any standards, a most unhappy chapter in the Department's history and I would be very distressed indeed if this was felt to be an adequate reason for their destruction." 302

Zubeda Seedat prepared a briefing for Sir Nigel to respond to Lord Jenkin. The briefing explained that:

"At your meeting with Lord Jenkin and his two visits to the Department to inspect the files, we made clear that many key papers from the 1970's and 1980's have been destroyed. These events took place a long time ago. However, our understanding is that during the HIV litigation in the 1990's many papers from that period were recalled. We understand that papers were not adequately archived and were unfortunately destroyed in the early 1990's.

In addition, we have established that many other important documents, mostly papers and minutes of the Advisory Committee on Virological Safety of Blood were destroyed in the 1990's. This should not have happened. During the discovery exercise for the Hepatitis C litigation in 2000 it emerged that many files were missing. A low key internal investigation was undertaken". 303

A letter to that effect was sent to Lord Jenkin. However, where the briefing had said "and were unfortunately destroyed in the early 1990s" the letter said "were subsequently destroyed in error in the early 1990's." The attribution of the destruction to "error", rather than it simply being something which had happened, led Lord Jenkin not unnaturally to think that whereas he had been told that there was a reasoned decision for the destruction (that the Department of Health thought there was no further point in keeping the documents) he was now being told that far from it being a reasoned decision, no-one had intended those documents should be destroyed: it was a mistake.

Lord Jenkin therefore replied on 14 December 2005 that he considered Sir Nigel's letter to contradict what he had been told in their April meeting: "You then gave me to understand that the destruction of the contaminated blood files was the result 'of a decision' to dispose

<sup>301</sup> Letter from William Connon to Lord Jenkin 19 October 2005 WITN3996014

<sup>302</sup> Letter from Lord Jenkin to Sir Nigel Crisp 25 October 2005 DHSC0046961 014

<sup>303</sup> Memo from Zubeda Seedat to Sir Nigel Crisp 29 November 2005 p1 WITN3996019

<sup>304</sup> Memo from Zubeda Seedat to Sir Nigel Crisp 29 November 2005 p7 WITN3996019

of them as, following the settlement of the HIV cases, there seemed to be no useful purpose in retaining them in the PRO. I am quite certain that I did not misunderstand you; there was no suggestion whatever in what you said that the destruction of the files was the result of an administrative cock-up!"<sup>305</sup> Lord Jenkin followed this up with a question to the Chairman of Committees of the House of Lords.<sup>306</sup>

Lord Jenkin then chased for a response to his letter on 31 January 2006 and an internal email shows that this reply was to be delayed until the date for the publication of the Self-Sufficiency Report was known.<sup>307</sup> On 6 February 2006, Sir Nigel wrote to Lord Jenkin stating that he had explained that certain papers had been destroyed following the HIV litigation and apologised for their destruction.<sup>308</sup> Matters rested there: a year later when Lord Jenkin wrote to Lord Hunt upon his return as a minister to the Department of Health, he was concerned about having access to documents that the Department was known to hold about infected blood, and correspondence followed in which arrangements were made for him to have it. No reference was made by either to the destruction of records.<sup>309</sup>

## Commentary

Both Lord Jenkin and Lord Owen (whose complaints about missing papers are considered below) had served as ministers in the Department of Health and Social Security. Both sought access to papers in respect of events in the late 1970s and early 1980s. Both were given to understand that the documents they sought had largely or entirely been destroyed.

The similarity, though, ends there. Lord Jenkin was seeking to review files which might have crossed his desk; Lord Owen was seeking his Private Office papers.<sup>310</sup>

Lord Jenkin understood from what he had been told that there had been a deliberate decision made within the Department of Health to destroy documents relating to contaminated blood, because the Department of Health saw no point in keeping them after the HIV litigation came to an end. When he gave evidence to the Archer Inquiry (in 2009) he expressed his recollection as being that Sir Nigel had told him (a) that **all** files that "bore upon the issue of contaminated blood products had been destroyed" and (b) that because the Department of Health saw no point in keeping the files any longer, they were accordingly destroyed.<sup>311</sup>

Though the Inquiry can no longer hear from Lord Jenkin, it is not difficult to see how this view arose. Lord Jenkin's own near-contemporaneous note of the meeting links the ending of the

- 305 Letter from Lord Jenkin to Sir Nigel Crisp 14 December 2005 p1 WITN3996020
- 306 Question to the Chairman of Committees House of Lords 12 January 2006 p5 WITN2050072
- 307 Email from Zubeda Seedat to Elisabeth Vanderstock 31 January 2006 pp4-5 DHSC5204958
- 308 Letter from Sir Nigel Crisp to Lord Jenkin 6 February 2006 p4 WITN3996022
- Letter from Lord Jenkin to Lord Hunt 8 January 2007 ARCH0002573, Letter from Lord Jenkin to Lord Hunt 26 February 2007 p1 WITN4680022
- 310 Written Statement of Lord Jenkin for the Archer Inquiry 20 April 2007 p1 ARCH0002968. Lord Jenkin said that as Secretary of State he had asked his Private Office to "make sure that any papers dealing with contaminated blood were passed to me for reading." Lord David Owen Transcript 22 September 2020 p134 INQY1000055
- 311 Written Statement of Lord Jenkin for the Archer Inquiry 20 April 2007 p2 ARCH0002968

HIV litigation with "most of" the relevant files being "scrapped":<sup>312</sup> but does so more to place it as an event in its time setting, rather than as providing a reason for it. It is often assumed because an event took place **when** another event also took place that it did so **because of** that other event. It was not unreasonable for Lord Jenkin to make that assumption in the present case: but given the briefing which the Inquiry knows Lord Crisp had been given beforehand, which included as a "line to take" that "papers were not adequately archived and were unfortunately destroyed"<sup>313</sup> it would not have been what was intended. Lord Crisp makes a valid point when in evidence he pointed out that he was relying on a briefing, which did not suggest that a reasoned decision had been made to destroy the relevant documents, let alone describe what that reason was.<sup>314</sup> There were most probably crossed wires.

Some recollections gain colour over time, as people reflect back on them. The recollection Lord Jenkin gave to the Archer Inquiry came some time after his first report (to Carol Grayson), and what was described to her within days of the meeting as "most of the relevant files" being scrapped had become "all files that bore upon the issue of contaminated blood products" by that time. Given that Lord Jenkin had also reported that Zubeda Seedat had produced a long list of files still in existence which related to "blood products policy over several years", and recognised that they might well contain relevant documents, this is a clear overstatement. It makes a point, forcefully: but it is most probably not a faithful report of what Sir Nigel had told him at the time.

By 2006 it was also the case that (see above) many of the files which had been missing had been recovered – even though some had not – including a substantial number from solicitors who had acted for the plaintiffs in the HIV litigation.

In short, the interchange between Lord Crisp and Lord Jenkin does not provide any further evidence – either way – on whether the loss of documentation before, and shortly after the HIV litigation, followed by the destruction of files relating to the work of the ACVSB was the result of muddle and mistake or the consequence of someone deciding that those documents in particular should "go missing".

# Lord Owen's papers

In evidence to this Inquiry, Lord Owen said that the entire set of his Private Office papers had been destroyed from his time as a minister in the Department of Health and Social Security. He compared this to the fact that he had the entirety of his private papers from when he was Foreign Secretary. Lord Owen said that he did not know any more than that

- 312 Letter from Lord Jenkin to Carol Grayson 14 April 2005 LDOW0000352
- 313 Memo from William Connon to Sir Nigel Crisp 11 April 2005 p2 DHSC0200075
- 314 Lord Nigel Crisp Transcript 12 September 2022 p89 INQY1000238
- Letter from Lord Jenkin to Carol Grayson 14 April 2005 LDOW0000352, Written Statement of Lord Jenkin for the Archer Inquiry 20 April 2007 p2 ARCH0002968
- Letter from Lord Jenkin to Carol Grayson 14 April 2005 LDOW0000352. Lord Jenkin noted that "It is already clear that most of the files are not relevant to this".

and declined to comment on the explanations given in other witnesses' evidence. He left it to the Inquiry to establish what had happened and why.<sup>317</sup>

In 1987, Lord Owen wrote to John Moore, the then Secretary of State for Health, seeking information about what had happened to the extra money he had allocated in 1975 for self-sufficiency of blood products. The Department of Health was subsequently unable to find John Moore's response but "Lord Owen is quoted as saying that he was told that papers had been destroyed." A note within his constituency files records "DHSS records. Papers have been destroyed. Normal procedure after 10 years." Lord Owen believes that this note was almost certainly written in January 1988.

On 22 February 2002, Carol Grayson wrote to Yvette Cooper raising issues related to self-sufficiency and noted that Lord Owen had been told that his files had been "'pulped". She asked how the self-sufficiency review could be undertaken in such circumstances.<sup>321</sup> In response to a briefing on responding to this letter, Yvette Cooper asked where Lord Owen's papers were.<sup>322</sup> She has told the Inquiry that she:

"was becoming increasingly concerned that, despite receiving previous advice that 'relevant facts [are] largely established; information in the public domain,'. The reality was that we did not have a clear account of decisions that had been taken in the 1970s and 1980s, and therefore I could not be confident in the advice I was being given to answer campaigners' serious questions, nor could I be confident that previous official advice or subsequent Ministerial decisions on this issue were right as a result."

She therefore commissioned a detailed review of the surviving papers.<sup>323</sup>

This led to the Self-Sufficiency Report, work on which began after Yvette Cooper had left office in the Department of Health.<sup>324</sup> However, this did not include any investigation into the destruction of Lord Owen's papers.<sup>325</sup> Peter Burgin is clear that he was not asked to address the destruction of Lord Owen's papers in his original draft.<sup>326</sup> This was not Yvette Cooper's expectation. She believed that the report should have addressed the missing documents and "given detailed advice about what papers had been destroyed, what the circumstances

- 317 Lord David Owen Transcript 22 September 2020 p134 INQY1000055
- 318 Email from Zubeda Seedat to John Chan 19 December 2005 p1 WITN3996021
- 319 Handwritten note by Mr Slater LDOW0000318
- 320 Written Statement of Lord David Owen para 58 WITN0663001
- 321 Letter from Carol Grayson to Yvette Cooper 22 February 2002 p1 LDOW0000173. Yvette Cooper was Parliamentary Under-Secretary of State for Public Health from 7 June 2001 to 20 July 2001 and 7 January 2002 to 28 May 2002
- 322 Memo from Jill Taylor to Sarah Whewell 22 March 2002 p3 DHSC0042461 064
- 323 Written Statement of Yvette Cooper para 3.22 WITN7187001
- Memo from Robert Finch to Parliamentary Under-Secretary for Public Health 27 June 2002 DHSC0041305\_030. See the chapter on the *Self-Sufficiency Report*.
- 325 Email from Charles Lister to Zubeda Seedat 10 June 2003 p1 DHSC0020720 081
- 326 Written Statement of Peter Burgin para 2.9 WITN7485001

appeared to be and what important questions this therefore raised about what happened in the 1980s and 1990s."327

Charles Lister tried to find, within the policy files, the submissions that had been sent to Lord Owen during his time in office, but they were not there. Charles Lister concluded that they had been extracted from the files and sent to the Solicitor's Division for the HIV litigation and then been lost.<sup>328</sup> Copies were not found.<sup>329</sup> It now appears, to this Inquiry, that this is some of the documentation counsel had been seeking when first instructed to act for governmental bodies in the HIV litigation.<sup>330</sup> The circumstances of their disappearance remain unclear.

On 3 April 2002, Lord Owen was interviewed on *Radio 4* discussing the issue of infected blood and blood products. He said that he had sought his Private Office papers but had been told they had been pulped on the basis of a "*bizarre*" ten year destruction rule. He considered this to be "*very odd because ... all my papers as Foreign Secretary are available to me.*"<sup>331</sup>

A meeting was held on 1 July 2002 with Hazel Blears, Lord Morris and Michael Connarty MP. Lord Owen was unable to attend. The meeting note records that Lord Owen was concerned that his Private Office papers had been destroyed, but it appears that no response to this concern was made in the meeting.<sup>332</sup>

On 5 June 2003, Zubeda Seedat forwarded a parliamentary question from Lord Clement Jones to Charles Lister which asked what review had been undertaken into the circumstances of Lord Owen's missing files. In response, Charles Lister told Zubeda Seedat that the Self-Sufficiency Report would not be covering this issue.<sup>333</sup> However, he thought that Lord Owen's "allegation about pulped papers refers to the papers kept by Private Office which are never kept after a change of Government. They are either shredded or handed back to the relevant policy section."<sup>334</sup> This was also Robert Finch's understanding.<sup>335</sup> It is echoed by Michael Lillywhite who was Principal Private Secretary to Dr David Owen during his time as Minister of Health.<sup>336</sup> Brendan Sheehy states that "the Departmental policy was not to

- 327 Written Statement of Yvette Cooper paras 3.24 and 3.25 WITN7187001
- 328 He added "I cannot now recall the detail of what led me to this conclusion." Written Statement of Charles Lister paras 3.1-3.4 WITN4505389. There is no direct proof of this. It is a question of what might reasonably be inferred from such documents as still exist, what people are able reliably to remember, and knowledge of the surrounding circumstances. It should not be understood therefore as established fact.
- 329 Written Statement of Charles Lister para 3.4 WITN4505389
- 330 See the section in this chapter on *Documents missing by the time of the HIV litigation (1990)*.
- 331 Radio 4 The World Tonight Transcript 3 April 2002 p2 DHSC0042461 027
- Minutes of self-sufficiency in blood products meeting 1 July 2002 p1 DHSC0003606\_083. Hazel Blears was Parliamentary Under-Secretary of State for Health 2001-2002 and Parliamentary Under-Secretary of State for Public Health 2002-2003.
- 333 Email from Zubeda Seedat to Charles Lister 5 June 2003 p1 DHSC0200024
- 334 Email from Charles Lister to Zubeda Seedat 10 June 2003 p1 DHSC0020720\_081, also addressed Written Statement of Charles Lister paras 3.14-3.16 WITN4505389
- Robert Finch was in the blood policy team and was later an assistant private secretary. Written Statement of Robert Finch paras 1.4, 1.7, 1.9, 2.21 WITN7480001
- "Trying my best to remember, I think that the procedure was that if there was a change of government then the papers would have been sent back to the relevant policy team. I cannot now recall anything further." Written Statement of Michael Lillywhite para 4.8 WITN7087001

store the papers that had been seen by Lord Owen personally or his personal responses as a complete set, but rather to keep complete 'policy' files." <sup>337</sup>

On 8 July 2003, Melanie Johnson was briefed after taking up office as Parliamentary Under-Secretary for Public Health and the email following the briefing records "Lord Owen: Not a priority". 338

However, on 7 October 2003, a further letter was received from Lord Owen asking for the outcomes of the Burgin report.<sup>339</sup> John Hutton declined to sign off the proposed reply and asked for a full explanation of Lord Owen's accusation.<sup>340</sup> Officials were unsure what to say to the Minister given that they had been unable to find Lord Owen's papers, and were concerned that it would "highlight the issue that the 'Burgin' report has not been published and he may well raise this with [Melanie Johnson]".<sup>341</sup> On 15 December 2003, Richard Gutowski prepared a memo in response and noted that the Self-Sufficiency Report was not set up to address Lord Owen's concerns that his papers had been pulped. He noted that official papers (namely, "the key submissions to Ministers about self sufficiency") had also been destroyed.<sup>342</sup>

In January 2004, Lord Owen chased a response to his October letter.<sup>343</sup> There were further delays in providing a response because the letter had been back and forth between the blood team and John Hutton and then been lost in the system for a month.<sup>344</sup> The reply that was finally sent to Lord Owen on 17 March 2004, signed off by Melanie Johnson, simply stated that the Self-Sufficiency Review was "based on papers available from the time. The review does not address why papers from your Private Office at the time may have been destroyed."<sup>345</sup>

<sup>337</sup> Written Statement of Brendan Sheehy para 57 WITN0001015. There seems to have been discomfort in the Department of Health as to the way in which private office papers had been handled, which was reflected in evidence to the BSE Inquiry (1998-2000). The Shepherd Review (1999) led to the DRO working with private office staff in the Department of Health "to set up a registered filing system ... Each Private Office is responsible for filing its own Minister's papers, including annotated documents and submissions." Written Statement of Brendan Sheehy para 38 WITN0001015. Brendan Sheehy provided a written statement as departmental records officer in the Department of Health and Social Care

Email from Robert Finch to Vicki King and Richard Gutowski 9 July 2003 p1 WITN5292003. Melanie Johnson was Parliamentary Under-Secretary for Public Health 2003-2005.

<sup>339</sup> Letter from David Owen to John Reid 7 October 2003 LDOW0000142

Email from Jill Taylor to Robert Finch 5 November 2003 p2 WITN7480002. John Hutton (now Lord Hutton) was Minister of State for Health 1999-2005.

<sup>341</sup> Email from Jill Taylor to Robert Finch 5 November 2003 p2 WITN7480002. Robert Finch, responding, asked "Am I correct in remembering that we didn't find the papers and were therefore at a loss about how to take forward without it looking quite bad?" Email from Robert Finch to Zubeda Seedat 10 December 2003 p1 DHSC6549832

<sup>342</sup> Memo from Richard Gutowski to Tony Sampson 15 December 2003 p1 LDOW0000350

<sup>343</sup> Memo from Richard Gutowski to Tony Sampson 15 December 2003 p3 LDOW0000350

<sup>344</sup> Memo from Richard Gutowski to Parliamentary Under-Secretary for Public Health 9 March 2004 p1 WITN5292012

<sup>345</sup> Letter from Melanie Johnson to Lord Owen 17 March 2004 p2 HSOC0010692

It appears that there was then no further contact from Lord Owen about his pulped papers until 2006.<sup>346</sup> In 2006, the issue arose again and in email correspondence with Caroline Flint's assistant private secretary, Zubeda Seedat said while it might be practice to send private office papers to the DRO, her understanding was that private office papers at that time were either destroyed or returned to the policy section after a change in Government.<sup>347</sup> After a meeting with Caroline Flint and Lord Warner on 18 April 2006, Caroline Flint's assistant private secretary noted that Caroline Flint was "not convinced by the argument about destruction of documents from Lord Owen's private office."<sup>348</sup> William Connon responded that "Private offices are not required to hold papers. All papers should be routinely either returned to officials in the department or destroyed. Cabinet Office have never issued quidance for that reason."<sup>349</sup>

Caroline Flint in her evidence to the Inquiry said that although she was unconvinced at the time, "I think it came later that actually it was down to individual departments as to what they did, and they tended to hand — either the private office themselves would destroy them or they would be handed on to somewhere else to destroy them."<sup>350</sup>

As a final footnote, when the further files were found in Wellington House in July 2008, it was noted that five documents related to Lord Owen and they "date from 1975 and either paraphrase his views or have his notes on them." <sup>351</sup>

## Commentary

A central issue here is a lack of clarity as to the status of private office documents. It is illustrated by Caroline Flint's evidence. Despite having, as a minister, probed what happened to Lord Owen's papers at one point she thought that ministerial documents were not in practice either destroyed by the private office itself, or passed on for destruction elsewhere, but subsequently changed her mind. It is shown by Lord Owen's own experience that practice differs between Departments: his Foreign Office papers remain available to him. If Caroline Flint and Lord Owen had differing views of what should have happened, the uncertainty seems to be reflected by other ministers. The way in which different senior politicians have approached Lord Owen's allegations suggest they did not instinctively think that his documents had obviously been disposed of in the normal course of business – John Hutton wanted an explanation; Yvette Cooper plainly did not dismiss the allegations

- 346 Email from Zubeda Seedat to John Chan 19 December 2005 p1 WITN3996021
- 347 Email from Zubeda Seedat to Jacky Buchan 13 April 2006 p1 DHSC0200119
- 348 Email from Jacky Buchan to William Connon 18 April 2006 p1 DHSC0200120
- 349 Email from Jacky Buchan to William Connon 18 April 2006 p4 DHSC0200120
- 350 Caroline Flint Transcript 16 September 2022 p83 INQY1000241
- Email from Laura Kennedy to William Connon 21 August 2008 p3 DHSC5061894, Fax from Richard Gutowski to Mike Arthur 20 October 1989 DHSC0006484\_009
- 352 "I think it came later that". Caroline Flint Transcript 16 September 2022 p83 INQY1000241
- 353 Lord David Owen Transcript 22 September 2020 pp128-130 INQY1000055
- Email from Jill Taylor to Robert Finch 5 November 2003 p2 WITN7480002

as a misunderstanding;<sup>355</sup> Hazel Blears faced the issue when it was raised before her in a meeting, and did not attempt to resolve it.<sup>356</sup> Yet officials (for example Charles Lister) note that papers kept by private office are never kept after a change of Government but are shredded or handed back to the policy section;<sup>357</sup> and the approach of officials seems consistent (at least so far as the Department of Health is concerned) that private office papers were not stored together as registered files.

When the Department of Health had to give evidence to the BSE Inquiry they realised that there had been shortcomings in their system of handling private office papers. They took some action in response. But this was a very long time after Lord Owen's papers had disappeared.<sup>358</sup>

When Lord Fowler gave evidence he recounted his experience of some of these shortcomings. When writing a book about AIDS he asked to see his own papers at the Department of Health. He was taken to a side room, presented with three unsorted bundles of papers in no order, and noted that a secretary had been taken away from her duties to watch over him. He wrote in his statement: "That was the first time in my experience of writing three books that this procedure had been decreed: normally it was assumed if an ex-Cabinet minister had been trusted with the secrets of the Falklands, he could be trusted not to make off with what arguably were his own papers." He thought "it was quite evident that they didn't have a system [for storing papers]." He added that he knew nothing of any rule or policy regarding the maintenance or destruction of ministerial papers.

It is easy to see why Lord Owen's Private Office papers may have been destroyed if they were not, in fact, passed to the policy department or DRO: it however remains concerning that he was not given to understand that this would happen. The choice (according to the Grigg Committee (1954)) was either to return them to the policy department or have them

- 355 Memo from Jill Taylor to Sarah Whewell 22 March 2002 p3 DHSC0042461 064
- 356 Minutes of self-sufficiency in blood products meeting 1 July 2002 p1 DHSC0003606 083
- Email from Charles Lister to Zubeda Seedat 10 June 2006 p1 DHSC0020720\_081, Written Statement of Charles Lister paras 3.14-3.16 WITN4505389
- 358 "There were no specific instructions to Private Office staff about which papers should have been kept for the permanent record and it has become clear that many of the original papers seen by Ministers have been destroyed. In practice, once the Minister's decision/comment has been communicated to the relevant officials, these papers were usually retained by the Private Office, in case they needed to refer to them again. Private Office papers were 'weeded' periodically, often during the Parliamentary recess, and it was at this stage that a decision would have been made about the need to return papers to the originating section. It is not possible to confirm that original papers were returned to officials for retention ... Searching for the original submissions seen by former Ministers has raised a number of questions about the Department of Health's handling of the original papers seen by Ministers." Memo from Department of Health to BSE Inquiry February 1999 pp2-3 WITN0001017
- 359 Written Statement of Lord Norman Fowler para 0.36 WITN0771001
- He commented further that: "Government Departments are not concerned about ex-ministers writing memoirs which might contain themselves, and they're not very interested in history, in any event, if that history happens to be beyond the public relations issues. So I think that all that kind of comes together to run a pretty awful system." Lord Norman Fowler Transcript 22 September 2021 pp127-128 INQY1000145
- 361 Lord Norman Fowler Transcript 22 September 2021 pp126-128 INQY1000145

stored separately in consultation with the DRO.<sup>362</sup> He was not told that was the choice. He was not told that they would be or were being destroyed, only – when he sought them – that they had been.

It is also concerning that when the HIV litigation began what in particular were thin on the ground were documents relating to self-sufficiency: Lord Owen's Private Office papers, had they survived, would most likely have filled some of that gap.

Though these concerns remain, there is no sufficient evidence of impropriety to lead to a conclusion that Lord Owen's papers were destroyed because of their contents, rather than because destruction was thought to be an appropriate procedure.

# Overall commentary on document destruction

The ACVSB files (probably) and most of the documents which went missing after the HIV litigation have been reassembled, painstakingly, though some are permanently lost – and many documents relating in particular to self-sufficiency have also disappeared. Although it is deeply regrettable and of significant concern that documents touching on the central thrust of the case for people with bleeding disorders who had been infected with HIV should have been so thin on the ground by 1990, it adds to that concern that in response to claims of infection through blood and blood products there may have been efforts to hide documents from view: a "cover-up" in that sense.

As to that, my conclusions are these:

- (a) It is highly unlikely that there was any conspiracy organised at a high level to destroy or "lose" documents.
- (b) It is more likely than not that someone in the Department of Health deliberately chose to mark files which related closely to decisions about the introduction of Hepatitis C screening for destruction because of their contents, albeit this conclusion has been reached tentatively because the evidence could be fuller. This marking was applied in 1993; the destruction took place on different dates thereafter.
- (c) The internal investigation into this was hampered by being some seven years after the event, was ineffective, did not speak to some principal witnesses,<sup>364</sup> and reached an unlikely and speculative conclusion. The person responsible for the destruction cannot now be identified.

<sup>362</sup> Committee on Departmental Records Report 31 May 1954 p34 WITN0001012

The Inquiry has been able to obtain from various sources all the minutes and most of the papers of the ACVSB meetings held between 4 April 1989 and 9 February 1993. However, five of the chairman's briefings have not been recovered. List of documents used at ACVSB meetings April 1989 to February 1993 INQY0000380. A similar schedule is available for the HIV Litigation public interest immunity papers. List of documents withheld under Public Interest Immunity during the HIV Litigation INQY0000379

<sup>364</sup> In particular Dr Rejman, Dr Metters, David Burrage, and John Rutherford.

- (d) This particular loss of files could probably have been put right if the Department had acted with reasonable speed once Anita James became aware that the file GEB/1 volume 4 had been destroyed; or if Dr Rejman had recalled files from the DRO (the internal investigation left it as an unanswered question why this was not done). It would also probably have been avoided if Anita James had approached Dr Metters for the copy files in his possession which, on her evidence, she knew he had at the time. She left this too late.<sup>365</sup>
- (e) It is possible but not probable that the same person was responsible, in whole or in part, for the loss of documents prior to the HIV litigation reaching a stage at which counsel were asked to advise; and/or for losses of documents after that litigation concluded; and for the loss of ACVSB files and/or those which had been on Dr Metters' shelf. However, though this cannot be ruled out, in particular given what on the evidence is an unusual pattern of loss of documents relating to principal matters of concern in any anticipated litigation, it cannot be said to be more likely than not.
- (f) It is on balance more likely than not that Dr Metters' files were destroyed at some point following his retirement to make room for his successor's files. The evidence does not establish who might have been responsible for that.<sup>366</sup> Though I cannot be sure that a clear out was the cause, it is difficult to envisage any other way in which they could have disappeared without this being noticed.
- (g) The interchange between Lord Crisp and Lord Jenkin does not provide any further evidence – either way – on whether the loss of documentation before, and shortly after the HIV litigation, followed by the destruction of files relating to the work of the ACVSB, was the result of muddle and mistake or the consequence of someone deciding that those documents in particular should "go missing".
- (h) There is no sufficient evidence of impropriety to lead to a conclusion that Lord Owen's papers were destroyed because of their contents, rather than because destruction was thought to be an appropriate procedure. There was at the time a regrettable lack of clarity, and some confusion, amongst ministers about what should happen to private office papers in the Department of Health.

The DHSC accepted in its closing submissions to the Inquiry that, having discovered the destruction of certain files in June 1995, the subsequent destruction of further files was avoidable and should not have happened. DHSC Closing Submissions 16 December 2022 para 12.90 SUBS0000057

There is no reason to doubt Yvonne de Sampayo's evidence that she did not destroy them. There is also no proper basis to think that Anita James herself disposed of the files.

# 7.2 Self-Sufficiency Report

In 2002 there were increasing calls for there to be appropriate recognition for people infected by NHS treatment with Hepatitis C. One response on the part of the Department of Health was the production of the Self-Sufficiency Report – **Self-Sufficiency in Blood Products in England and Wales: a Chronology from 1973 to 1991.** This chapter details how that report underwent substantial changes in scope, purpose and content with consequential changes to its timescale and its essential nature.

#### **Key Dates**

**May 2002** Yvette Cooper commissions a formal internal review on self-sufficiency between about 1973 and 1985. She is concerned that the advice she has been given by officials, and that given to previous ministers, may not be right.

September 2002 Peter Burgin commences work on the review.

**24 December 2002** Peter Burgin emails his draft report to Charles Lister.

**June 2003** Richard Gutowski becomes the civil servant principally responsible for blood policy succeeding Charles Lister.

**7 June 2004** Dianthus Medical Ltd signs a contract with the Department of Health to undertake work on the report, essentially to add a summary and references.

4 August 2004 Dianthus sends an amended version of report to Richard Gutowski.

8 October 2004 Dianthus sends a further version of the report to Richard Gutowski.

20 July 2005 Near-final version of the Self-Sufficiency Report.

**27 February 2006** Self-Sufficiency Report is published.

#### **People**

Peter Burgin conducted the initial document review in 2002

William Connon head of blood policy, Department of Health (2004 - 2008)

**Yvette Cooper** Parliamentary Under-Secretary of State for Public Health (1999 - 2002)

Richard Gutowski head of blood policy, Department of Health (2003 - 2004)

Dr Adam Jacobs owner, Dianthus Medical Ltd

Charles Lister head of blood policy, Department of Health (1998 - 2003)

Dr Shanida Nataraja junior medical writer, Dianthus Medical Ltd

**Dr Hugh Nicholas** senior medical officer in the Health Protection Division, Department of Health

In early 2002 there was an increasing call from people with bleeding disorders and people who had received transfusions who had suffered infection with Hepatitis C for recognition that they deserved compensation or at least an inquiry, and an increasing strength of feeling that the Government had not responded properly to their cases.

It is probable that a number of background events contributed to this.

First, in March 2001 the High Court ruled in favour of compensating a cohort of people who had suffered Hepatitis C infection, on the grounds that they had been supplied with a defective product (blood or blood products). A number of findings critical of decision-making about testing for Hepatitis C, or non-A non-B Hepatitis ("NANBH") as it had been known, were made in the course of the judgment.<sup>367</sup>

Second, in 2002 in Ireland the Irish Haemophilia Society reached an agreement with the Irish Government that members infected with HIV should be compensated for suffering from HIV, and bereaved family members of people infected with HIV and Hepatitis C through blood products should become eligible to claim for the awards that would have been due to the deceased.<sup>368</sup>

Third, there was concern about the absence of documents relating to decision-making on self-sufficiency during the mid 1970s and early 1980s, which had come to light. Lord David Owen in particular was publicly complaining that his files had been "pulped". In the autumn of 2001 Louella Holdcroft had written an article in *The Journal (Newcastle)* headed "Owen's outrage at Failure over Blood". See Lord Owen was concerned that officials failed to honour his pledge to Parliament that the UK would achieve self-sufficiency in blood products.

Fourth, the Health and Community Care Committee of the Scottish Parliament published a report in which it recommended that the Scottish Executive establish a mechanism to provide financial and other appropriate practical support to those who had suffered Hepatitis C from receiving blood or blood products from the NHS.<sup>370</sup> An expert group had been established under a Court of Session Judge, Lord Donald Ross, to look at the pros and cons of a system of financial and other support.<sup>371</sup>

National media became interested. BBC Radio 4, in its programme *The World Tonight* on 3 April 2002, reported on Lord Owen's concerns about Hepatitis C infection.<sup>372</sup> This was

Self-Sufficiency Report

<sup>367</sup> A and Others v National Blood Authority Judgment 26 March 2001 PRSE0003333

<sup>368</sup> Minister Martin welcomes agreement with the Irish Haemophilia Society 11 April 2002 DHSC0041379\_019, Written Statement of Brian O'Mahony paras 51-61 WITN7418001

<sup>369</sup> The Journal Owen's outrage at Failure over Blood 2 August 2001 ARCH0001895

<sup>370</sup> Health and Community Care Committee Report on Hepatitis C 2001 p26 MACK0001929 001

<sup>371</sup> The announcement of an expert group was made in December 2001, with the expert group under Lord Ross being established in March 2002. Scottish Executive News Release *Executive to look at future health compensation system* 11 December 2001 SBTS0000358\_040, Parliamentary Question by Lord Morris 2 September 2003 p19 DHSC0006217\_027

<sup>372</sup> Radio Four The World Tonight Transcript 3 April 2002 DHSC0041379 024

followed closely by *You and Yours* on 30 April 2002 which highlighted the response in Ireland to people with haemophilia suffering from Hepatitis C infection.<sup>373</sup>

Haemophilia Action UK and the Manor House Group were two self-organised groups which actively highlighted some of the issues. On behalf of Haemophilia Action UK, Carol Grayson wrote a letter to the Department of Health on 22 February 2002. Lord Alf Morris, well known for his campaigning stance on behalf of people with disabilities, and president at the time of the Haemophilia Society, forwarded her letter separately to the Minister for reply. Before there was a response to it, Yvette Cooper, Parliamentary Under-Secretary of State for Public Health (including blood policy), met the All-Party Parliamentary Group on Haemophilia.<sup>374</sup> Her Private Office asked a civil servant (Jill Taylor) for advice about the response Yvette Cooper should give to the letter.<sup>375</sup> Jill Taylor referred in her submission to documents which Carol Grayson had mentioned in her letter, and said that:

"We have concerns that Ms Grayson has evidently obtained Government documents from the 1970s/1980s and is basing some of her arguments on information gleaned from these papers ... given pressures on time and resources, we have not looked in detail at the decisions made during that period, an exercise requiring several weeks of work. We have therefore not responded to the some [sic] of the detailed questions in Ms Grayson's letter which are partly based on those documents. We recognise that this is not a sustainable position and will provide further advice on handling shortly." 376

The submission has written onto it in manuscript, in response to those words: "Yes, it is unsustainable. Are they going to look into this or not. Seems they have to. And where are the Owen documents."<sup>377</sup>

Accordingly, Charles Lister, head of blood policy in the Department of Health, understood he should look into it, and sought the funds to employ an official for a short period to undertake a detailed review of the surviving papers between "*roughly, 1973 and 1985*" and put together a chronology of events.<sup>378</sup>

A sense of the content is given in three examples of correspondence from Carol Grayson: Email from Carol Grayson to Lord Owen 30 April 2002 HSOC0010778\_006, Email from Carol Grayson to Lord Owen 30 April 2002 HSOC0010778\_007 and Letter from Carol Grayson to Yvette Cooper 30 April 2002 HSOC0010778\_008

<sup>374</sup> It was known by the end of April that Haemophilia Action UK and the Manor House Group planned a demonstration, together with the Haemophilia Society, for May 2002, echoing one the previous year. Email from Charles Lister to Rachel Clinton 25 April 2002 DHSC0041379\_020

<sup>375</sup> Jill Taylor was a senior executive officer in the blood policy team led by Charles Lister. Written Statement of Zubeda Seedat para 9 WITN4912001

<sup>376</sup> Memo from Jill Taylor to Sarah Whewell 22 March 2002 p3 DHSC0042461\_064

The comment was from Yvette Cooper. Memo from Jill Taylor to Sarah Whewell 22 March 2002 p3 DHSC0042461 064, Written Statement of Yvette Cooper para 2.48 WITN7187001

<sup>&</sup>quot;Surviving" because it was well recognised by now that a number of papers, believed to include submissions to the Ministers at the time, had gone missing. Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p2 DHSC0041379 025

There is much of interest in his advice. First, he noted that without a chronology "it will be difficult to answer any detailed accusations levelled against the Department by Lord Owen and others."<sup>379</sup> He thought it would take at least two to three months, adding:

"We have considered whether it would be better to hold the meeting with Lord Owen before or after we have completed our chronology. On balance we think an earlier meeting has several advantages — we would be taking the initiative immediately after the You and Yours programme (broadcast 30 April) by contacting Lord Owen & Lord Morris with a desire to be helpful and open on the self sufficiency issue and hopefully reduce the chances of further comment from them suggesting that the Department has something to hide. Leaving a meeting until we have all the facts at our disposal would only perpetuate the current situation which places us too much on the defensive." 380

In the same vein he recommended that the Minister should meet Michael Connarty MP and the Haemophilia Society about a scheme for recompense for people with haemophilia with Hepatitis C: "for presentational reasons, we would recommend that you meet them. There are advantages in showing a willingness to listen".<sup>381</sup> As to meeting the Manor House Group and Haemophilia Action UK "Any future meetings will have to involve all haemophilia representative groups together and it is for them to sort out how they do this. This will not go down well but, presentationally, is a perfectly reasonable position to take."<sup>382</sup>

Finally, Michael Connarty had requested papers from Frank Dobson's review of the question of compensation.<sup>383</sup> Charles Lister's memo comments that he made this request:

"under the assumption that a detailed analysis would have been undertaken by the Department. The papers show this not to have been the case. The debate was focussed around concerns that such a scheme would open the flood gates to further claims. If papers are released they will show that Frank Dobson was

Self-Sufficiency Report

<sup>379</sup> He was relaying advice from the Department of Health's Investigation and Inquiries Unit. Janet Walden who headed the unit had advised "I think it is important that you locate whatever papers are now in existence and ask someone fairly senior and experienced to put together a chronology of events and key background papers. Without that it will be difficult to answer any accusations levelled against the Department by Lord Owen and others." Memo from Janet Walden to Charles Lister 17 April 2022 DHSC0041379\_023, Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p2 DHSC0041379\_025

<sup>380</sup> Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p2 DHSC0041379 025

<sup>381</sup> Emphasis added. "Given that ministers have made clear repeatedly that there will be no financial settlement for these patients, there is nothing to be gained by such a meeting." Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p2 DHSC0041379\_025

Charles Lister said a meeting with Manor House Group was going ahead only because it had been requested by an MP. Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p2 DHSC0041379 025

Frank Dobson had been Secretary of State for Health between May 1997 and October 1999. His review of the compensation question is considered in the chapter on *Government Response to Hepatitis C Infections*. Margaret Jay was Minister of State for Health between May 1997 and July 1998.

minded to support a scheme limited to haemophiliacs with Hepatitis C but was persuaded from this by officials and Margaret Jay." 384

The next day, Yvette Cooper decided that a formal internal review should be undertaken on self-sufficiency between about 1973 and 1985,<sup>385</sup> because the Department "did not have a clear account of decisions that had been taken in the 1970s and 1980s, and therefore I could not be confident in the advice I was being given to answer campaigners' serious questions, nor could I be confident that previous official advice or subsequent Ministerial decisions on this issue were right as a result."<sup>386</sup> She also expected the review to address the issues of the destruction of departmental papers and Lord Owen's Ministerial papers.<sup>387</sup> It was expected that the work would take at least four to five months.<sup>388</sup>

An internal advert was placed and Peter Burgin, senior executive officer at the Department of Health, was appointed to the role.<sup>389</sup> He started work on the report in September 2002, working out of a departmental building in Leeds, receiving boxes of documents to review from Charles Lister's team in London.<sup>390</sup> He also recalls interviewing Dr Terry Snape, Blood

- The submission went on to suggest that Yvette Cooper might "wish to consider writing to Michael Connarty explaining that the decision was taken after a discussion on the principles and wider implications of offering a scheme rather than on the basis of a detailed analysis of costings etc." By way of comment, this is perhaps best described as "defensive" rather than open. Memo from Charles Lister to Parliamentary Under-Secretary of State for Public Health 8 May 2002 p3 DHSC0041379\_025
- 385 Memo from Robert Finch to Parliamentary Under-Secretary of State for Public Health 27 June 2002 p2 DHSC0041305\_030
- 386 Written Statement of Yvette Cooper para 3.22 WITN7187001
- Written Statement of Yvette Cooper para 3.24, para 2.64 WITN7187001, Minutes of NHS London/Manor House Group/Haemophilia Action UK/MP meeting 15 May 2002 p3 HSOC0010634\_093
- 388 Memo from Robert Finch to Parliamentary Under-Secretary of State for Public Health 27 June 2002 p2 DHSC0041305\_030. Yvette Cooper says in her written statement that in the light of her experience with CJD and vaccines, where she had become aware that previous advice to ministers had not been reliable, she had asked for reviews and this had led to very quick responses. She sought this review in the light of this experience, and it seems clear she expected a relatively quick response. Written Statement of Yvette Cooper para 3.22 WITN7187001. The answer to a Parliamentary Question in October 2002 anticipated the completion of the review in the new year. Parliamentary Question and Written Answer 23 October 2002 p1 DHSC0041332\_038. In November 2002, Hazel Blears (now the Minister) was "keen to see a detailed report as soon as possible." Minutes of Department of Health Blood Stocktake meeting 7 November 2002 p1 DHSC0042275\_153
- Email from Peter Burgin to Zubeda Seedat 16 March 2005 WITN7485002. In Peter Burgin's statement he describes how the role involved a three-month temporary promotion to Grade 7. Written Statement of Peter Burgin para 1.2 WITN7485001. Richard Gutowski (who was not involved in his appointment) appears to question the wisdom of appointing someone "who I now understand was a DH official (on temporary promotion to Grade 7) with no prior involvement in blood policy". Written Statement of Richard Gutowski para 1.11 WITN5292109. However, the ambition which Yvette Cooper had for the work was significant: it was not only to draw up a chronology but to enable her to understand whether previous official advice and ministerial decisions based on it had been right. In short, if it had been prepared by an official who had already been involved in blood policy, she might have expected simply a reiteration of the previous and existing "lines", and it was these she wished to test. Notwithstanding this point, given that her purpose, as described to the Inquiry, was to have "a thorough review that uncovered new questions, that investigated the campaigners['] concerns and exposed any further problems so that we could then consider what the next appropriate steps might be." Written Statement of Yvette Cooper para 3.22 WITN7187001). A more senior civil servant would have been better suited for the task. At the least, it would have given less scope for the extensive editing of Peter Burgin's work such as took place after 2002.
- Written Statement of Peter Burgin para 3.1 WITN7485001

Products Laboratory ("BPL"); Dr Mark Winter, consultant haematologist; Dr Frank Hill, consultant haematologist; and Chris Hodgson, chair of the Haemophilia Society.<sup>391</sup>

In the event, the work was completed so far as Peter Burgin was concerned within four months. He emailed his report to Charles Lister on 24 December 2002.<sup>392</sup>

# Principal issues arising

The decision to conduct an internal review had been taken in May 2002. By the time Peter Burgin began his work, Hazel Blears had taken over as Parliamentary Under-Secretary of State for Public Health from Yvette Cooper. The material parts of the job for which he was recruited were set out in the job description. The key responsibilities were to:

- "(i) Review documents held by the Department and other bodies for the period 1971 to 1985,<sup>393</sup> identify key documents and produce a chronology of events. Interviews with officials, clinicians and others active in this area at the time may be necessary to build up a full picture.
- (ii) Produce an analysis of the key issues, including:
  - the development of policy on UK self sufficiency in blood, the factors that influenced it and the reasons why it was never achieved;
  - the ability of NHS blood products fractionators to produce the volumes of product required;
  - the evolving understanding of the viral risks associated with pooled blood products, both domestically produced and imported, and how this influenced policy;
  - the extent to which patients were informed of these risks;
  - the developing technologies to enable viral inactivation of blood products and the timing of their introduction in the UK.
- (iii) Summarise these findings in a report for Ministers." 394

Although what gave rise to the report was infection with Hepatitis C an initial paragraph in the job description said "Almost all haemophilia patients treated with blood products in the 1970s and early 1980s were infected with hepatitis C, many with HIV. Lord Owen, a Health Minister in the 1970s, has suggested that this might have been avoided had the UK achieved self sufficiency in blood products, a policy he initiated in 1975."<sup>395</sup>

Self-Sufficiency Report

<sup>391</sup> Dr Snape prepared various documents for Peter Burgin prior to his visit. Memo from Dr Snape to Charles Lister 28 August 2001 WITN3431005

<sup>392</sup> Email from Peter Burgin to Dr Lister p2 WITN4505402, England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 WITN7485005

<sup>393</sup> Note that the time period had been extended to 1971. No reason is known.

<sup>394</sup> Email from Peter Burgin to Zubeda Seedat 16 March 2005 p2 WITN7485002

<sup>395</sup> Email from Peter Burgin to Zubeda Seedat 16 March 2005 p1 WITN7485002

After Peter Burgin had completed his work the task he had performed was described in slightly different terms (by Charles Lister) as being to address a number of issues chiefly:

- "- how the Department implemented the policy of UK self sufficiency in blood products begun in 1973 (Lord Owen has said publicly that officials did not carry out his wishes);
- to chart the developing understanding of the seriousness of non A/non B hepatitis (later identified as hepatitis C);
- to examine the extent to which problems at BPL delayed the achievement of self sufficiency;
- whether the achievement of self sufficiency would have led to fewer cases of hepatitis C in haemophilia patients.

It was not set up to address Lord Owen's allegation, dating from the late 80s, that the papers from his period as a Minister had been 'pulped'.

Unfortunately, none of the key submissions to Ministers about self sufficiency from the 70s/early 80s appear to have survived. Our search of relevant surviving files from the time failed to find any ... the fact that we can no longer find any of these documents — so can't say what Ministers did or didn't know about the state of play on self sufficiency — just plays into the hands of the conspiracy theorists." <sup>396</sup>

Accordingly, the focus was on Hepatitis C and it did not (despite Yvette Cooper's understanding as the Minister commissioning the work)<sup>397</sup> seek to deal with the destruction of Lord Owen's papers.

The first concern, therefore, is the different emphases in scope of the Minister and the lead official involved in commissioning the report.

There were very substantial differences between the project as envisaged initially and as eventually delivered to the public:

(a) Whereas Peter Burgin considered the period from 1973-1985,<sup>398</sup> the report as eventually produced had a very substantial change in perspective – from 1973 to 1991. Instead of 12 years being in scope, there were eventually 18.<sup>399</sup> There is no documented reason for this change, though the evidence set out below suggests that the idea that there might be an extension might have come from a medical researcher engaged to reference Peter Burgin's draft.<sup>400</sup>

<sup>396</sup> Email from Charles Lister to Zubeda Seedat 10 June 2003 p1 DHSC0020720\_081

<sup>397</sup> Written Statement of Yvette Cooper para 3.24 WITN7187001

<sup>398</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 WITN7485005

<sup>399</sup> Half as much again.

Her suggestion might owe something to discussions with Richard Gutowski who in the March before Dianthus were contracted had told his boss that it would be helpful to have a subsidiary report on when HCV was first identified, and what decisions were taken at the time and for what reasons. Email from Richard Gutowski to Gerard Hetherington 1 March 2004 p2 DHSC6259005. He is likely to have planted the seeds of the idea.

- (b) It was intended to be an internal review, though perhaps a summary to the public might have been envisaged (if this had not been the case initially, it became so when Hazel Blears said words to that effect in a parliamentary reply, which had been inspired by concern that documentation about Lord Owen's initiative on self-sufficiency had gone missing).<sup>401</sup> It moved, instead, to a document designed for publication to the public, which no longer concentrated on seeing if it could fill in the gaps left by missing documentation so that ministers could take informed decisions and more faithfully relay the facts to the public.
- (c) It moved from a document essentially concerned with the facts in relation to self-sufficiency (a factual account of what documents said) to become one which was argumentative (expressing opinions about the quality of what had happened). This should not of course be overstated: it may rightly be said that when recounting the facts which deserve to be recounted they will first have to be selected, and that both what is selected and what emphasis is given to facts within that selection will inevitably depend to an extent upon the viewpoint and opinion of people recounting the facts that seem important to them. Much may depend upon the perspective of the author as to what facts are seen as such. However, in the case of the Self-Sufficiency Report the changes in the document as eventually produced go well beyond a question of there simply being a change of author and with that a change of perspective.
- (d) There were very significant changes in the content of the document. As published, it presented a different picture in many respects to the initial document. None of those who might be thought responsible for producing the document accept that this was the result of their input. All seek to say that the Self-Sufficiency Report, as it became in each of four differing editions after the first, was in essence the same as the report initially had been, with no change to the substance of what was reported. This was not the case.<sup>402</sup>
- (e) There was a very considerable delay in finalising the report. It had been commissioned in May 2002, work started in September 2002 and it was substantially completed by Peter Burgin when he handed over a draft on Christmas Eve 2002.<sup>403</sup> Ministers (Yvette Cooper, Hazel Blears, Melanie Johnson, Lord Norman Warner) pressed for it to be completed.<sup>404</sup> Yet the Self-Sufficiency Report, as finally completed, was not published until 27 February 2006.<sup>405</sup>

<sup>401</sup> Parliamentary Question and Written Answer 23 October 2002 p1 DHSC0041332 038

<sup>402</sup> The reasons for saying this follow later in this section.

<sup>403</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 WITN7485005

<sup>404</sup> Memo from Jill Taylor to Sarah Whewell 22 March 2002 p3 DHSC0042461\_064, Minutes of Department of Health Blood Stocktake meeting 7 November 2002 p1 DHSC0042275\_153, Email from Richard Gutowski to Gerard Hetherington 6 May 2004 p2 DHSC5336358, Letter from Lord Warner to Lord Morris 7 March 2005 HSOC0001762. Lord Warner was Parliamentary Under-Secretary of State for Health in the Lords 2003-2005 and Minister of State for Health (NHS Reform) in the Lords in 2006.

<sup>405</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 DHSC0200111

Why was there such a delay when a report was (according to those involved in its production) complete in essence by Christmas Eve 2002, and required only some finessing and referencing for it to be suitable for publication?<sup>406</sup>

Charles Lister was succeeded in post as the civil servant principally responsible for blood policy by Richard Gutowski in June 2003. 407 During his time in post, the work on the report became much more substantial than had been envisaged by Charles Lister. It was no longer simply a matter of tidying up the referencing and clarifying parts of the text. Many parts of the substance of the report were changed. Peter Burgin gave evidence to the Inquiry that the draft he submitted was substantially rewritten before the final report was published. As he demonstrates in his written statement, the changes go well beyond merely clarifying the text and fundamentally change the meaning, content and substance of the conclusions which were reached. 408 Some indication of this is given by the fact that Peter Burgin's conclusion would sit neatly on one page of A4; as published, the conclusions (in a smaller point size) occupied three pages. 409

# The process by which the Self-Sufficiency Report was produced

Both Charles Lister, and in turn Richard Gutowski, worked under strong pressures. Having received the draft report on Christmas Eve 2002 Charles Lister had done nothing with it before he departed his post in May 2003. He regrets that he "simply had not been able to take the drafting forward [between those dates] ... I can offer no justification for the delay, save that the Inquiry will be well aware ... of the massive pressures on my team."<sup>410</sup> Despite officials being aware of the need for the report to be published, ministers pressing for progress and campaigners persistently asking for answers about when it would be

<sup>406</sup> See below

<sup>407</sup> Written Statement of Richard Gutowski para 9 WITN5292001

<sup>408</sup> Written Statement of Peter Burgin paras 3.25-3.26 WITN7485001

Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 pp32-34 DHSC0200111, to be compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 pp19-20 WITN7485005

<sup>410</sup> Written Statement of Charles Lister para 4.76, para 4.85 WITN4505389

published, nothing happened.<sup>411</sup> Richard Gutowski explained that "speaking for 'my half' of 2003, this reflected I am afraid, the very great pressures that my team were under."<sup>412</sup>

Charles Lister had plainly envisaged making the report as drafted by Peter Burgin more widely available but in his handover notes said he thought it needed an executive summary, and references to the documents quoted and to back up statements which otherwise would remain unsubstantiated; and that they might wish to consider sending (with ministers' agreement) a final draft to some of the people consulted for comments on the factual accuracy.<sup>413</sup>

Counsel to the Inquiry asked Richard Gutowski when he gave oral evidence: "Is it fair, then, that, as at June 2003, there was only minor work on referencing that was required on this report?" to which the answer was: "On the basis of this note from Charles, yes."<sup>414</sup>

Despite the work being minor, by March 2004 nothing had happened about finalising the referencing. Richard Gutowski considered that due to the pressures he was under external consultants were required to finalise the report<sup>415</sup> and a contract with Dianthus Medical Ltd ("Dianthus") was signed on 7 June 2004.<sup>416</sup> The scope and nature of their work is discussed below. Much of the actual work in producing it was delegated to Dr Shanida Nataraja, a junior medical writer in her first job since completing her PhD.<sup>417</sup>

Dr Adam Jacobs, the owner of Dianthus, sent their final version of the report to Richard Gutowski in October 2004.<sup>418</sup>

- 411 See for example Letter from Melanie Johnson to Peter Mossman 28 August 2003 PMOS0000153, Letter from John Hutton to Lord Owen DHSC0003606\_078 and Memo from Richard Gutowski to Tony Sampson 15 December 2003 LDOW0000350. An example is from November 2003 when Melanie Johnson was the Parliamentary Under-Secretary of State for Public Health. Jill Taylor in Richard Gutowski's team wrote to the Private Office to say that a letter to Lord Owen about his papers had gone to John Hutton for signature. He had refused to sign, seeking a full explanation of Lord Owen's accusation. Jill Taylor's memo continued "We could go back to him and explain that Lord Owen's [sic] alleges that his papers, when he was Health Minister, were 'pulped' and provide him with a copy of the meeting note between Connarty, Morris (Owen failed to attend) and Hazel Blears in July 2002 (attached) where the matter was discussed, however all of this highlights the issue that the 'Burgin' report has not been published and he may well raise this with PS(PH).
  - We would be grateful for a steer on this please, are we to hold the line as given in the rejected letter and provide John Hutton with all the background information or do you think PS(PH) will want to take any action on the report?" Email from Jill Taylor to Robert Finch 5 November 2003 p2 DHSC6549832. Embarrassment over the non-publication of the Self-Sufficiency Report is clear but an inference is that the civil servants were not keen to move ahead with it quickly.
- Written Statement of Richard Gutowski para 4.45 WITN5292016. See also Richard Gutowski Transcript 10 June 2022 pp119-120 INQY1000214
- 413 Email from Charles Lister to Zubeda Seedat 10 June 2003 p1 DHSC0020720 081
- 414 Richard Gutowski Transcript 10 June 2022 p112 INQY1000214
- He emailed his boss to this effect: Email from Richard Gutowski to Gerard Hetherington 1 March 2004 DHSC6259005, Written Statement of Richard Gutowski para 1.15 WITN5292109
- 416 Agreement between the Department of Health and Dianthus Medical Limited 7 June 2004 WITN5292057
- Written Statement of Dr Shanida Nataraja paras 1, 2 and 5(a) WITN7663001. Although she had impressive academic qualifications, it is surprising that it should have been thought that letting a minister know whether the facts her predecessors had stated were accurate or not, and why, should be assigned to a person with such limited experience and seniority.
- England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1991 8 October 2004 WITN5292116. They had produced a first version in August 2004 (misdated on the front cover).

No further progress was made with any speed by officials despite being asked in January 2005 to complete the report "as quickly as possible." Nevertheless, on 7 March 2005 Lord Warner reported to Lord Morris that "officials have not yet been able to progress this review to completion" and said that he had "asked officials to complete the report as soon as possible." This followed letters between Lord Owen and Lord Morris about the (lack of) progress with the Parliamentary Ombudsman. 421 A further version was produced by July 2005, with there being only one insubstantial change after that before eventual publication. 422

In his written statement Richard Gutowski says:

"Viewed against an objective standard, I entirely accept that work on the internal review took far too long and we made inadequate progress when I was Head of Blood Policy. The Inquiry may well conclude that – again judge [sic] by objective standards – it did not get the priority it deserved. I would not seek to argue against that. What I do wish to convey however, is that my team worked exceptionally hard and were under huge pressures." 423

The slow progress was caused by "our sheer workload." 424

When William Connon became head of blood policy in December 2004<sup>425</sup> it seems he had little awareness initially that an internal review was ongoing. When seeking to respond to correspondence from Carol Grayson, a campaigner, he asked Zubeda Seedat to "see if you can identify which report the person is referring to."<sup>426</sup> However, on 11 April 2005 he was able to tell Sir Nigel Crisp, who was about to meet with Lord Patrick Jenkin, that "The report is now complete and a submission is in preparation for PS(PH) on handling and making the results of the analysis of the papers public."<sup>427</sup> The version, said to be final, <sup>428</sup> was sent to Peter Burgin on 12 May 2005. He reviewed it, though briefly, and made some minor suggestions on both the report and the draft submission. <sup>429</sup> He had had no contact with

Email from Dr Nataraja to Richard Gutowski 4 August 2004 WITN5292112, England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 WITN5292113

<sup>419</sup> Background note on the review of internal papers 1973-85 27 January 2005 p2 DHSC0038551\_022

<sup>420</sup> Letter from Lord Warner to Lord Morris 7 March 2005 HSOC0001762. Another minister who was pressing for the report to be produced.

Letter from Lord Owen to Lord Morris 25 January 2005 LDOW0000146, Letter from Lord Morris to Lord Owen 1 February 2005 LDOW0000145

<sup>422</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 20 July 2005 DHSC0200084\_002, Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 DHSC0200111

<sup>423</sup> Written Statement of Richard Gutowski para 4.54 WITN5292016

<sup>424</sup> Written Statement of Richard Gutowski para 4.56 WITN5292016

<sup>425</sup> William Connon Rule 9 Requests: Chronology of Documents 31 August 2022 para 1.1 WITN6887001

Zubeda Seedat was a higher executive officer in his team. Email from William Connon to Zubeda Seedat 3 February 2005 p1 DHSC0006164\_024, Written Statement of Zubeda Seedat para 5.6 WITN4912001

<sup>427</sup> Submission from William Connon to Sir Nigel Crisp 11 April 2005 p13 WITN3996010

<sup>428</sup> The version of 8 October 2004.

Email chain between Zubeda Seedat and Peter Burgin 12 May 2005 DHSC5368830, Draft Memo from William Connon to Parliamentary Under-Secretary of State for Public Health May 2005

anyone about his report since submitting it in 2002: indeed, he then remained unaware that the report had been published until 2018.<sup>430</sup>

On 16 May 2005, William Connon circulated the draft Self-Sufficiency Report to officials in the Scottish Government explaining that "Due to other work pressures we have been unable to complete work on the report before now." He prepared a submission for the Minister on 20 July 2005. The timing was now marked as "Urgent." This appears to be because there had been numerous requests for the release of papers dating back to the 1970s, and parliamentary questions and correspondence about when the outcome of the review would be finalised. Nonetheless, publication of the Self-Sufficiency Report was further delayed. Zubeda Seedat told the Private Secretary to the Parliamentary Under-Secretary of State for Public Health on 3 February 2006 that the report would be published on 16 February 2006. On 6 February, however, she then updated the Minister that the publication had now been moved back to 27 February 2006.

Just before publication a submission was put up to Caroline Flint, Parliamentary Under-Secretary of State for Public Health, so that media handling around the publication of the report could be agreed. The submission noted: "There may also be accusations that the report took so long to be published. The reason for this was having to check for accuracy of the report which took a significant amount of time. In 2004, officials commissioned independent consultants to analyse the papers and finalise the report. We have also consulted with colleagues in the devolved administrations, BPL, National Blood Service and some clinicians for factual accuracy." It is clear from the chronology above that none of those reasons actually explains the delays and that the Minister was not therefore being given an accurate or transparent explanation.

The Self-Sufficiency Report was finally published on 27 February 2006.<sup>436</sup>

Charles Lister offered no justification for his part in the delay, which was the period between 24 December 2002 and his departure five months later in May 2003, beyond the massive pressures on his team. From mid 2003 until December 2004 Richard Gutowski was responsible. He, too, referenced the pressures his team was under. However, it took almost nine months for him to decide that a sensible way of dealing with those pressures building over a report which was a priority for many, when he had inadequate resources within his team, was to involve external consultants.

Self-Sufficiency Report

DHSC5367051, England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 8 October 2004 WITN7485007

<sup>430</sup> Written Statement of Peter Burgin para 4.1 WITN7485001

<sup>431</sup> Email from William Connon to Caroline Lewis and others 16 May 2005 pp4-5 WITN4912043

<sup>432</sup> Memo from William Connon to Parliamentary Under-Secretary of State for Public Health 20 July 2005 DHSC0006259 020

<sup>433</sup> Email from Zubeda Seedat to Jacky Buchan 3 February 2006 p4 DHSC0200104

<sup>434</sup> Background Note from Zubeda Seedat 6 February 2006 DHSC0041198 138

Memo from Sophie Coppel to Caroline Flint 23 February 2006 p2 DHSC0200112. Caroline Flint was Parliamentary Under-Secretary for Public Health from May 2005 to May 2006 and then Minister of State for Public Health May 2006 to June 2007.

<sup>436</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 DHSC0200111

# Commentary

That delay is inexcusable, and although Richard Gutowski says with some force that he, too, was subject to very great pressure it should not have taken much time for him to take a decision to involve external consultants.

More particularly, too, Richard Gutowski had before him the handover memo from Charles Lister which told him that what needed to be done was to provide an executive summary, and to reference the statements in the report. That is a task which can be time consuming but, if it had been handed to external consultants, and if that was all that was involved, should have been capable of being done by the end of 2003 or start of 2004. Instead, it took two years longer.

The work which Peter Burgin did would indeed have required referencing, and would have benefited from (though did not need) an executive summary at the start. However, as Peter Burgin wrote it, it is a reasonable account of the facts he would have gleaned from the documents available to him. Objectively viewed, the content of his report did not require much, if indeed any, time to be spent adjusting it.

Finally, William Connon became the head of blood policy in succession to Richard Gutowski. The report went through a further revision whilst William Connon had responsibility for its progress. It is difficult to see any justification for this further delay, though he too may have been under serious work pressures. At that stage, it might be thought that, after he had reviewed the document to check it appeared fit for publication, it would simply take an instruction to a junior civil servant to arrange for publication, and the draft then in existence could have been produced.

# Content of the original draft – broad overview as at Christmas Eve, 2002

Parts of Peter Burgin's original draft would have been uncomfortable reading for a Department which considered that little was known of NANBH until the mid 1980s, and that it was essentially regarded as benign. Thus his report said, as part of its factual account:

- (a) "the risk of viral infection was greater with factor concentrates than with other plasma derivatives for example immunoglobulin preparations and for albumin preparations, where any viruses were inactivated by pasteurisation." 437
- (b) that there was documentary evidence that NANBH, later known as Hepatitis C, had been identified in August 1974 by Dr Alfred Prince and others. In 1975, Dr John Craske and others linked an outbreak of hepatitis, some of which was NANBH, to injections of commercial Factor 8 concentrate; in 1975 Professor Arie Zuckerman had warned that hepatitis ranged from very mild to a disabling illness, and in some cases progressed to chronic liver damage and cirrhosis. By 1980 there was known from

a Public Health Laboratory Service study in the UK to be a high risk of patients contracting the virus from the use of Factor 8 or Factor 9 concentrates. In 1980, Professor Zuckerman had said that NANBH was associated with continuing liver damage which was potentially serious, and an internal Department of Health and Social Security ("DHSS") memo in September 1980 said that that form of hepatitis could be rapidly fatal or could lead to progressive liver damage. In 1981, the *British Medical Journal* ran an article on post-transfusion hepatitis which said that NANBH was then thought to be the main cause of chronic liver disease in patients with haemophilia.<sup>438</sup>

Despite documents, therefore, identifying both that factor concentrates were inherently risky, that NANBH was known of by 1974, and by 1975 commercial concentrates were suspected of causing an outbreak of infections which included NANBH, the report went on to say that it was not until 1981 that the Advisory Group on Hepatitis began to consider NANBH. The report recorded that in 1982 studies were published showing NANBH was more serious than previously thought. Scientific papers postulated that liver function abnormalities in people with haemophilia might be related to treatment with blood products, and these were largely thought to have arisen in relation to commercial concentrate because the large donor pools used to produce those products would increase the risk of any viruses present. However, Peter Burgin also noted that in most of the reports the illness was stated to be mild and short lived.

He added that it was "likely that clinicians who prescribed clotting factors in the 1970s and early 1980s would have been aware of the viral risks attached to the use of Factor VIII." 443

He noted too that it was "reasonable to suppose that the Government would have known of the risks of contracting hepatitis from blood products". 444

These statements were balanced to an extent by noting, from "a Scottish review in 2000",<sup>445</sup> that haemophilia centre directors thought that many saw NANBH as a mild non-progressive condition until the late 1980s, and that there was no real consensus on whether Hepatitis C led progressively to serious liver damage, cirrhosis and cancer; that Dr John Barbara had said in the course of litigation against the National Blood Authority<sup>446</sup> that it was vital to

Self-Sufficiency Report

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 pp2-3 WITN7485005. The text is a summary of the five paragraphs set out there.

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p3 WITN7485005. In fact this was inaccurate: see the chapter on *Role of Government: Response to Risk*. The Advisory Group on Hepatitis did not give any substantive consideration to NANBH during the 1980s.

<sup>440</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p3 WITN7485005

<sup>441</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p5 WITN7485005

<sup>442</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p5 WITN7485005

<sup>443</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p6 WITN7485005

<sup>444</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p19 WITN7485005

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p4 WITN7485005. A reference to the Scottish Executive Report, examined in the chapter on *Scotland*.

<sup>446</sup> A reference to A and Others v National Blood Authority, decided in 2001. A and Others v National Blood Authority Judgment 26 March 2001 PRSE0003333

balance the concept of maximum safety with the need for continuity of blood supply; and he, Peter Burgin, had deduced that the potential seriousness of the condition would not have been appreciated until the mid to late 1980s if infections had begun in 1972, because of the long time it would take for serious liver damage to become apparent.<sup>447</sup>

It is clear that there was substantial factual content in what Peter Burgin reported supportive of an argument, for those who wished to make it, that although risks of infection were known by clinicians and virologists, and that many of them saw these risks as potentially serious, little was done to advise patients of this or to protect them from those risks. The documents reviewed by his report might fuel an argument that commercial concentrates carried with them greater risks than the concentrates that would have been available to patients in the UK if self-sufficiency had been achieved. The report supported the view that these risks arose because of the nature of the populations from which the plasma supplies to make the products were drawn, but also because of the pool sizes used. On the other hand, it also noted that the "prevailing view seems to have been that [the] risks were worth taking given the beneficial impact of clotting factors on the quality of patients' lives", and drew attention to the Haemophilia Society's support for the continued use of Factor 8.448

As to AIDS, Peter Burgin reported that evidence emerged in 1983 that people with haemophilia in the US were contracting AIDS, and it was presumed that it had been transmitted through the use of blood products such as Factor 8 although the mechanism of infection was not known. He recorded that the Government nonetheless wrote to the Haemophilia Society to reassure them of the Government's commitment to self-sufficiency in blood products, but said "In considering whether the imports should cease it was necessary to weigh the possible risks of infection from AIDS against the obvious risks from not having enough Factor VIII."449

He noted that self-sufficiency remained the policy throughout.

His review showed that the problems in achieving self-sufficiency were not simply a question of there being too few donations of blood or plasma. In his section on BPL, he noted that the existing plant could by 1985 "only process 150 tonnes of plasma per year, yielding some 40% of the Factor VIII required. It was thus this manufacturing capacity which limited output at this point, not the ability of regions to supply plasma. Regions at this stage were already supplying BPL with 250 tonnes of plasma per year. The extra plasma was stockpiled deep frozen". 450

<sup>447</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p4 WITN7485005

<sup>448</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p6 WITN7485005

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p9 WITN7485005. It was incorrect that this evidence emerged in 1983: there were reports of AIDS in people with haemophilia in July 1982 – see the chapter on *Knowledge of the Risks of AIDS*.

<sup>450</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p18 WITN7485005. It should be noted that the DHSS had directly funded BPL, or did so through the Central Blood Laboratories Authority, whereas regional health authorities funded the supply of plasma to BPL. This was thus again a potentially uncomfortable conclusion for the Department of Health.

These particular matters have been set out in some detail, because there is a striking contrast between them and the messages the Government felt able to relay from the final version of the report over three years later.

# Contrast with ministerial briefing in 2006

By the time the review was to be published in February 2006 the communications unit of the Department of Health briefed the Parliamentary Under-Secretary of State for Public Health that:

"The review concludes that:

- Clinicians acted in the best interest of their patients in the light of the evidence available at the time.
- The more serious consequences of hepatitis C only became apparent in 1989 and the development of reliable tests for its recognition in 1991.
- Attempts to devise a procedure to make the virus inactive, tests were developed and introduced as soon as practicable.
- Self sufficiency in blood products would not have prevented haemophiliacs from being infected with hepatitis C. Even if the UK had been self sufficient, the prevalence of hepatitis C in the donor population would have been enough to spread the virus throughout the pool." 451

These comments would not have represented a fair reading of the material which Peter Burgin had set out over three years earlier.

When William Connon had presented the final version of the Self-Sufficiency Report to the Minister the previous July, he had set out these bullet points – it was these which were picked up by the communications branch – but he added two further points: that an analysis of the review of the available papers confirmed that there was no alternative treatment that could have been offered to people with haemophilia at the time, and that "Risk management and the precautionary principle are key issues for the Health Service today. We are committed to better communication between clinicians and patients – especially on risk."<sup>452</sup>

As to the developing understanding of the seriousness of NANBH, he told ministers in his submission that the review concluded that the prevailing medical opinion in the late 1970s and early 1980s was that NANBH was perceived as a mild and often asymptomatic disease, and the advantages of treatment with Factor 8 concentrates were perceived to far outweigh its potential risks, adding that "This view was supported by patients, their clinicians and the Haemophilia Society" and that "by the time it became apparent that NANBH was more

Self-Sufficiency Report

<sup>451</sup> Memo from Sophie Coppel to Caroline Flint 23 February 2006 p2 DHSC0200112

Memo from William Connon to Caroline Flint 20 July 2005 p3 DHSC0006259\_020. At the head of his analysis he said "We do not believe that anyone acted wrongly in the light of the facts that were available to them at the time." This became the top line in the suggested press release. Memo from Sophie Coppel to Caroline Flint 23 February 2006 p4 DHSC0200112

serious than initially thought, all domestic and imported concentrates were already routinely heat-treated and therefore conferred little risk of infection with NANBH or HIV."453

It may be of significance that in setting out the background to the Self-Sufficiency Report, William Connon dealt with the commissioning of the work by Yvette Cooper by saying "Without this [ie the contemporaneous material revealed by the review] it is difficult to answer any detailed accusations levelled against the Department".<sup>454</sup>

The implication of these words – "answering" accusations, rather than "responding" to – could be read as indicating a defensive frame of mind, seeking material to bolster a defence, rather than seeking neutrally to see if anticipated accusations were fair; but it is open also to the explanation that it may just be a turn of phrase used where the intention is to know more of the facts and answer honestly.

# How and when the Self-Sufficiency Report was changed

How did it come about that, as presented to ministers in 2006, the report had a different thrust to it than it did in its first form?

Richard Gutowski first addressed bringing someone in to finish off the report on 1 March 2004. He sent an email to that effect to Gerard Hetherington, his director. Nothing in that email suggests he intended any change to the content of the report. He emailed Gerard Hetherington again on 6 May 2004 saying (in words which suggested there had been a conversation between them about it) that: "We have a report produced – the Burgin Report – but it is not in [a] form to be published or conclusions drawn from it. We agreed I should pursue appointing a medical drafter to redraft the Report in a more robust form."

A number of points arise from the language that he used. First, he was looking for a report which stated conclusions. Peter Burgin had been concerned to establish the facts rather than reaching an overall judgement on what they meant. Second, it uses the word "redraft". That suggests substantial rewording, rather than finessing. Third, it looks for the report to be produced in "a more robust form." However, Richard Gutowski rejected the idea that this word indicated that he had intended to make any alteration to the substantive content of the report: "Had I thought that there was any prospect of the draft report's substantive

Memo from William Connon to Caroline Flint 20 July 2005 p2 DHSC0006259\_020. He had missed the point that commercial concentrates were not free of hepatitis risk. If there had been self-sufficiency in Factor 8 concentrates by 1985, then all people with Haemophilia A in England and Wales would have received hepatitis free product (8Y). Instead, the failure to achieve self-sufficiency meant that very substantial numbers went on receiving commercial concentrates which continued to infect them with hepatitis (though he would not have known this from Peter Burgin's draft, it is right to record here that this only ended when commercial concentrates across the board managed more effective viral inactivation probably around the end of the 1980s).

Memo from William Connon to Caroline Flint 20 July 2005 p1 DHSC0006259\_020. This was another reference to the initial advice, over three years earlier, from the Department of Health's Investigation and Inquiries Unit. Memo from Janet Walden to Charles Lister 17 April 2022 DHSC0041379\_023

<sup>455</sup> Email from Richard Gutowski to Gerard Hetherington 1 March 2004 DHSC6259005. Gerard Hetherington was director of health protection. Written Statement of Dr Ailsa Wight 20 June 2022 para 2v WITN4509001

<sup>456</sup> Email from Richard Gutowski to Gerard Hetherington 6 May 2004 p2 DHSC5336358

conclusions changing, I believe this would have been discussed in my email" was what he said in evidence.<sup>457</sup>

Fourth, he had, however, also expressed the hope in his email that Dr Hugh Nicholas, the senior medical officer in his division, would have been involved in "assessing whether the decisions made at the time stand up in the light of the knowledge at the time and the information available", 458 which suggests a desire to introduce an element of judgement which was not previously present.

In oral testimony, he said that when he said "redraft" he meant "actually pull together into a stronger form for it to be published. Because when we first got the Burgin Report, it wasn't in a format that was okay to put out into the public domain. It needed to be pulled together. I didn't use the word 'robust' there in the sense of trying to strengthen up any of the conclusions that were -- or to undermine any of the conclusions that were reached ... I think a better use -- a better word would have been to 'finalise' the report rather than 'redraft'."<sup>459</sup>

The defensive approach of the Department of Health as a whole has already been commented on in respect of the words William Connon later used in sending his submission to ministers, and the content of that submission shows a mindset which appears to be selecting points supportive of a view that nothing untoward had happened in respect of self-sufficiency, or indeed in respect of the infection of many people by blood and blood products during the 1970s and 1980s.<sup>460</sup> The particular wording that Richard Gutowski used is consistent with that, though his explanation needs to be borne in mind.

Back in 19 September 2003, therefore over nine months after the Department of Health had received the work which Peter Burgin had done, and some three months after Richard Gutowski came into a role as head of blood policy, there was an exchange of correspondence between him and Graham Bickler.<sup>461</sup> In forwarding a note to Graham Bickler about a call in Scotland for a public inquiry he commented that "the driving force behind the call" was a document held by Haemophilia Action UK which was purported to be a note of a meeting of haemophilia centre directors, at which the DHSS was present, which took place in 1982. Richard Gutowski said the note "supposedly records that the existence of non-B and Non-A hepatitis in the blood supply was known at the time and that it was serious enough to warrant monitoring."<sup>462</sup>

Self-Sufficiency Report

<sup>457</sup> Written Statement of Richard Gutowski 11 May 2022 para 4.48 WITN5292016

Email from Richard Gutowski to Gerard Hetherington 6 May 2004 p2 DHSC5336358, Written Statement of Richard Gutowski 11 May 2022 para 2.164 WITN5292016

<sup>459</sup> Richard Gutowski Transcript 10 June 2022 p122 INQY1000214

This approach might seem to be exactly that which Yvette Cooper had been seeking to avoid by wanting a review of contemporaneous material: her aim was to see if the facts previously stated to Parliament were correct or not, and the basis for that, so as to ensure that she stated them accurately after this. It was not preferentially to select material which supported the arguments already being made.

<sup>461</sup> Another civil servant in the Department of Health.

<sup>462</sup> Email from Richard Gutowski to Graham Bickler 19 September 2003 p1 DHSC0004294 004

If he had read what Peter Burgin had to say he would have realised that the existence of NANBH had been known since 1974 (on Peter Burgin's research) and that in 1980 the DHSS itself had described it as a serious disease with serious long-term consequences.<sup>463</sup> It seems he did not realise this at the time.

He went on to say in his second paragraph "Our position is that it was 1985 when non-hep A and b came to light and we started to take measures. We have a strong line in that the virus was unknown, it could not be grown and there was no test available. In addition it has to be remembered that at the time there was no alternative". In his third paragraph he added that although the claims about the document currently arose in Scotland it will "clearly cross the border so we must get our lines straight. I will put in hand some defensive work once we have the document." Although he had not seen the document he also observed that it "could cause some embarrassment particularly as it now looks as if it will come into the public domain."<sup>464</sup> The following exchange took place during his oral evidence to the Inquiry:

"Q: At this point, not having seen the document that was relied on, why do you say you'd put in place some defensive work?

A: Because I said 'once we had the document'.

Q: Why was there an assumption at this stage that that work would be defensive?

A: Because the information that was coming out from Scotland was that this document could be an embarrassment, therefore it that proved to be the case then we would need to do a defensive briefing.

Q: So the defensiveness was about the embarrassment?

A: The defensiveness was about what would be -- what was contained within the document, just in case it was embarrassing.

Q: Was any thought given at this stage to the fact that the document might undermine what you understood the position to be and had set out in paragraph 2?

A: Could have been, yes, but without having seen the document, we didn't know.

Q: I think that's what I'm trying to explore with you, Mr Gutowski. Without knowing what was in the document, was there an assumption that it would be defensive?

A: I think we need to put it into context of the fact that a lot of the information that was being -- at the time was being put into the public domain was highly critical of what various Government departments had or hadn't done over the years. And there was an assumption, therefore, made that whenever such documents were threatened -- we were threatened with such documents or such documents came to hand, that we would have to look at it on the basis of providing a defensive position on it.

Because, otherwise, they wouldn't be going to the press, if you like, with a document that was supportive of the line that we were taking. So it was just

<sup>463</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 pp2-3 WITN7485005

<sup>464</sup> Email from Richard Gutowski to Graham Bickler 19 September 2003 p1 DHSC0004294\_004

a pragmatic Civil Service approach, that you consider putting up a defensive briefing in case it is needed.

In some cases it is not needed; in other cases it will be needed." 465

The email to Graham Bickler, and this exchange, shows that Richard Gutowski thought that a document showing that in 1982 haemophilia doctors and the DHSS knew of NANBH, and knew that it might be serious, would potentially be "an embarrassment" to the Government, which would require "defensive work", presumably on the assumption that the line previously adopted – that it was unknown until 1985, and was thought to be of no great seriousness at all when it emerged – was to be maintained.

In his first email to Gerard Hetherington he had said in respect of finalising the Self-Sufficiency Report that "It would also be useful if at the same time someone ie Hugh Nicholas, could produce a subsiduary [sic] report on the issue of when NonA, NonB and Hepatitis C was first identified and what decisions were taken at the time and for what reasons. This would give us an extra degree of confidence in our line that we dealt with Hepatitis C as soon as we became aware of it."<sup>466</sup>

It appears from these documents that Richard Gutowski was expressing departmental views that it was not until 1985 that NANBH "came to light"; that the Department of Health had confidence that it dealt with Hepatitis C "as soon as we became aware of it"; that the suggestion that there had been a meeting of haemophilia centre directors in 1982, with the DHSS in attendance, which had suggested that NANBH was known, and known to be serious, was something to defend against; and that there was no alternative to the treatment offered to people with bleeding disorders. He also appears to have thought that the position of the Department of Health was "strong" because the virus was "unknown" (ie had not yet been identified, isolated or cloned) and there was no direct test available for it.<sup>467</sup>

To someone with these views the contents of Peter Burgin's original draft would be challenging. Their reaction might well be "defensive". They may well seek to make arguments against them.

This does not mean that the changes to the Christmas Eve report were made because he, or the Department of Health, asked for any changes to be made in the Self-Sufficiency

<sup>465</sup> Richard Gutowski Transcript 10 June 2022 pp114-115 INQY1000214

<sup>466</sup> Email from Richard Gutowski to Gerard Hetherington 1 March 2004 p2 DHSC6259005. These words are stating that the Department of Health (that is the significance of the word "we") had confidence that it dealt with Hepatitis C as soon as the Department of Health became aware of it. A further point arises: the need for, and nature of, a "subsiduary [sic] report". It seems to be seeking an opinion as to the position at the relevant times as seen by a civil servant with medical expertise, not necessarily based on the documents reviewed by Peter Burgin. Was it for internal use (and if so what) alongside the "main" report or was it to have been published? If it had been, what explanation would have been given to the public as to the need for two reports rather than one incorporating the other? The answers to these questions are unclear: but it does show, more clearly, Richard Gutowski's assumption that his personal understanding was so correct that medical expertise would support it, and help to convince others of its correctness.

Email from Richard Gutowski to Graham Bickler 19 September 2003 p1 DHSC0004294\_004, Email from Richard Gutowski to Gerard Hetherington 1 March 2004 p2 DHSC6259005

Report to accord more closely with what may have seemed to be articles of faith. It is equally consistent with someone who believes they have a fairly firm grasp of what took place, beginning to grapple with the fact that evidence of what actually took place might present a different picture, and seeking to explore whether this is indeed an accurate one.<sup>468</sup> Challenging long held assumptions is never easy. (Nor, necessarily, should it be. There may be greater dangers in accepting newly found "facts" too readily, for they may turn out not to be accurate).

That said, Richard Gutowski had some involvement in the HIV litigation 14 years before this. 469 Part of the argument between the parties involved hepatitis. It was being suggested by the plaintiffs in that litigation that there should have been self-sufficiency in part because it would reduce the risks of hepatitis, and that if it had been achieved, there would have been very much less infection by other viruses endemic to North America (such as that which caused AIDS). If what he wrote about a document being "potentially embarrassing" because it suggested both that the risk of NANBH was known about in 1982 and that the risk was regarded as of some importance then, it is surprising that he should say that the Department of Health's position was that this was not the case until 1985.

As with the words "robust", "redraft", "defensive" and "embarrassing", this may be symptomatic of a person who has not had the time (due to pressure of work) to look more carefully at the documents, and tends to develop fixed views from which it may not be easy to shift; it may also represent the culture in which he worked. As first read by Richard Gutowski, probably following his exchange with Graham Bickler, he may well have thought many of the matters in Peter Burgin's draft would be of some embarrassment to the Department of Health, and would instinctively have hoped they had not been there. This is not, however, sufficient evidence that he caused, intentionally, the original draft by Peter Burgin to be changed so as to tone down those points critical of the Department of Health which might have been made from its contents.

That said, the bulk of the changes which occurred did so whilst he was the person responsible for blood policy. In that sense he had some responsibility for those changes, but I should make it clear that I cannot conclude on a fair view of all the evidence that he personally sought to change the terms of the Self-Sufficiency Report and has hidden that from the Inquiry. It would not be, in my view, a proper conclusion to draw.

<sup>468</sup> If Dr Nicholas had told him that the facts were different to those he supposed, he would presumably have had to deal with it – so commissioning further views would have helped. Though Dr Nicholas' involvement was limited by the time he had to spend on the report (it was taken up with the Hepatitis C strategy and the Skipton application form: Email from Richard Gutowski to Gerard Hetherington 6 May 2004 p2 DHSC5336358) it was he who pointed out some problems with the external medical writer's first effort produced in August 2004, leading to the October revision (see the text below).

Written Statement of Richard Gutowski 10 May 2022 para 8.5 WITN5292001, Richard Gutowski Transcript 10 June 2022 pp3-17 INQY1000214

#### **Involvement of Dianthus**

Dianthus was a medical writing consultancy owned by Dr Adam Jacobs. On 7 June 2004, following approval of Richard Gutowski's suggestion to involve an external consultancy in finalising the Self-Sufficiency Report, the agreement signed with Dianthus was "to improve the quality of referencing in a report of hepatitis C and blood transfusions."

The work was undertaken by Dr Jacobs and one of his junior medical writers, Dr Shanida Nataraja, who describes the work she was doing as "both sourcing references when none had been cited, and checking cited references to ensure they were appropriate."<sup>471</sup> She has a "vague recollection" of attending the Department of Health to look at files made available to her, and a "very limited recollection of the project".<sup>472</sup> Being as junior as she was, she "rarely had direct contact with clients".<sup>473</sup>

Dr Jacobs recalls looking at files in the Department of Health that were provided to them by Richard Gutowski, who was their main contact, and that they would have done literature searches online.<sup>474</sup> He understood his task to be "making sure that the report was properly referenced: the initial draft of the report made reference to many external documents, but in a way that made it hard to know exactly what documents were being referenced. Our task was to ensure that referencing was clear and complete. In addition, I think we were probably asked to edit the text for clarity and consistency."<sup>475</sup>

The way in which the work most probably proceeded is shown from documents which Dr Jacobs located for the Inquiry from his system. They were organised into two folders, "Work in Progress" and "Previous Drafts". Each contained different versions of the report. Dr Jacobs said: "I cannot recall with precision [what] the difference is between the 'previous drafts' and the 'work in progress' folders, but I think it is likely that the documents in the 'previous drafts' folder would have been shared with DoH and [the] 'work in progress' folder contains working files shared only between myself and Dr Nataraja. However, I cannot be completely sure." 478

These documents show that by 13 July 2004 the Christmas Eve version had been referenced, all bar some 26 matters which had obviously not been traced to a source, or had no reference

- 470 Agreement between the Department of Health and Dianthus Medical Limited 7 June 2004 WITN5292057
- 471 Written Statement of Dr Shanida Nataraja 28 February 2023 p7 WITN7663001
- 472 Written Statement of Dr Shanida Nataraja 28 February 2023 p10, p13 WITN7663001
- 473 Written Statement of Dr Shanida Nataraja 28 February 2023 p13 WITN7663001
- 474 Written Statement of Dr Adam Jacobs para 17 WITN7662001
- 475 Written Statement of Dr Adam Jacobs para 12 WITN7662001
- 476 Versions identified as England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 12 July 2004 WITN7662002, England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 WITN7662007
- Versions identified as Annotation of Draft Report on Self-Sufficiency in Blood Products WITN7662008,
   England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft)
   8 October 2004 WITN7662013
- 478 Written Statement of Dr Adam Jacobs para 24 WITN7662001

Self-Sufficiency Report

that could be given. These were labelled "(? Source)" in the draft.<sup>479</sup> This 13 July version was very little different from Peter Burgin's original draft except for (a) these references (b) two paragraphs being moved (they now fitted in chronologically, rather than being out of step)<sup>480</sup> and (c) the occasional re-ordering of words in the same sentence, apparently so that it read more easily. In short, at this stage there was no detectable change of substance from Peter Burgin's original draft. The 13 July version purported to cover the same time period (1973-1985). It did however contain, in capital letters, the following: "NEED TO ADD INFORMATION HERE ABOUT SURROGATE TESTING FOR NON-A NON-B HEPATITIS; ... AND FIRST, SECOND, AND THIRD-GENERATION TESTS", and two references were given.<sup>481</sup> There was no executive summary in this version.<sup>482</sup>

This version was in the folder which Dr Jacobs was inclined to think was internal to Dianthus, and not discussed with the Department of Health.<sup>483</sup>

These are important findings. They show that Dianthus had done as they had been contracted to do, and that any changes made to the substance thereafter are unlikely to have come on their initiative (except for the suggestion about dealing with surrogate testing for Hepatitis C, though it is noticeable that the decision on this was specifically left as a note for others).<sup>484</sup>

At this stage, it would seem probable that Dr Nataraja had done the work on seeking to find references. She had a PhD, but was very junior. She had managed to find references for most of the documents to which Peter Burgin had referred. The executive summary had been drafted as a separate document in the "*Work in Progress*" folder.<sup>485</sup>

It is highly unlikely (especially given her junior status at the time) that Dr Nataraja went on to make substantive changes to the report on her own initiative. This is particularly underlined

<sup>479</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 WITN7662007. There were 142 references in a reference list at the end.

The text that was moved related to a newspaper article and Adjournment Debate in 1980. England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p7 WITN7485005, England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 p10 WITN7662007

England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 p6 WITN7662007

This appears to have been added later: a version dated 12 July (England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 12 July 2004 WITN7662002) did not have them. The "Work in Progress" folder however also contains an executive summary without any following text, so the inference is that it was the work of a separate drafter, added later to the body of the text. There were the same number of references, but they were not all the same as in the earlier version. This suggests there may have been some discussion between Dr Nataraja and Dr Jacobs, internally. It supports the attribution of the two versions to the "Work in Progress" folder.

<sup>483</sup> Written Statement of Dr Adam Jacobs para 24 WITN7662001

There is no formal request made here, though it may be implicit. This may gather some support from the fact that before commissioning Dianthus, Richard Gutowski had emailed Gerard Hetherington to say that "Ideally I would have liked Hugh Nicholas to get involved in assessing whether the decisions made at the time stand up in the light of the knowledge at the time and the information available. Unfortunately he is tied up with work ... If the Consultancy Firm feel that they are able to do the work the same question then applies, have we the money". Email from Richard Gutowski to Gerard Hetherington 6 May 2004 DHSC5336358

<sup>485</sup> Executive Summary: England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1991 WITN7662003

by the fact that, instead of offering text to cover the point she suggested in capitals should be addressed, she drew the attention of others to what might be included without herself making any change at that point.

It was at this time that the scope of the report shifted from 1973-1985 to cover also the period from 1985 to 1991. Although the draft of 13 July was filed in "Work in Progress", the work was discussed with the Department of Health. There is a comment on it, from "DH user", saying "Shouldn't this be extended to 1991?" 186 It is not clear to whom this question is addressed: internally, to Richard Gutowski or others, nor who wrote it.487 However, Dr Nataraja also refers to making amendments to the report "on the advice of David" in an email to Richard Gutowski on 20 July 2004.488 She recorded in her email "Of the remaining 15 statements in the text for which I have failed to find an appropriate reference to support them, I have addressed some of these issues by re-wording the text or removing them together, on the advice of David, and plan to address the remaining issues in the same manner."489 "David" was likely to be David Reay who was an executive officer in Richard Gutowski's team. 490 He could, possibly, have been the "DH user" – but whoever it was, it is plain that there were exchanges between Dianthus and the Department of Health as the report went from draft to draft, though few written records of this seem to have survived. 491 It is possible therefore that although the main contact which Dianthus had with the Department of Health was with Richard Gutowski, 492 different civil servants in the Department of Health had some input into shaping the report as they considered appropriate, as the contemporaneous email suggests.

The email of 20 July 2004 also specifically raised two matters which Dr Nataraja suggested might be added to the report.<sup>493</sup> One was rewriting or restructuring the development of

- 488 Email from Dr Nataraja to Richard Gutowski 20 July 2004 p1 WITN5292111
- 489 Email from Dr Nataraja to Richard Gutowski 20 July 2004 p1 WITN5292111
- 490 Written Statement of Richard Gutowski para 10 WITN5292001
- The probability that there were unrecorded conversations is consistent with Dr Jacobs' account: "most of the work was done on site at DoH." Written Statement of Dr Adam Jacobs para 19 WITN7662001
- 492 Significant Department of Health input is most likely to have come from discussions with Richard Gutowski. Dr Jacobs said: "Our main contact was Mr Gutowski, so if it was relevant for us to identify the Department's views, we would have spoken to him." Written Statement of Dr Adam Jacobs para 29 WITN7662001. The use of the words "main contact" nonetheless shows that there were others who had some input.
- Email from Dr Nataraja to Richard Gutowski 20 July 2004 p2 WITN5292111, which read in the material parts: "1) There are sections of the report that could be re-written and/or re-structured for clarity, such as the section on the development of understanding on the long-term health consequences of Hepatitis C. Do you want me to modify the report in this manner?
  - 2) There is additional information that could be included in the report, such as the availability of surrogate and first/second generation Hepatitis C testing, and the rationale for the Government not implementing these test [sic] when they became available. Do you want me to include this extra information in the first draft of the report or merely indicate in the text where this information could be added if necessary?"

England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 p2 WITN7662007. This is one of 21 comments by "DH user".

Neither Dr Jacobs nor Richard Gutowski make reference to "DH user" in their evidence. It is also a possibility that it may be because in the course of their work, Dianthus went to the Department of Health (there is evidence that the consultants were seen looking at files at the Department: Written Statement of Dr Adam Jacobs para 19 WITN7662001) and may have used a departmental computer to send a copy document or comment back to their own offices. In such a case, the commentator may show as a "DH user".

understanding of the long-term consequences of Hepatitis C; the other was that which she had highlighted in capital letters on the draft of 13 July, with the addition of "the rationale for the Government not implementing these tests when they became available." She anticipated meeting in person to "discuss how you would like me to address these issues."

It is clear that at some stage in the three weeks between 13 July and 4 August (when the first draft was formally submitted to the Department) a decision was relayed to Dianthus that it should extend to cover the further six year period. It seems likely, given the email of 20 July, that this was discussed at a face to face meeting; and as a result of that the most significant of the changes were made.

Dr Nataraja was asked about the changes. She states "on reviewing the materials provided to me in the context of this inquiry, I note that, many of the statements that have been added are referenced to specified sources cited in the reference list at the end of the document. They therefore reflect a fact or opinion expressed in that source reference ... Changes to the content of the report would be expected as a result of this expanded evidence base, and validating the content of the original report against this evidence base."<sup>494</sup>

Dr Jacobs considers that it "seems entirely possible" that they were asked to make changes to the report "primarily to improve the quality of the referencing". <sup>495</sup> He recalls having discussions with Richard Gutowski about the contents of the report and assumes that changes to the report were made because they were requested by Richard Gutowski because "we did not consider it part of our job to substantially change the content of the report on our own initiative". <sup>496</sup>

The version of the report as then amended by Dianthus which is available to the Inquiry is dated 4 August 2004. It was sent electronically to Richard Gutowski on that date. This version not only covered an increased period of time – it was now 1973-1991 – but also made a number of changes to Peter Burgin's original draft.<sup>497</sup>

## Significant changes

By comparison with the Christmas Eve draft the Self-Sufficiency Report, after all the work done by Dianthus, included an executive summary and much expanded conclusions.

The executive summary of the report was entirely new with the exception of the words "With the development of tests for hepatitis A and B in the 1970s, it became clear that non A non B hepatitis (NANBH) could be transmitted by blood". 498 It addressed what had happened

- 494 Written Statement of Dr Shanida Nataraja para 15c WITN7663001
- 495 Written Statement of Dr Adam Jacobs para 14 WITN7662001
- 496 Written Statement of Dr Adam Jacobs para 22 WITN7662001
- England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 WITN5292113 (misdated on the front cover), Email from Dr Nataraja to Richard Gutowski 4 August 2004 WITN5292112, Written Statement of Richard Gutowski para 1.26 WITN5292109, England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 WITN7485005
- 498 England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 p3 WITN5292113

in respect of the failure to introduce surrogate tests, which had (as the passage in capital letters had shown) been entirely missing from the original, and made claims that doctors had carefully explained the risks of viral infection from concentrate as follows:

growing concerns over the safety of commercial concentrates imported from the US reinforced the need for self-sufficiency, the development of both an appropriate screening assay for NANBH and an effective viral inactivation treatment at BPL. In the meantime, the Haemophilia Society appealed to the Government not to ban American blood supplies and advised their members not to stop treatment in response to concerns over potential risks. Furthermore, doctors treating patients with haemophilia were, we believe, careful in explaining the risk of viral infection to their patients. 499 Before 1989, potential blood donors could only be screened for NANBH using surrogate tests; however, these were perceived to be crude and inappropriate for use in the UK. With the cloning of a portion of the virus in 1989, the C100-3 antibody test became available. This was associated with a large number of false positive and negative results and, once again, was not approved for use in the UK. It was only in 1991 that a number of validated second-generation assays became widely available and routinely used to screen potential blood donors for NANBH infectivity.

The prevailing medical opinion in the 1970s and the early 1980s was that NANBH was mild and often asymptomatic. Research into NANBH was hindered by the lack of a definitive serological assay, the reluctance of clinicians to perform liver biopsies in patients with a very high risk of bleeding, and the fact that, in the majority of patients, the chronic sequelae of NANBH only became apparent after more than a decade. Even in the mid-1980s, however, when it became apparent that

<sup>499</sup> It is unclear what the factual basis for this assertion could have been. As reported elsewhere in the Report there is a preponderance of testimony that this did not happen, given by very many patients from different walks of life, coupled with observations by doctors about the practices of their colleagues, and sometimes their own. This testimony is consistent both with a finding by Mr Justice Burton to the same effect in A and Others v National Blood Authority, and inferences drawn by the Inquiry from a body of documentation leads this Inquiry to conclude that what was generally the case was the direct opposite of that which the writer wished to include in this draft. Though the same wording was removed from the published version of the report it may nonetheless give some insight into the approach which the writer (either instinctively or after discussions within the Department) was adopting. The words used may be seen as promoting a perspective which so far as attributing responsibility for infection was concerned would have the effect of removing blame from clinicians, whilst suggesting that if it was wrong for them to take the concentrates, the responsibility for doing so lay with the patients, and may go so far as to suggest that that responsibility was shared by the Haemophilia Society. As it happened, the Society and other groups of patients were those who were campaigning for compensation and an inquiry at the time. Given the reference to the file in the Dianthus references ("*BLH 1*" England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 p32 WITN5292113) the assertion most probably derives from what appears to be a briefing note (Haemophiliacs and AIDS DHSC0002291 004, which bears that reference in handwriting) for Baroness Jean Trumpington to use in replying to a letter in March 1986. She wrote (in words which appear in what may be the briefing note) "Doctors treating haemophiliacs were, we believe, careful in explaining these risks to their patients." Letter from Baroness Trumpington to Anthony Nelson18 March 1986 p1 DHSC0000194. Lord Norman Fowler was asked about this and said: "I don't know where that phrase came from. Lady Trumpington ... was pretty new to it. I think most ministers would have queried that particular sentence ... we should have looked at the whole thing rather more constructively and rather more widely than we did." Lord Norman Fowler Transcript 22 September 2021 pp114-116 INQY1000145

NANBH was associated with long-term chronic sequelae, including liver failure, cirrhosis and hepatocellular carcinoma, the consensus of medical opinion was that clinicians should continue using the concentrates. Patients, their physicians, and the Haemophilia Society all maintained that the improvement in quality of life and dangers of bleeding outweighed the potential risks of treatment." 500

Of particular note, the **original** words in Peter Burgin's draft that "The risk of viral infection was greater with factor concentrates than with other plasma derivatives – for example immunoglobulin preparations – and for albumin preparations" were **rewritten** to say "Furthermore, although the UK was striving to achieve self-sufficiency in all therapeutic blood products ... the risk of viral infection from albumin and immunoglobulin preparations is thought to be minimal."<sup>501</sup>

Although the **original** had spoken of Professor Zuckerman's warning, in the 1975 TV programme about the risks of hepatitis from commercial concentrates, that hepatitis linked to factor concentrates could lead to cirrhosis and liver cancer, **the Dianthus version** left this entire paragraph out.<sup>502</sup>

Where the **original** said "An internal DH memo said on 15 September 1980 that this form of hepatitis could be rapidly fatal ... or could lead to progressive liver damage" the **Dianthus version** said: "in December 1980, a report was submitted to the Department summarising the findings of a study into the epidemiology and chronic sequelae of factor VIII and IX associated hepatitis in the UK. It stated that, despite multiple transfusions and large numbers of grossly abnormal liver function tests, very few patients showed any evidence of chronic liver disease". <sup>503</sup>

<sup>500</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 pp3-4 WITN5292113

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p2 WITN7485005 compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-1991 (Draft) 22 February 2023 p6 WITN5292113

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p2 WITN7485005. The 13 July Dianthus draft noted that they would need to request a transcript or video. England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 p3, p24 WITN7662007. Since the observations made by Professor Zuckerman were significant, and the source a scientist of renown, who had often been invited by the Department to give it his views, it is surprising this was not done.

England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1985 p3 WITN7485005 compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 p7 WITN5292113. An annotation on the 13 July Dianthus draft noted "Chronologically, this document should be in Binder 10; however, it is not. Furthermore ... Craske reports". His was the report that was then substituted. England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 p4 WITN7662007, Second Annual Report on Project Number J/S240/78/7: Studies of the Epidemiology and Chronic Sequelae of Factor VIII and IX Associated Hepatitis in the United Kingdom November 1980 pp35-38 HCDO0000135\_021. The effect of this alteration, and the one mentioned in the previous footnote, was to neuter much of the material suggestive of awareness from the mid to late 1970s of the potential seriousness of infection with NANBH. It is surprising, too, that no-one (Dianthus or the Department of Health) seems to have picked up that during the recently completed litigation about Hepatitis C (A and Others v National Blood Authority) Mr Justice Burton had relied on the defendants' "own determination to give priority" to NANBH/Hepatitis C, noting a letter from the MRC dated 7 February 1979 confirming that the DHSS Chief Scientist had informed the MRC that NANBH was "being given high priority

Where the **original** said "the prevailing view seems to have been that these risks [of clotting factors] were worth taking given the beneficial impact of clotting factors on the quality of patients' lives" **this now became** "the prevailing view was that, as always, patients with haemophilia, their parents, and doctors were required to balance the improvements in quality of life and the dangers of bleeding against the risks of treatment ... [65].<sup>504</sup> Furthermore, doctors treating patients with haemophilia were, we believe, careful in explaining these risks to their patients [66]".<sup>505,506</sup>

Where the original had included three paragraphs about the reasons for pursuing selfsufficiency within a chronology from 1973 to 1993 these were now removed - with the result that a reader could easily miss the centrality of safety to self-sufficiency. They had referred to the "primary aim" being "to make the NHS self sufficient in Factor VIII concentrate within two to three years", and said that the reason for doing so was to "reduce the cost of importing products. Although several of those we interviewed gave the reason for pursuing self-sufficiency as a need to reduce the risk of patients contracting hepatitis from the concentrates, there is no indication in the Departmental papers that safety was a consideration at this point." The paragraphs also referred to an internal minute on 10 July 1978 that spoke of there being "doubt about the circumstances in which the plasma is collected abroad which largely influenced Ministers (so I understand) to enunciate the doctrine of NHS self-sufficiency in blood products." The Dianthus version did not refer to the evidence from interviewees that safety was the reason for pursuing self-sufficiency and summarised the 1978 minute as follows: "Although in 1975, cost and loss of the volunteer donor system were cited as the major motivating factors for the push towards self-sufficiency [78], by the middle of 1978, concerns over the methods of plasma collection, and safety, of imported blood products were also reported to reinforce the need for NHS self-sufficiency in blood products [86]."507 Figures 1 to 3 show the process by which the three paragraphs about the reasons for pursuing self-sufficiency within a chronology from 1973 to 1993 were removed.

by the Department." A and Others v National Blood Authority Judgment 26 March 2001 para 100v PRSE0003333, Letter from Dr Tony Dickens to Dr Craske 7 February 1979 DHSC6887734\_041

This reference was to Professor Bloom's letter to Haemophilia Society members dated 4 May 1983. Letter from Reverend Alan Tanner to members of the Haemophilia Society 4 May 1983 DHSC0001228

This reference was to an internal DHSS briefing from 1985 and the wording was in Parliamentary correspondence from Baroness Trumpington. Haemophiliacs and AIDS p5 DHSC0002291\_004, Letter from Baroness Trumpington to Anthony Nelson 18 March 1986 p1 DHSC0000194

<sup>506</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-1985 p6 WITN7485005 compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 p11 WITN5292113

England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p7 WITN7485005 compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 pp12-14 WITN5292113. The references in the Dianthus version are: Blood Products Production pp1-2 DHSC0100005\_188, Memo from Thomas Dutton to Sally Holtermann 10 July 1978 DHSC0002325\_033. The other evidence in the three paragraphs was moved elsewhere in the chronology. The executive summary said "In the late 1970s and early 1980s, these concerns [about expensive imports and threat to the volunteer based donor system] were accompanied by fears of the risk of both hepatitis and HIV infection from imported factor VIII concentrate." The changes are illustrated in Figure 1.

The changes were made in three steps. Figure 1 shows the text of the original Christmas Eve draft; figure 2 shows the changed text in the 13 July Dianthus draft; and figure 3 shows the text of the 4 August Dianthus draft that followed.

"The primary aim of the allocation was to make the NHS self-sufficient in Factor VIII concentrate within two to three years. The reason for seeking to achieve self-sufficiency was to reduce the cost of importing products. Although several of those we interviewed gave the reason for pursuing self-sufficiency as a need to reduce the risk of patients contracting hepatitis from the concentrates, there is no indication in the Departmental papers that safety was a consideration at this point.

However, an internal minute on 10 July 1978 does say that 'there is doubt about the circumstances in which the plasma is collected abroad which largely influenced Ministers (so I understand) to enunciate the doctrine of NHS self-sufficiency in blood products.' In addition, a January 1980 Sunday Times article states that the Department was concerned about using imported blood products because of the attendant risk of passing on infectious diseases, particularly hepatitis, although we have found no written evidence of this.

In an Adjournment Debate on 15 December 1980, Sir George Young replied for the Government that the Government fully endorsed the principle of self-sufficiency. In doing so, he referred to the risk of contracting hepatitis from imported products, although he did not specifically mention NANBH, and the only reference in his speech is to Hepatitis B.

On 29 April 1976, the Department issued a Press Release re-affirming that the UK was aiming to become self-sufficient in the supply of blood products by mid-1977."508

Figure 1. The original Christmas Eve draft

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"The primary aim of this allocation of funds was to make the NHS self-sufficient in Factor VIII concentrate within two to three years. The **stated** reason for seeking to achieve self-sufficiency was to reduce the cost of importing products. Although several of those interviewed gave the reason for pursuing self-sufficiency as a need to reduce the risk of patients contracting hepatitis from the concentrates, there is no indication in Departmental papers that safety was a consideration at this point. However, an internal minute on 10 July 1978 does say that 'there is doubt about the circumstances in which the plasma is collected abroad which largely influenced Ministers (so I understand) to enunciate the doctrine of NHS self-sufficiency in blood products.

On 29 April 1976, the Department issued a Press Release re-affirming that the UK was aiming to become self-sufficient in the supply of blood products by mid-1977. 511"512

Figure 2. The 13 July Dianthus draft

References were added to this draft.

The other evidence was moved elsewhere in the chronology.

Reference added to: Memo from Donald Jackson to Dr Irene Blakeney 18 November 1974 DHSC0002359\_012, Blood Products Production pp1-2 DHSC0100005\_188

<sup>510</sup> Reference added to: Memo from Thomas Dutton to Sally Holtermann 10 July 1978 DHSC0002325 033

<sup>511</sup> Reference added to: UK aims to be Self-Sufficient in Supply of Blood Products 29 April 1976 LDOW000044

<sup>512</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1985 (Draft) 13 July 2004 pp8-9 WITN7662007

"On 29 April 1976, the Department issued a Press Release re-affirming that the **aim of the** UK <del>aiming</del> to become self-sufficient in the supply of blood products by mid-1977. Furthermore, it stated that, since the screening of blood donors for hepatitis was less rigorous in some countries than in the UK, the Government's policy of making the UK self-sufficient in the supply of blood products commanded wide support.<sup>513</sup>

[three-quarters of a page of chronological developments]

The primary aim of the allocation was to make the NHS self-sufficient in Factor VIII concentrate within two to three years. The stated reason for seeking to achieve self-sufficiency was to reduce the cost of importing products. Although several of those we interviewed gave the reason for pursuing self-sufficiency as a need to reduce the risk of patients contracting hepatitis from the concentrates, there is no indication in the Departmental papers that safety was a consideration at this point. Although in 1975, cost and loss of the volunteer donor system were cited as major motivating factors for the push towards self-sufficiency 514 by the middle of However, an internal minute on 10 July 1978, concerns over the methods of plasma collection, and safety, of imported blood products were also reported to reinforce the need for does say that 'there is doubt about the circumstances in which the plasma is collected abroad which largely influenced Ministers (so I understand) to enunciate the doctrine of NHS self-sufficiency in blood products. 515°, 516

# Figure 3. The 4 August Dianthus draft

The evidence from interviewees was removed and the referenced documents were summarised.

This text was retained in the version published in 2006.<sup>517</sup>

From the revised chronology it is unlikely that a reader would realise the centrality of safety to the pursuit of self-sufficiency – with Professor Richard Titmuss' book The Gift Relationship being widely read in 1970 and Dr David Owen seeing safety as a major motivating factor behind his policy announcement in 1975 – as described in the chapter on *Self-Sufficiency*.

Reference to: UK aims to be Self-Sufficient in Supply of Blood Products 29 April 1976 LDOW0000044. This sentence was moved up.

<sup>514</sup> Reference to: Memo from Donald Jackson to Dr Irene Blakeney 18 November 1974 DHSC0002359\_012, Blood Products Production pp1-2 DHSC0100005\_188

<sup>515</sup> Reference to: Memo from Thomas Dutton to Sally Holtermann 10 July 1978 DHSC0002325 033

<sup>516</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 pp12-14 WITN5292113

<sup>517</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 pp18-19 DHSC0200111

Dr Jacobs considered that such alterations and omissions were "standard ways of improving the clarity of the document" and did not consider the material to be substantive. <sup>518</sup> However, the changes that were made go well beyond simple clarifications of the text, and change the meaning and conclusions in the report substantially.

Following the extensive work which resulted in a version of 4 August 2004 (the Dianthus version) there were two further drafts. The first was of 8 October 2004<sup>519</sup> and the second one of 20 July 2005.<sup>520</sup> The final version of 27 February 2006<sup>521</sup> was published seven months later with only one alteration from the July 2005 version – an additional paragraph, largely duplicating a paragraph which appears earlier in the text.<sup>522</sup>

#### The version of October 2004

The October version followed comments about the August edition made by Dr Nicholas, the senior medical officer in the Health Protection Division, in September 2004.<sup>523</sup>

He observed that one thing that frequently seemed to be missing were the actual views of the Department of Health in this, and it might be difficult to attribute to the Department of Health some of "their more intuitive views". <sup>524</sup> One of those "intuitive views" was the statement in the report that "Doctors treating patients with haemophilia were, we believe, careful in explaining the risk of viral infection to their patients." Dr Nicholas observed that "Unless there is some objective evidence for this, such a statement coming from the Department might prove somewhat contentious among any patients who were not informed, and we should think carefully before including it." <sup>525</sup>

- 518 Written Statement of Dr Adam Jacobs para 26 WITN7662001
- 519 England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1991 (Draft) 8 October 2004 DHNI0000006\_005, Email from Dr Nataraja to Richard Gutowski 8 October 2004 WITN5292115
- 520 England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 DHSC0200084 002
- 521 Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 DHSC0200111
- 522 Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 p7, p34 DHSC0200111
- 523 Email from Dr Nicholas to Richard Gutowski 22 September 2004 WITN5292114, Draft Report on Self-Sufficiency in Blood Products September 2004 DHSC0041232\_006, Annotation of Draft Report on Self-Sufficiency in Blood Products WITN7662008
- In detail his comments read: "further work will need to be done if it is proposed to make the report public (under a DH imprimatur) in any way in the future, and care should [be] taken if quoting from the report in its current state. Whilst the drafting by the authors is OK from their perspective and the information available to them, it is not always written in a from [sic] which could be used by DH e.g. their various speculations on what DH policy may have been (when we should know), and it might be difficult to attribute to DH some of their more intuitive views." Dr Nataraja responded by saying: "I can certainly remove or clarify statements that appear to speculate on DH policy ... Need to clarify with Richard [Gutowski] who is going to put their name to the report, and whether this person would therefore take responsibility for the more intuitive opinions within this report." Annotation of Draft Report on Self-Sufficiency in Blood Products p1 WITN7662008
- 525 Annotation of Draft Report on Self-Sufficiency in Blood Products p4 WITN7662008

These comments were responded to electronically by Dr Nataraja.<sup>526</sup> They resulted (amongst a number of other changes) in the removal of the words about doctors being careful to explain risks to patients, but an inclusion of greater emphasis on what was framed as the "considerable morbidity and a low life expectancy" without concentrates.<sup>527</sup> It was said that, when deaths related to viral infection were excluded, "the life expectancy of these patients almost equals that of the general male population".<sup>528</sup>

What was also added was that "the majority of patients with clinical liver disease were also reported to have a history of alcohol abuse [40] ... Not only is alcohol abuse one of the most common causes of chronic liver disease in Western Europe and North America but it is known to increase the risk of cirrhosis, hepatocellular carcinoma, and possibly death from liver disease in patients with HCV infection [41]". 529

The sentence (in the conclusions section of the report) that "Although it is reasonable to suppose that the government would have known of the risks of contracting hepatitis from blood products, this does not seem to have been the driving force behind development of policy, particularly in the 1970s" was now omitted.<sup>530</sup>

Richard Gutowski had already formed his views about what the report would conclude before he received Dianthus' final version on 8 October 2004. In an email to Dr Ailsa Wight on 29 September 2004 following further emailing from Haemophilia Action UK he wrote:

"On the question of an enquiry our line is that we have no evidence to show that there was any wrong doing at the time and that an enquiry was not justified. We recently commissioned further work, following [sic] agreement by Melanie Johnson, into the allegations being made. That report, which is currently

- Annotation of Draft Report on Self-Sufficiency in Blood Products WITN7662008. There are 16 observations in numbered paragraphs and then detailed comments. The responses of Dr Nataraja can be seen in pink.
- 527 England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1991 (Draft) 8 October 2004 p7 DHNI000006\_005. The references which Dianthus found were to articles about changing life expectancy in Finland (1930-79) and Sweden (1831-1980). The first speaks of the drop in death rates taken over ten year periods to be due respectively to increased use of blood transfusion, the use of fresh frozen plasma, and then the use of cryoprecipitate: "The occurrence of only one death from simple bleeding after 1960 also emphasizes the role of replacement therapy." Ikkala et al Changes in the life expectancy of patients with severe haemophilia A in Finland in 1930-79 British Journal of Haematology 12 February 1982 p6 DHSC0002341\_005. The second flags the risk of liver disease altogether changing the favourable outlook on life expectancy. Larsson Life expectancy of Swedish haemophiliacs, 1831-1980 British Journal of Haematology 12 September 1984 p10 DHSC0041232 015
- 528 England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1991 (Draft) p7 DHNI000006\_005, Triemstra et al *Mortality in Patients with Hemophilia: Changes in a Dutch Population from 1986 to 1992 and 1973 to 1986* Annals of Internal Medicine 1 December 1995 p1 DHSC0004527\_002, Annotation of Draft Report on Self-Sufficiency in Blood Products p4 WITN7662008
- 529 England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973 to 1991 (Draft) 8 October 2004 p9 DHNI0000006\_005, Annotation of Draft Report on Self-Sufficiency in Blood Products p7 WITN7662008
- Omitted in the 8 October draft; present in several previous drafts: England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1985 p19 WITN7485005, England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 22 February 2023 p25 WITN5292113, Annotation of Draft Report on Self-Sufficiency in Blood Products p10 WITN7662008

being peer reviwed [sic], has concluded that the government at the time acted reasonably. We will therefore be putting a submission to Ministers in the near future on how the conclusions of the review can be made public." <sup>531</sup>

## Peter Burgin's observations

In his statement to the Inquiry Peter Burgin compared his own report of 2002 with the report from 8 October 2004 which had been sent to him by Zubeda Seedat. He said that the 2004 report "is materially different to my report." Quite apart from the list of abbreviations, executive summary, list of references and an expanded chronology of events "there were aspects of the analysis that had changed." 532 As well as the matters to which attention has been drawn in this chapter already, many of which he noted, he identified the addition of the words "There is therefore no evidence to suggest that the NANBH outbreak in the late 1970s and early 1980s could have been avoided had England & Wales been completely self-sufficient in blood products during this period" 533 and, in respect of tests for Hepatitis C "At this time, the knowledge that adequate methods of inactivating pooled plasma products were already available were thought to negate the need to introduce routine screening before it could be demonstrated that such screening would be cost-effective and lead to an increase in the safety of transfusion." 534

#### Final amendments

It is unclear who made the further amendments for the version of July 2005, or why they were made. They were comparatively minor apart from the first.<sup>535</sup>

- Email from Richard Gutowski to Ailsa Wight 29 September 2004 pp1-2 DHSC5041563. He repeated these conclusions in an email to the Head of Customer Service at the Department of Health on 4 October 2004. Email from Richard Gutowski to Linda Percival 4 October 2004 p1 DHSC0041333\_004. Dr Ailsa Wight was the deputy director of infectious diseases and blood policy. Written Statement of Dr Ailsa Wight para 2v WITN4509001
- 532 Written Statement of Peter Burgin para 3.25 WITN7485001
- Written Statement of Peter Burgin para 3.25 WITN7485001. In her response to Dr Nicholas' comment that a "key issue that may need further exploration in terms of this report is whether, even if we had achieved self-sufficiency in the UK, the outbreak of hepatitis C among haemophiliacs might have been averted", Dr Nataraja concluded "There is therefore no evidence that the hepatitis outbreak would have been prevented if England & Wales had been completely self sufficient in blood products in the late 70s/early 80s". She added that "if we are to [make] statements such as this, which reflect the opinion of the author, it is important that the report has been approved by the person within the Department chosen to be named author." Annotation of Draft Report on Self-Sufficiency in Blood Products 2004 p3 WITN7662008
- Written Statement of Peter Burgin para 3.25 WITN7485001. The referenced source is not a sufficient basis for what is said in the text; the relevant part reads: "Many countries have already introduced (or will soon) anti-HCV screening of blood donors. Regulations on product liability provide a powerful stimulus to override considerations of strict cost-effectiveness, even though adequate methods for inactivating pooled plasma products are widely available." Barbara and Contreras Non-A, Non-B Hepatitis and the Anti-HCV Assay Vox Sanguinis 1991 p5 NHBT0000030\_054
- When the 20 July 2005 version (England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 DHSC0200084\_002) is compared with the 8 October 2004 version (England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1991 (Draft) 8 October 2004 DHNI0000006 005) the July 2005 version:
  - (a) eliminates the reference to the risks of imported concentrate in the opening paragraph "concerns were accompanied by fears of the risk of both hepatitis and HIV infection from imported factor

# Commentary

In evaluating the evidence about the delay, the change of scope, and the various alterations

VIII concentrate" to read "concerns were accompanied by fears of the risk of both hepatitis and in the early 1980's the additional potential risk of Human Immunodeficiency Virus (HIV) infection." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p3 DHSC0200084 002

- (b) adds the words "It became clear that HCV was the cause of the majority of cases previously labelled as Non A Non B Hepatitis (NANBH)." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p3 DHSC0200084 002
- (c) changes the words "it is likely that, over time, the majority of haemophiliac patients ... would have come into contact with contaminated product" to "it is likely that, over time, the majority of haemophiliac patients ... would have contracted the hepatitis C virus." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p3 DHSC0200084 002
- (d) changes the words "However, in the majority of cases, the yield of whole blood or plasma was not sufficient to control bleeding ... Furthermore, in 1968, a process was developed to fractionate factor IX from the supernatant plasma obtained from the satellite bag after cryoprecipitate" to read "However, in the majority of cases, the volume of whole blood or plasma that could be safely transfused was not sufficient to control bleeding ... Furthermore, in 1968 ... supernatant plasma obtained from the satellite bag after cryoprecipitate could also be used as a source of factor IX." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p7 DHSC0200084 002
- (e) adds "However there were further incidents in 1993" to a description of transmission through immunoglobulins. England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p8 DHSC0200084 002
- (f) adds "With the isolation and full identity of HCV in 1989, it became clear that the vast majority of cases of NANBH were in fact due to HCV." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p8 DHSC0200084 002
- (g) alters the words "and two confirmatory supplementary assays (recombinant immunoblot assay [RIBA] from Ortho and Organon ... most RIBA confirmed positive sera were strongly reactive in all the three screening assays" to read "and two supplementary assays (recombinant immunoblot assay [RIBA] from Ortho and Organon ... most RIBA positive sera were strongly reactive in all of the three screening assays suggesting confirmed HCV infection." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p13 DHSC0200084 002
- (h) changes "Only 15% more factor VIII (approximately 15m iu) was issued for the year 1977 ending than in 1976" to read "87% more NHS produced factor VIII (approximately 5m iu) was issued for the year 1977 ending than in 1976". England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 pp19-20 DHSC0200084 002
- (i) changes "Since 2 June 1986, for operational reasons unconnected with the safety of factor VIII, all plasma processed at BPL was derived from individually screened donations for HIV antibody" to read "Since 2 June 1986 all plasma processed at BPL was derived from donations individually screened for HIV antibody." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p23 DHSC0200084\_002
- (j) omits the description of the sources of microbial contamination of products from a list. England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p24 DHSC0200084 002
- (k) changes "In late 1988, it was discovered that past errors in estimating the current stockpile of plasma meant only 330 tonnes rather than 450 tonnes of plasma were available for processing at BPL" to read "In late 1988, it was reported that a large quantity of plasma (about 120 tonnes) had not been subjected to individual donation screening for HIV-Ab which meant that the current stockpile of plasma available for processing at BPL was only 330 tonnes rather than 450 tonnes of plasma." England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p25 DHSC0200084\_002
- (I) deletion of the final paragraph; a similar paragraph would be reinstated in the February 2006 version. England and Wales Self-Sufficiency in Blood Products: A Chronology from 1973-1991 (Draft) 8 October 2004 p29 DHNI0000006\_005 compared with England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-91 (Draft) 20 July 2005 p29 DHSC0200084\_002 compared with Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 p34 DHSC0200111

to the text of the initial Christmas Eve draft, the first question to be answered is whether Peter Burgin's draft was a fair reflection of the documents available to him – he described it as a "document review". There is nothing to suggest that it was not.

The second question is whether the eventual report was significantly changed from the original. It is clear that it was.

The third question is why it was changed. The reasons for this are more elusive. Part of the reason for changes was that an early decision was made that the report should be published. Publication required an executive summary, and it was reasonable to think it would be helpful to have references. Parts of the text might, in the views of some, have benefited by their expression in a slightly different form for a document intended for the public.

Part of the reason for change may also have been the change in timescale. The Christmas Eve report centrally concerned 1973-1985, and its heading said so.<sup>536</sup> This was changed after discussions at the Department of Health (of which no documentary record survives) between Dianthus, Richard Gutowski, and it may well be others.<sup>537</sup>

Part of the reason is more troubling: there was a change of approach. The intention had been to produce a review of contemporaneous documents from the 1970s and 1980s so that a minister could understand what they showed, and decide what their view was as to the conclusions to be drawn from them. Yvette Cooper's purpose in commissioning the study was to see if the conclusions of fact which had hitherto been expressed by ministers and by the Department of Health were justified or not, and to find out what had become of Lord Owen's papers. This intention was not honoured. The document became, instead, one intended for publication consistent with, indeed inclined towards, drawing conclusions in support of the line thus far taken, rather than asking any awkward questions about it.

A particularly egregious example of this is that the very last words before the conclusions are stated are "It is now known that it is an indisputable reality that very few counties [sic] are capable of completely satisfying their blood needs (i.e. becoming self-sufficient) without acquiring a proportion of blood from paid donors [158]."538 The reference for this is an article which says what is effectively the opposite:

"Unpaid donation is proven to be much safer for receivers and supply problems can be attributed fundamentally to inefficiencies in the organization of transfusion services. Voluntary and non-remunerated donation may be sufficient for a country/region to cover all its blood product needs, but requires an efficient organization and the elimination of 'spurious altruism', non-monetary forms of

<sup>536</sup> England and Wales Self-Sufficiency in Blood Products: A Chronology 1973-85 p1 WITN7485005

<sup>537</sup> Email from Dr Nataraja to Richard Gutowski 20 July 2004 p2 WITN5292111

<sup>538</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 pp30-31 DHSC0200111

compensation that harm the social image of voluntary donation and obstruct its further development." 539

In other words, if countries organise their transfusion services efficiently there is no supply problem, and safety is provided better by a system of voluntary donations than one which involves supplies which are bought from individual people wishing to sell their blood. This addition is first referenced in Dr Nataraja's response to Dr Nicholas' comments.<sup>540</sup>

Not only is the statement in the report simply wrong but the addition of a reference to it is unrelated to any document from the 1970s and 1980s (or later) which Peter Burgin was tasked to review. It represents not fact, but opinion. The opinion, though mis-characterised, is plainly given in order to support a case – it minimises any blame for not achieving self-sufficiency, in essence because (as portrayed) it says the task was impossible. This was obviously incorrect (not least because Scotland managed self-sufficiency, demonstrating it can and has been done without particular difficulty), but more to the point it is purely argumentative, and should have had no place in a document which intended not to make a case, but rather to explore whether the available documents supported or detracted from the case already being made.

It would be too easy to suggest that Dr Nataraja erroneously mis-stated what the article says – the real criticism here is that she appears to have been looking for material which might be taken to support the departmental line as taken thus far. She must have thought this is what the Department of Health wanted. There is no other obvious reason for her referring to an article which was not part of the chronology of decision-making nor part of the contemporaneous context. Though there had to be time spent trawling through literature searches to support some of the points, the original work was to review what contemporaneous documents showed. Peter Burgin may not have referenced what he said but he had sources – and could have been asked. His evidence is that he was not.<sup>541</sup> There is no document to show that he was. The failure to ask him what his sources were for particular statements is surprising. Time was spent extending the time period which the report covered. There is thus little to support time pressure being a reason.

Fernandez-Montoya *Altruism and Payment in Blood Donation* Transfusion Science September 1997 p1 DHSC0004527\_130

Dr Nicholas had posed the question "whether (over a period) the UK products would still have caused most patients with haemophilia to become infected" and suggested "Perhaps we need some input on the relative risks of imported and UK products from a haematologist/plasma fractionators etc, and on the expected outcomes from using UK sourced products." Dr Nataraja was confident of the answer and as part of her evidence summarised the article in similar terms to those she would use in the report: "it is indisputable reality that very few countries are capable of satisfying their blood needs (i.e. becoming self-sufficient) without acquiring a proportion of blood from paid donors." Annotation of Draft Report on Self-Sufficiency in Blood Products 2004 p3 WITN7662008. Dr Jacobs said: "I do not remember the details of how we arrived at the views in Dr Nataraja's comments, but I assume it would have been from reading the report and the reference material we looked at as part of our task, and possibly also discussion with Mr Gutowski." Written Statement of Dr Adam Jacobs para 35 WITN7662001

<sup>541</sup> Written Statement of Peter Burgin paras 3.10, 3.21 WITN7485001

Part of the reason for the changes might have been because of the change in the timescale the report was intended to cover – though no one has ventured that as a reason for changes, since no one involved in the later changes appears clearly to accept in evidence that the document has been materially changed.

The fact that no one accepts that they played a part in making a material change to the report is also troubling: for although there may have been some good reasons for amplification of parts, it is more difficult to see why a document intended as a review of the factual documentation should have become so significantly changed as to support a number of conclusions, and in part to fashion arguments in support of the line the Department of Health had taken in public. It can be seen that these alterations, broadly viewed, fall in line with the approach the Department of Health had adopted to issues of infected blood and blood products during the 1990s and early 2000s.

There is no good reason why a person concerned with making the sort of alterations that were made should not wish to admit it.<sup>542</sup>

Though it is common for government departmental reports not to name authors other than senior civil servants, it is also concerning that despite Dr Nataraja suggesting that an individual took responsibility as a named author for the various opinions in the text, this was not done. The report is, rather, a departmental offering.

Ultimately, what started out as a project to inform ministers of materials that were available about self-sufficiency, so that they might consider for themselves whether the current line adopted by the Department of Health was properly justified, became itself a document the effect of which was to justify that line.

It seems plain that Richard Gutowski himself did not have the time readily to write the detailed changes that were made. The medical writers did, but deny having changed the content. They did, however, have a number of conversations with Richard Gutowski: that is to be inferred from what Dr Jacobs says in evidence, and a contemporaneous email. <sup>543</sup> Dr Jacobs did not consider it part of the job of Dianthus to "substantially change the content of the report on our own initiative" though plainly it was responsible for many of the references, and Dr Nataraja volunteered some changes that might be made, albeit leaving it to the Department of Health to decide, and actually made others in response both to her understanding of some of the references she had found and to Dr Nicholas' comments. <sup>544</sup> Though the Fernandez-Montoya article relied upon at footnote 158 in the final report for

Due allowance has to be given to the time that has elapsed – some 17-20 years. This may make it more difficult to recall, and being able to give accurate dates cannot be expected. Nonetheless, on balance, changes of the nature described in the text were not minor ones, and the report was to help assess the approach the Department of Health had hitherto taken to issues around blood-borne infections: these involved whether calls for a public inquiry should be resisted or welcomed, so they were of some consequence. Major changes would normally be recalled if any one person regarded themself as responsible for them.

<sup>543</sup> See the expectation of a meeting in the email of Dr Nataraja of 20 July 2004. Email from Dr Nataraja to Richard Gutowski 20 July 2004 WITN5292111, Written Statement of Dr Adam Jacobs para 20 WITN7662001

<sup>544</sup> Written Statement of Dr Adam Jacobs para 22 WITN7662001

the statement "it is now known that it is an indisputable reality that very few counties [sic] are capable of completely satisfying their blood needs (ie becoming self-sufficient) without acquiring a proportion of blood from paid donors" was out of place, and the statement incorrect, it was a statement first included in the 8 October 2004 version. Yet the most substantial changes to the content came between the production of Peter Burgin's draft and the draft submitted by Dianthus on 4 August. Dr Nicholas had an influence, but largely after the Dianthus report had been produced. His review led to some further changes.

My conclusion is that the likeliest cause of what occurred is that when discussing the report with Dianthus, and when responding to Dr Nataraja's suggestion that the timescale should be extended, Dianthus became aware of the general approach within the Department of Health. Richard Gutowski was inclined to use words such as "robust", "rewrite", "strong line" and "defensive". He had worked for some thirty years in the Department, and his instinct was strongly to be protective of it. It is likely that views such as his were echoed by others working hard on the latest issues of the day within the Department of Health. It is more likely than not that Dianthus took their line from what they would have seen as the prevailing attitudes within the Department of Health – essentially, that the Department of Health was keen to defend the position they had habitually adopted.<sup>545</sup>

Charles Lister spoke of "groupthink". 546 He was talking reflectively, rather than expressing the view that this was true of the team which he had headed up before Richard Gutowski took over. The word does, however, describe the striving for a consensus within a group which in many cases leads to people setting aside their independent beliefs to adopt the opinion of the rest of the group. The Department of Health had, in the 1990s, maintained a line that patients had received the best available treatment in the light of medical knowledge at the time. Ministers were set against no fault liability, and it is clear that the Department of Health saw itself as being on the defensive. 547 There was disguiet within the Department of Health at the start of its preparation of the Self-Sufficiency Report about proposals in Scotland which might suggest there was a basis for paying ex gratia sums to those who had been infected with Hepatitis C as a result of treatment. It is almost inevitable that those who were setting others the task of seeing what early documents could show would hope that they would turn up documents which would support these near instinctive views. The likelihood is that departmental groupthink (or attitudes such as these) led to a desire to see the eventual report reflect some of the views which departmental officials felt should be defended. It may be indicative of this that around a page of the final report<sup>548</sup> appears

<sup>545</sup> There is considerable evidence of this: see the chapters on *Role of Government: Response to Risk, Lines to Take* and *Delay in Holding a Public Inquiry.* 

Charles Lister Transcript 8 June 2022 pp78-79 INQY1000212. "Groupthink" is perhaps best understood as a mode of thinking in which individual members of small cohesive groups tend to accept a viewpoint or conclusion that represents a perceived group consensus, whether or not the group members would individually believe it to be valid, correct, or optimal if they took time to reflect on it.

<sup>547</sup> See the exchanges between Richard Gutowski and Robert Stock, and Richard Gutowski and Graham Bickler, set out above.

<sup>548</sup> Self-Sufficiency in Blood Products in England and Wales: A Chronology 1973-91 2006 pp14-15 DHSC0200111

to argue a justification for there being no surrogate testing, and for the introduction of screening for Hepatitis C only after second-generation tests were available, yet there is no sense that those writing the report had had any regard for the careful factual consideration of these very same issues in Mr Justice Burton's judgment in *A and Others v National Blood Authority* delivered in March 2001.<sup>549</sup>

Sir John Major, giving evidence, talked of government policy making and changes of direction as resembling a supertanker changing course. Just as Charles Lister when speaking of "groupthink" was describing what may often happen within small groups of decision-makers, he too was describing a general experience of the way in which people often react. It is often difficult for a small group of people to decide that a previous approach, enshrined over time as the proper one to adopt, should be questioned, let alone changed, and to see the work and effort they had put in to advancing it no longer to hold value and give them high regard amongst others but, instead, to have been misguided and their time misspent.

It was partly because of the need for the public to be properly informed and to ensure that Parliament and departments of government were responsive to their concerns, that the Freedom of Information Act was passed in 2000. This was not long before Yvette Cooper, probably in line with the principles underpinning that Act, called for the report. Ultimately, however, the defensiveness of a Department to concerns expressed by citizens about what had happened in respect of infected blood remained. Selective information, giving less than a full and balanced perspective of that which those contemporaneous documents still available showed, runs counter to the spirit of freedom of information: sadly, that is what happened here, both in relation to the delays in producing a report and the changes of substance made to it during the period of delay.

In the text above I have indicated that there is insufficient to say that, except as being responsible as head of the team for the 18 months that he was, Richard Gutowski was responsible personally for the changes which occurred; nor, insofar as he was personally responsible, that this was with any intention of misleading the public. Nor can I say with any assurance that any of the other civil servants involved was responsible. Some of the alterations made when Dianthus were producing the August draft were not adequately justified by the references. Some told only part of what was there to be recounted. But this was, I consider, symptomatic not of any personal desire to mislead but rather a reflection of the general attitude of those in the Department of Health which Dr Nataraja (principally) thought herself tasked to follow. Dianthus though was not responsible for the alterations which followed after October 2004, though they were less significant than those which arose between July and October.

Though there is insufficient evidence to identify personal responsibility of any one person (as opposed to the collective responsibility of the Department of Health) for what occurred,

<sup>549</sup> A and Others v National Blood Authority Judgment 26 March 2001 PRSE0003333

<sup>550</sup> Sir John Major Transcript 27 June 2022 p39, p135 INQY1000219, Written Statement of Sir John Major para 3.52 WITN5284001

there is abundant material to show that, in the end, a version was published which tended to reflect the defensive approach which government had adopted in the 1990s, rather than – as it should have done – reflecting carefully upon the decision-making from 1973 onwards, and producing a more balanced view.<sup>551</sup>

The production of the Self-Sufficiency Report in the form it eventually took was part of the government response to what had happened. The Self-Sufficiency Report was promised, expected and then unjustifiably delayed. As this Inquiry now knows, but the public receiving the report will not have realised until very recently if, indeed, at all, it represented a report which had undergone substantial change from draft to draft, altering the timescale, and its essential nature. As published it was defensive of the line which had been taken but, as examined elsewhere in this Inquiry, much of what was recorded in it presented an incomplete picture of the material that was there to be seen.

Campaigners may not have known the process by which the Self-Sufficiency Report was produced, but they knew that it did not represent the full truth. Gaynor Lewis described how her late husband, Haydn, had been "spurred on" by the death of Colin Smith aged seven in 1990 and had become "a walking encyclopaedic guide to the thousands of Government documents in which officials, scientists, doctors and politicians revealed how thousands of haemophiliacs had became infected."552 Haydn Lewis and Andrew March had put together the Tainted Blood Accusations Document, with the starting point of their analysis being:

"In 1974, Dr David Owen, then Health Minister, decided that if enough money were to be invested, the United Kingdom could become self-sufficient in blood products and they would only need to be sourced from Britain and would thus be much more likely to be free from contamination." 553

Carol Grayson had also been researching since the 1990s and wrote the letter that prompted Yvette Cooper's request for a formal review. Carol Grayson told the Inquiry: "I had always believed that if we could get the government to provide a written response to some of our questions, I would be able to critique whatever we received. Very quickly it became apparent that many key documents were missing so I decided to analyse the Department of Health, Self-Sufficiency Report using documents I had researched". 554 She went on to write a dissertation critiquing the Self-Sufficiency Report. 555

The Inquiry has come to its own conclusions in respect of the issues which were discussed in the Self-Sufficiency Report. They are expressed throughout but principally in the chapters on *Knowledge of Risk Before 1970*, *Self-Sufficiency*, *Regulation of Commercial Factor Concentrates*, *Viral Inactivation*, *Hepatitis C Surrogate Screening*, and *Hepatitis C Screening*. They need not be re-stated here.

<sup>552</sup> Written Statement of Gavnor Lewis pp7-8 WITN2368019

Tainted Blood Accusations Document p6 WITN2368023. Submitted to the Archer Inquiry on 4 June 2006. Written Statement of Gaynor Lewis pp3-4 WITN2368019, Written Statement of Andrew March paras 9-17 WITN1369014

Written Statement of Carol Grayson paras 98-122 WITN1055004

<sup>555</sup> Blood Flows Not just Through our Veins but Through our Minds. How has the Global Politics of Blood impacted on the UK Haemophilia Community? 12 January 2007 WITN1055006

When the Self-Sufficiency Report was published, the Haemophilia Society's response was unequivocal. Margaret Unwin, the chief executive, said: "Reading the report – which does not have a named author – it appears to be a fairly blatant attempt to gloss over the details of the events of the time and even to lay blame at the door of the patients themselves ... This document is greatly flawed and has, I believe, been produced to deflect the call for a wide-ranging public inquiry into the whole issue. The report has been produced internally, informally and very poorly by the Department of Health ... [it] merely reflects the views of the Department itself."556

The Haemophilia Society renewed their call for a public inquiry. Eighteen years later, the rest of this Report conveys a definitive view of what happened.

This chapter has, as its focus, whether there has been a hiding of the truth. The way the Self-Sufficiency Report came into circulation in its (defensive and argumentative) final form, after a series of alterations, shows how its thrust was altered. When it is realised that material was written out that showed that the DHSS had knowledge in the mid and late 1970s that there was an appreciable risk from hepatitis, that NANBH carried serious long-term consequences, and that commercial concentrates were especially risky, and this is then coupled with the way in which the reasons for seeking self-sufficiency were restated so as no longer to recognise that a reason for the policy of self-sufficiency was patient safety, it is obvious that the effect of the rewritten draft was to hide this material.

Was this intentional? Plainly, yes – for decisions were taken to rewrite some parts and omit others. However, that does not tell us what the motive was. As to that, there is no sufficient evidence to conclude that it was because one, or a number, of individuals set out to hide the truth of what had happened. It is more likely that what has just been summarised is the effect of strong and honest (though ill-considered) beliefs within the Department of Health setting out an account as they wished to believe it should be seen - the effect of a strong bias towards a particular view of the rights and wrongs of what had happened – which in turn were reflected by the medical writers, rather than a deliberate intention to hide "embarrassing" material and to rewrite history. Supportive of this view is that reference was made in the final text in both the executive summary and the text to some medical opinion in the late 1970s and early 1980s about risks of hepatitis, in particular from concentrate: it was thus not hidden that some experts spoke of risks, albeit this was downplayed where NANBH was concerned. What was no longer recorded was that this was part of the reason for the policy of self-sufficiency; and that in 1980 the DHSS had itself clearly understood that NANBH was a significant disease with serious long-term consequences. The Self-Sufficiency Report in its final form led to a ministerial briefing in the terms William Connon used;557 on a fair reading, the same briefing could not have accompanied the original Christmas Eve draft.

Haemophilia Society Press Release *Haemophilia Society condemns Department of Health report* 28 February 2006 pp1-2 PMOS0000106

<sup>557</sup> Memo from William Connon to Caroline Flint 20 July 2005 DHSC0006259 020

The Self-Sufficiency Report was an inadequate response to the request made by Yvette Cooper and a disservice to campaigners who, despite the challenges of ill-health and grief, had determinedly pieced together a fuller understanding of self-sufficiency than the report published by the Department of Health.

# 7.3 Lines to Take

The infection of thousands of NHS patients with HIV, Hepatitis C and Hepatitis B has been described as the "worst treatment disaster in the history of the NHS". This chapter examines how, for a prolonged number of years, governments relied on particular "lines to take" including: that patients had received the "best treatment available"; that Hepatitis C screening could have been introduced earlier than it was; and that infections were "inadvertent."

### **Key Dates**

**June 1989** Ministerial submission relating to the HIV Litigation asserts the government acted as swiftly as possible in the light of the best expert opinion available at the time.

**November 1989** Prime Minister says that people infected with HIV from blood products "had been given the best treatment available on the then current medical advice".

**January 1995** "best treatment available" line used for those infected through transfusion.

**November 1995** Briefing for the Prime Minister includes "Greatest sympathy for those inadvertently infected ... Patients concerned received best treatment in the light of medical knowledge at the time. As soon as reliable test became available (1991) all blood donations tested to prevent Hepatitis C infection."

**January 2004** Line that screening could not have been implemented earlier proposed as response to calls for public inquiry.

### **People**

**Stephen Dorrell** Secretary of State for Health (1995 - 1997)

**Caroline Flint** Parliamentary Under-Secretary of State for Public Health (2005 - 2006) Minister of State for Public Health (2006 - 2007)

John Horam Parliamentary Under-Secretary of State for Health (1995 - 1997)

John Hutton Minister of State for Health (October 1999 - May 2005)

John Major Prime Minister (1990 - 1997)

**Alan Johnson** Secretary of State for Health (2007 - 2009)

**Dawn Primarolo** Minister of State for Public Health (June 2007 - June 2009)

**John Reid** Secretary of State for Health (June 2003 - May 2005)

**Tom Sackville** Parliamentary Under-Secretary of State for Health (1995 - 1997)

Margaret Thatcher Prime Minister (1979 - 1990)

Norman Warner Parliamentary Under-Secretary of State for Health (2003 - 2005)

Lines to Take 105

## "Best treatment available"

On 22 November 1989, at a meeting at Number 10 Downing Street, Prime Minister Margaret Thatcher rebuffed a proposal by an MP that the Government should take special action on moral and political grounds<sup>558</sup> by stating that "The position was" that people infected with HIV from blood products "had been given the best treatment available on the then current medical advice, and without it many of the haemophiliacs would have died."<sup>559</sup>

This was part of the Government's reasoning for resisting the argument that compensation should be paid. It reflected the briefing that had been provided in advance of the meeting at Number 10, which argued that an out-of-court settlement of the then ongoing HIV litigation "could set an unacceptable precedent by implying NHS liability for treatment which reflects the best available medical information at the time but turns out later to be wrong." 560

In March 1990 the Parliamentary Under-Secretary of State for Health, Roger Freeman, told Parliament that: "I stress again that the Department of Health believed that it was offering the best available treatment, in good faith, at the time."<sup>561</sup>

Thus, this particular line to take was first used as part of the justification for not providing compensation to people with haemophilia who had been infected with HIV.

- The Government was, however, already planning that it would make a further ex gratia payment to the Macfarlane Trust. This was announced in Parliament by the Secretary of State for Health on 23 November 1989. Hansard written answer on Haemophiliacs 23 November 1989 HMTR0000001\_023
- Letter from Prime Minister's Private Secretary Paul Gray to Private Secretary to Minister of State for Health Virginia Bottomley 22 November 1989 p2 DHSC0002536\_031. The meeting involved a Conservative Parliamentary delegation who went to see the Prime Minister about the position of people with haemophilia infected with HIV. That they had received the best treatment at the time plainly remained the Prime Minister's view because in October 1990 she had a discussion about the HIV litigation with the Secretary of State for Health, Kenneth Clarke, in which she said that the Government "could not be considered negligent for having offered treatment which was considered safe in the light of the best scientific advice at the time even if, subsequently, such treatment was shown to have had harmful effects." Letter from Andrew Turnbull to Stephen Alcock 18 October 1990 p1 CABO0000044 002
- 560 Briefing for meeting on 22 November between the Prime Minister and Robert Key 21 November 1989 p4 CABO0100002 011. (An earlier draft of the briefing is at: DHSC0003989 043). This particular line to take may have developed from an earlier ministerial submission from Charles Dobson in June 1989, in which it was asserted that at every stage the Government had acted as swiftly as possible to minimise the risk of infecting people with haemophilia with AIDS in light of the best expert opinion available at the time. Memo from Charles Dobson to Alan Davey, copying in Dr McInnes the Private Secretary to the CMO, 26 June 1989 p3 MHRA0017681. See the chapter on HIV Haemophilia Litigation. Charles Dobson reported through the Under-Secretary to Strachan Heppell (Deputy Secretary) who in turn reported to the Permanent Secretary. Virginia Bottomley, the Minister of State for Health in November 1989, attended the meeting at Number 10 on 22 November but had no recollection of it. Written Statement of Baroness Virginia Bottomley para 4.27 WITN5289001. However a minute dated 7 November 1989 (authored by Strachan Heppell) recorded the Minister's aim as being to identify proposals which, amongst other matters, did not set any unacceptable precedent for the future "eg by implying NHS liability for treatment which reflects the best available medical information at the time". Memo from Strachan Heppell to Mr McKeon 7 November 1989 p1 DHSC0004415\_156. On 10 November 1989 Strachan Heppell repeated these words in a minute of his meeting with the Haemophilia Society chair and general secretary: "It [the Government] could not concede liability for action taken on the best available advice at the time. To do so could undermine the future ability of the NHS to do its best for patients." Memo from Strachan Heppell to Alan Davey 10 November 1989 p2 DHSC0004415 155

561 Hansard extract on Blood Transfusions (HIV Infection) 6 March 1990 p4 BNOR0000359

By 1994 – the HIV litigation having been settled – the focus had begun to shift to the question of whether people with haemophilia who were infected with Hepatitis C should receive some form of financial settlement. The lines to take in a Department of Health briefing for the Prime Minister – by now John Major – in November 1994 included that: "We have great sympathy with those who may have been infected with hepatitis C through NHS treatment. These patients will have received the best treatment available in the light of the medical knowledge at the time." The briefing said further that there were no plans to extend the HIV settlement scheme to those infected with Hepatitis C.<sup>562</sup> The line was repeated by a Department of Health spokesman and reported in *The Independent* newspaper on 16 November 1994.<sup>563</sup>

On 6 December 1994 a parliamentary question asked what plans the Secretary of State (by now Virginia Bottomley) had to compensate those who had contracted Hepatitis C from contaminated blood products. The response from Tom Sackville, Parliamentary Under-Secretary of State for Health, simply stated that there were "no plans to make payments to patients who may have been infected with hepatitis C as a result of National Health Service treatment", 564 but a briefing document prepared for the Minister contained the assertion that "Most haemophilia patients infected before heat treatment introduced – received best treatment available in light of medical knowledge at the time." 565

In January 1995 it was announced that a lookback exercise would be conducted across the UK to identify and follow up people who might have been infected with Hepatitis C through NHS treatment. The lines to take prepared in advance of the announcement included that: "We have great sympathy with those who may have been infected with Hepatitis C through NHS treatment. We do not accept that there has been negligence, these patients will have received the best treatment available in the light of medical knowledge at the time. We have no plans to compensate those who may have been infected with Hepatitis C."567 That same month a letter from the Parliamentary Under-Secretary of State for Health in the House of Lords, Baroness Julia Cumberlege, to John Marshall MP asserted that "Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time." 568

- 562 Briefing note for the Prime Minister on Hepatitis C 16 November 1994 DHSC0003527\_009. As well as being sent to Number 10 it was provided to all Department of Health ministers on 16 November 1994. Memo from David Burrage to Mr Mogford and others 16 November 1994 DHSC0003527\_008. See also the Written Statement of Tom Sackville paras 8.21-8.22, paras 8.26-8.27 WITN5249001
- 563 The Independent *Contaminated blood kills 12* 16 November 1994 HSOC0021551. And also in the *Evening Standard* on the same date. Evening Standard *Thousands at risk in diseased blood alert* 16 November 1994 DHSC0004738 087
- 564 Hansard written answer on Hepatitis C 6 December 1994 DHSC0041152 021
- 565 Briefing document "Bull points and elephant traps" DHSC0041152 027
- 566 Hansard written answer on Hepatitis C Lookback Exercise January 1995 NHBT0005796
- 567 Lines to take on Hepatitis C Lookback Exercise p1 DHSC0003555\_130
- Letter from Baroness Cumberlege to John Marshall 19 January 1995 p1 DHSC0004478\_024. A similar letter was sent by the Parliamentary Under-Secretary of State for Health in the House of Commons, Tom Sackville, on 31 January 1995, to Winston Churchill MP and on 11 April 1995 to Ann Winterton MP. Letter from Tom Sackville to Winston Churchill 31 January 1995 HSOC0004917, Letter from Tom Sackville to Ann Winterton 11 April 1995 DHSC0006946\_067

In a briefing prepared for a parliamentary question in the House of Lords in January 1995, the line to take in relation to haemophilia patients infected with Hepatitis C included that: "These patients received the best treatment available in the light of medical knowledge at the time". It was further suggested that non-A non-B Hepatitis was considered to be an "acceptable side effect" of treatment with blood products, "both by physicians and the patients themselves." There is no evidence of any enquiries being undertaken to justify the assertion that patients regarded Hepatitis C as an "acceptable side effect" of their treatment. 570

The standard line was duly repeated by Baroness Cumberlege in responding to the parliamentary question on 30 January 1995. Lord Jack Ashley, asking if there were plans for a compensation scheme, raised the position of those infected with Hepatitis C through blood transfusions, as well as those with haemophilia. The Minister's response was that: "People are given the best treatment available at the time in good faith. As regards haemophiliacs, without the blood they would certainly have died."571 It is apparent from this answer that the line was now being applied not only to those with haemophilia infected with Hepatitis C but also to those infected through transfusion. The suggestion that the former would "certainly have died" without the treatments that infected them was quite wrong. 572

A briefing for the Prime Minister on 31 January 1995 likewise covered both those who had been infected with Hepatitis C following transfusion and haemophilia patients infected through blood products. The briefing included the line that: "We do not accept that there has been negligence. These patients will have received the best treatment available in the light of medical knowledge at the time. We therefore have no plans to compensate those who may have been infected with Hepatitis C."<sup>573</sup>

In March 1995 the Haemophilia Society launched a campaign which, amongst other matters, called for financial assistance for haemophilia patients infected with Hepatitis C from contaminated blood products. A background note prepared within the Department of Health in relation to the campaign explained that: "Although patients received the best treatment available based on existing knowledge it has to be recognised that not all medical interventions are risk free. Risks may be evident at the time of treatment or may be discovered later. If payments were to be offered for each such incident we would soon slip

<sup>569</sup> Briefing for parliamentary question 27 January 1995 p6 NHBT0005768 002

Of course, in order for a person to form such a view they would have to have been given information about the potential seriousness of Hepatitis C (or non-A non-B Hepatitis). As detailed elsewhere in this Report, the evidence establishes overwhelmingly that people were not given that information.

<sup>571</sup> Hansard extract on Haemophiliacs: Contaminated Blood Transfusions 30 January 1995 p2 NHBT0009775

This suggestion that the introduction of concentrate therapy led to increased life expectancy amongst those with bleeding disorders is a line that was trotted out over the years without thought or proper consideration. The evidence in fact suggests that treatment with cryoprecipitate, which was inherently less risky, had a significant impact on life expectancy.

Briefing for the Prime Minister: Hepatitis C Look-back Exercise and Compensation 31 January 1995 p1 DHSC0002552\_011. The Prime Minister had been given a similar briefing a little earlier in January in light of the broadcast of a *Panorama* documentary on 16 January 1995. Briefing for the Prime Minister: Hepatitis C Look-back Exercise and BBC "Panorama" 17 January 1995 p1 DHSC0002552 022

*into a general no fault compensation scheme.*"<sup>574</sup> Baroness Cumberlege repeated the line in Parliament on 15 March 1995.<sup>575</sup>

In April 1995 officials within the Department of Health prepared a paper for the Minister of State for Health, Gerald Malone, who had asked for advice on how a payments scheme might be constructed for those suffering life-threatening complications caused by Hepatitis C contracted through blood transfusions and blood products. The covering minute asserted that "Ministers have denied that the Department have been in any way negligent and indeed the Haemophilia Society representatives have been at pains to make clear that their campaign is not in any way based on such a charge. Those patients who were infected were given the best treatment available at the time."<sup>576</sup>

This line to take was not unique to England. On 17 May 1995 the Parliamentary Under-Secretary at the Welsh Office, Gwilym Jones, wrote to the father of a son with haemophilia that: "I am advised that most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses and patients received the best treatment available at the time". The Government had, he said, no plans to make payments to individuals infected with Hepatitis C.<sup>577</sup> On 24 May 1995 the Minister of State in the Scottish Office, Lord Fraser QC, wrote to an MP in Westminster with the same assertion: "Most haemophilia patients were infected with Hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time."<sup>578</sup> In June 1995 the Minister for Health and Social Services in Northern Ireland, Malcolm Moss, wrote to Seamus Mallon MP that: "These patients received the best treatment available in the light of medical knowledge at the time."<sup>579</sup>

It is reasonable to infer that officials and ministers in Wales, Scotland and Northern Ireland decided to adopt the UK Government's line to take. 580

- 574 Background note on Haemophilia Society's campaign p2 DHSC0003539 051
- 575 Hansard extract *The McFarlane* [sic] *Trust* 15 March 1995 p6 BART0000791. "In these incidents haemophilia patients received the best treatment available in the light of the medical knowledge at the time."
- 576 Memo from Roger Scofield to Mr Abrahams 6 April 1995 p2 MHRA0024541. The minute was from Roger Scofield, head of the Department of Health's Corporate Affairs Operational Policy Unit, to Mr Abrahams, the Assistant Private Secretary to Gerald Malone.
- 577 Letter from Gwilym Jones to Anon 17 May 1995 p3 HSOC0019803. At the same time the Department of Health line to take continued to be that "Haemophilia patients received the best treatment available in the light of the medical knowledge at the time." Parliamentary question on Hepatitis C and Haemophilia Sufferers 22 May 1995 DHSC0006774\_065
- 578 Letter from Lord Fraser to Rachel Squire 24 May 1995 p1 SBTS0000367\_050
- 579 Letter from Malcolm Moss to Seamus Mallon June 1995 p1 DHNI0000054\_039. Malcolm Moss wrote in similar terms to Reverend Dr Ian Paisley MP and Peter Robinson on 18 July 1995. Letter from Malcolm Moss to Reverend Dr Ian Paisley 18 July 1995 DHNI0000054\_006, Letter from Malcolm Moss to Peter Robinson 18 July 1995 DHNI0000054\_013
- See for example a minute from Peter Davenport in the Health Services Division in the Welsh Office, to Welsh ministers in May 1995, referring to the Government's position and repeating without dissent or question the line that "Patients received the best treatment available at the time." Memo from Peter Davenport to R Williams and others 25 May 1995 p1 DHSC0002549\_154. John Breen, of the Health Promotion Policy Branch of the Northern Ireland Department of Health and Social Services, wrote in June 1995 to Margaret Ann McIlwrath who had been infected with Hepatitis C, as had her son, that "All patients received the best treatment available in the light of medical knowledge at the time." Letter

Briefings for the Prime Minister on the question of financial payments to those infected with Hepatitis C, through transfusion or blood products, continued to emphasise that "the patients concerned received the best treatment available in the light of medical knowledge at the time." One particular briefing added that: "Since 1991, when a reliable test became available, all blood donations have been tested for Hepatitis C to prevent such infection."<sup>581</sup> It is clear, therefore, that by the mid 1990s what had begun as a line to take relating to treatment for bleeding disorders with infected blood products had been effortlessly and unthinkingly extended to encompass people who had been infected with Hepatitis C through transfusion.

On 15 June 1995 John Marshall MP suggested that it was morally and logically unfair to deny compensation to those who had been infected with Hepatitis C, "perhaps mortally, through treatment on the national health service." Tony Newton, answering questions on behalf of the Prime Minister in his capacity as Leader of the House of Commons and Lord President of the Council, responded that it was "of course, an unhappy fact that the patients about whom he is concerned received the best treatment available in the light of medical knowledge at the time."<sup>582</sup>

This line continued to be used in Parliament: the Parliamentary Under-Secretary of State for Health, Tom Sackville, responding to an adjournment debate in July 1995, stated:

"Let us look at the facts of hepatitis C. Most haemophilia patients infected with hepatitis C were so infected before blood products were treated to destroy viruses in 1985. That was well before the first hepatitis C tests were available in 1989. Those patients received the best treatment available in the light of medical knowledge at the time. When those patients were infected, little was known about hepatitis C, or non-A, non-B hepatitis as it was then known, and even today a lot more information is needed." 583

This reflected the speech drafted by civil servants for him, as well as the Q&A briefing that he received.<sup>584</sup>

The same line was taken in Scotland in July 1995: a memo seeking Scottish ministers' agreement to the continued resistance to pressure to establish a compensation scheme, asserted that the Government "has never accepted that there has been negligence in the

from John Breen to Ann McIlwrath 30 June 1995 DHNI0000054\_008. He did so using a stencil letter provided by the NHS Executive in April 1996 to the Welsh Office, Scottish Office and Department of Health and Social Security Northern Ireland. Written Statement of John Breen para 28.1 WITN7515001, Letter from Leonard Levy to John Breen and others 26 April 1995 DHSC0006946\_046. Similar standard replies were provided to the Scottish Home and Health Department in April 1996 and again in June 1996. Fax from Leonard Levy to Sandra Falconer 23 April 1996 BNOR0000471\_037, Fax from Ann Towner to Gary Wildridge 14 June 1996 BNOR0000471\_035

<sup>581</sup> Briefing for the Prime Minister on Hepatitis C 12 June 1995 DHSC0014961\_022

<sup>582</sup> Hansard extract on Business of the House 15 June 1995 p2 DHSC0006231\_029

Hansard extract on Haemophiliacs (Hepatitis C) 11 July 1995 p2 HSOC0026481\_010. The Secretary of State for Health, Stephen Dorrell, used the same line to take in September 1995, writing to Roy Hattersley MP. Letter from Stephen Dorrell to Roy Hattersley 19 September 1995 DHSC0003552\_041

Debate on the motion for the summer adjournment – calls for compensation for haemophiliacs infected with Hepatitis C p1 DHSC0032176\_112, Briefing for Q&A p2 DHSC0004521\_065

treatment of haemophiliacs or other patients who became infected with Hepatitis C through blood transfusions or blood products. These patients received the best treatment available in the light of medical knowledge at the time."585

In September 1995 Dr Andrzej Rejman, in a minute to the Department of Health's Information Division copied to the Chief Medical Officer ("CMO") and to Dr Jeremy Metters (Deputy CMO), gave a similar line to take in response to an announcement of compensation in Ireland: "It is unfortunate that some individuals became infected with hepatitis C following blood transfusion or treatment with blood products. There was no negligence and treatment was given in accordance with the best medical and scientific knowledge at the time." 586

By November 1995 the briefing for the Prime Minister had become more assertive: "I have great sympathy with those who may have been inadvertently infected with Hepatitis C through NHS treatment. I am confident that the patients concerned received the best treatment available in the light of medical knowledge at the time."<sup>587</sup>

In December 1995 the Parliamentary Under-Secretary of State for Health – by now John Horam – held the same line in Parliament: "The patients we are now discussing received the best treatment available in the light of medical knowledge at the time." He emphasised too the "great benefits" of Factor 8 concentrate. John Horam wrote along similar lines to the Reverend Alan Tanner on 21 December 1995: "You are familiar with the Government's position on the question of compensation to haemophiliacs who were inadvertently infected. I think it fair to say that it is acknowledged by all concerned that these patients received the best treatment available in the light of medical knowledge at the time and indeed treatment which provided substantial benefits and to which there was no real alternative." It was of course wrong to say there was no real alternative to the use of Factor 8 concentrates: cryoprecipitate was (for example) a very real alternative.

Scottish ministers used the same line to take: James Douglas-Hamilton, the Minister of State in the Scottish Office, wrote to Dr Winifred Ewing MEP in January 1996 in near identical terms to the letters produced by the Department of Health: "We have great sympathy with those patients who may have become infected with Hepatitis C through blood transfusions

<sup>585</sup> Memo from Ian Snedden to Gerald Malone, the Minister of State 13 July 1995 p3 SCGV0001032 008

<sup>586</sup> Memo from Dr Reiman to L French 21 September 1995 p2 DHSC0006307 062

Emphasis added. Briefing for the Prime Minister 21 November 1995 p1 DHSC0042937\_057. See also: Briefing for the Prime Minister 27 November 1995 p1 DHSC0042937\_075, Briefing for the Prime Minister 4 December 1995 p1 DHSC0006774\_053. The latter again used the phrase "I am confident that". This is all the more surprising given that by this time the Department of Health anticipated litigation in respect of Hepatitis C, and it was known within the Department of Health that the UK was one of the last developed nations to introduce Hepatitis C screening of donated blood. See the chapter on Hepatitis C Screening.

<sup>588</sup> Hansard extract on Haemophiliacs 13 December 1995 p4 HSOC0002072

Letter from John Horam to Reverend Tanner 21 December 1995 HSOC0014333. In January 1996 a briefing on the line to take in response to an *Evening Standard* article of 23 January referred to the pressure that ministers were under to make payments to people with haemophilia infected with Hepatitis C and observed that "The Government has said that these patients received the best treatment available in the light of knowledge at the time". Briefing on line to take in response to Evening Standard article 23 January 1996 DHSC0002467 003

or blood products. Most haemophilia patients were infected with Hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time."<sup>590</sup>

In February 1996 the Haemophilia Society sent to ministers a report which they had commissioned on the impact of Hepatitis C. A minute to the Department of Health's Information Division, copied to the Private Offices of the Secretary of State, Minister of State and Parliamentary Under-Secretary of State, gave as part of the line to take in response to the Society's report the following: "The Government has great sympathy for those infected with hepatitis C as a result of NHS treatment. But these patients received the best treatment available in the light of medical knowledge at the time. No fault or negligence on the part of the NHS has been proved, and we have no plans to make special payments." 591

On 24 April 1996 the Secretary of State, now Stephen Dorrell, met with John Marshall MP to discuss compensation for people with bleeding disorders infected with Hepatitis C. The first item in the line to take for the Secretary of State was "*Great sympathy for those infected with hepatitis C as a result of NHS treatment, but these patients received the best treatment available in the light of medical knowledge at the time.*"<sup>592</sup>

A May 1996 briefing produced by officials for Hepatitis Awareness Week suggested, as a reply to calls for compensation for those infected through blood or blood products, that "these patients received the best treatment available in the light of medical knowledge at the time." 593 John Horam wrote to Sir Thomas Arnold MP on 23 May 1996 that "medical procedures rarely come without risk and these are not always fully known or capable of being guarded against at the time. Most haemophilia patients were infected with hepatitis C before blood products were treated to destroy viruses. These patients received the best treatment available in the light of medical knowledge at the time." 594

The Scottish Office fielded the same line in response to enquiries about the likelihood of an ex gratia payment scheme being established for those infected with hepatitis as a result of NHS treatment with blood or blood products: a letter of 24 July 1996 affirmed that "The Government has great sympathy with those patients who have become infected with Hepatitis through blood transfusions or blood products. These patients however received the best treatment available in the light of medical knowledge at the time." <sup>595</sup>

Letter from James Douglas-Hamilton to Dr Winifred Ewing 12 January 1996 p1 SCGV0000166\_019. James Douglas-Hamilton wrote in identical terms to Gordon Brown on 29 February 1996. Letter from James Douglas-Hamilton to Gordon Brown 29 February 1996 p1 HSOC0012458\_008

<sup>591</sup> Memo from Kevin Guinness to Mr Billinge 20 February 1996 p1 DHSC0004469\_007, The Haemophilia Society *Haemophilia and Hepatitis C Research Repor*t January 1996 HSOC0002726\_001

<sup>592</sup> Note of meeting between Stephen Dorrell and John Marshall 24 April 1996 p2 DHSC0041255 074

<sup>593</sup> Memo from Ann Towner to Paul Pudlo and Mr Robb 24 May 1996 DHSC0004768\_145. This line was then agreed by ministers to be used on questions about Hepatitis C compensation. Memo from Paul Pudlo to Mr Robb 31 May 1996 DHSC0006324\_139

<sup>594</sup> Letter from John Horam to Sir Thomas Arnold 23 May 1996 p1 DHSC0006324 153

<sup>595</sup> Letter from the Department of Health Scottish Office to Brian Donald 24 July 1996 p1 BNOR0000130\_036

A Q&A briefing from September 1996 repeated the same line to take but also attempted to answer the question: "How can the use of blood products from blood from paid donors in USA be described as 'the best treatment available' when it was potentially infected?". The answer to this was said to be that even if treated with cryoprecipitate multiple times "then the patients would all have become infected whether the blood came from paid donors in the United States or was from UK voluntary donors."<sup>596</sup> This was not correct.<sup>597</sup>

In October 1996 the Secretary of State wrote to Roy Hattersley MP regarding compensation. He set out the Government's decision on the issue of financial compensation for people with haemophilia infected with Hepatitis C, asserting that: "Firstly, we do not accept that there has been negligence on the part of the NHS. Tragic though it is that the very treatment designed to help those patients infected should have caused them harm, there can be no question that they received the best treatment available at the time. That treatment was essential for their survival." 598

John Horam wrote in identical terms to the Reverend Tanner on 1 October 1996 and to Joan Walley MP on 22 November 1996.<sup>599</sup> The following month he defended the Government's position in Parliament, asserting that Factor 8 treatment "was undoubtedly the best treatment available for people with haemophilia in the light of medical knowledge at the time." <sup>600</sup>

The "*Tragic though it is*" formula was used in the briefing to the Prime Minister on 27 January 1997, continuing with the now familiar "*there is no question that they received the best treatment available at the time.*"<sup>601</sup>

The May 1997 General Election resulted in the formation of a new government, under Tony Blair, and a new Secretary of State for Health, Frank Dobson. This did not result in any change in the line to take. In September 1997 a briefing for the Secretary of State in advance of a meeting with the Haemophilia Society informed him that the previous administration had rejected claims for a special payments scheme covering Hepatitis C on grounds which included "that the patients concerned received the best treatment available at the time, treatment which was essential for their survival". 602

- 596 Q&A Briefing 10 September 1996 p1 DHSC0041255 107
- It can be shown to be wrong in retrospect, for people with haemophilia in those countries which had used little or no commercial concentrates and had instead used cryoprecipitate suffered minimally by comparison. Moreover, the "line to take" omitted any consideration of those people whose haemophilia was classed as mild or moderate, and did not recognise that even among those whose haemophilia was to be classed as severe there were some who required few infusions of clotting factor replacement therapy.
- 598 Letter from Stephen Dorrell to Roy Hattersley 1 October 1996 pp1-2 DHSC0041255\_063, Written Statement of Stephen Dorrell para 2.92 WITN5290001
- 599 Letter from John Horam to Reverend Tanner 1 October 1996 HSOC0023572, Letter from John Horam to Joan Walley 22 November 1996 DHSC0004482\_023. A similar letter was sent by John Horam to Toby Jessel MP on 19 December 1996. Letter from John Horam to Toby Jessel 19 December 1996 p2 HSOC0004815
- 600 Hansard extract on Haemophiliacs (Compensation) 11 December 1996 p3 DHSC0041255 130
- Briefing for the Prime Minister: Haemophiliacs with Hepatitis C 27 January 1997 p1 DHSC0006572\_165
- 602 Memo from Christine Corrigan to Ms Murie 8 September 1997 p2 DHSC0003883 048

In June 1998, in response to a question from Lord Alf Morris regarding help for those infected with Hepatitis C, Baroness Meta Ramsay, speaking on behalf of the Government in the House of Lords, said that: "Those blood products were undoubtedly the best treatments available for people with haemophilia at the time that those who are infected with hepatitis C contracted the infection. Without those treatments, many people with haemophilia would not be alive today, and, if they survived, it would only be with significant and crippling damage to their health." 603

In December 1998 the Department of Health, writing to an individual with regard to the Government's decision not to set up a special payment scheme for people infected with Hepatitis C, stated that: "Regrettably, some people were infected with hepatitis C through NHS treatment, but this was not through negligence. Patients received the best treatment available based on the knowledge which existed at the time." 604

The indefatigable Lord Morris raised the issue again in May 1999: Baroness Helene Hayman, the Parliamentary Under-Secretary of State for Health in the House of Lords, described the treatment given as "the best at the time", such that it was not "appropriate to offer special compensation." This no doubt reflected the speaking notes provided to her for the purposes of responding to Lord Morris' parliamentary question, which stated that "In the 1970s/80s the blood products became widely available and were the best treatments."

The same line continued to be taken in Wales. A submission dated 4 August 1999 strongly advised that "Wales maintains the Government position on no-fault compensation": the background to this advice repeated that: "Most patients, including haemophiliacs who developed hepatitis 'C' as a result of NHS treatment, were infected before blood products were heat treated. As this was the best practice available at the time, claims of negligence have not been accepted."<sup>607</sup>

Even after the decision was taken in August 2003 to establish an ex gratia scheme for Hepatitis C (the Skipton Fund), the best treatment available line was maintained: Lord Norman Warner, the Parliamentary Under-Secretary of State for Health in the House of Lords in December 2003, referring to "inadvertent infection", emphasised that: "These

- 603 Hansard extract on Haemophiliacs and Hepatitis C 5 June 1998 p6 NHBT0134365
- 604 Letter from Department of Health to Anon 10 December 1998 DHSC0041179 230
- 605 Hansard extract on Hepatitis C Infection 24 May 1999 p1 HSOC0023993. Helene Hayman was Parliamentary Under-Secretary of State for Health in the House of Lords from July 1998 to July 1999. Written Statement of Baroness Helene Hayman para 2.5 WITN5523001
- Briefing note for parliamentary question on special needs of people with haemophilia infected with Hepatitis C 24 May 1999 p8 WITN5523012, Written Statement of Baroness Helene Hayman para 6.2 (16)-(20) WITN5523001
- Memo from Sue Paterson to T Kirby and Jane Hutt 4 August 1999 HSSG0000140\_076. The suggested line to take provided at the end of 1999, in response to calls for compensation, was that: "We believe that haemophiliacs in Wales who developed hepatitis C as a result of NHS treatment did so before blood products were heat treated from 1985; this heat treatment counters the hepatitis C and HIV virus. While we have every sympathy with those infected there are no plans to make special payments to these individuals on the grounds that they received the best available treatment at the time." Memo from Sue Paterson to J Gregory and Jane Hutt 20 December 1999 p4 HSSG0000140 074

patients were at the time given what was considered by professionals to be the best treatment available."608 Indeed it was the Government's position still that "everything was done as it should have been."609

In May 2006, at a time of renewed calls for a public inquiry, Lord Warner, who was now a Minister of State within the Department of Health, asserted that:

"The blood infected with hepatitis C was used in circumstances where there was no means of identifying hepatitis C in the blood. The clinical opinion at the time was that hepatitis C was a mild infection, and it took 25 years to find out its seriousness. There was no means of treating the blood in those circumstances. This was blood given to people when it was a matter of life or death whether they received that blood, and we were acting on the best scientific and clinical advice at the time." 610

The Government's response to the Archer Inquiry is considered elsewhere in this Report. 611 However, it is significant to note that the "best treatment available" line was relied on by officials when advising ministers how to respond to Lord Peter Archer's report. Thus, on 10 March 2009, a briefing for a meeting between the Secretary of State (Alan Johnson), the Minister of State for Public Health (Dawn Primarolo) and Lord Archer, emphasised that it was "important to remember" that "the treatment given to haemophiliacs was the best available at the time and action was taken in good faith";612 in May 2009 the Department of Health's director of health protection, Elizabeth Woodeson, suggested for inclusion into a Parliamentary Labour Party brief on the Government response to the Archer Inquiry the point that "We believe that people were offered the best treatment available at the time";613 and on 2 June 2009 a submission to the Minister of State for Public Health sought to distinguish the position in Ireland on the basis that "The Government here has never accepted any liability. We believe that people were offered the best treatment available at the time". 614

# Line to take regarding the introduction of Hepatitis C screening

A further line to take which began to feature prominently in the 2000s was the assertion that screening for Hepatitis C could not have been introduced earlier than it was (in September

- 608 Hansard parliamentary debates House of Lords Official Report 11 December 2003 p55 HSOC0003140
- 609 Hansard extract on Haemophiliacs with Hepatitis C: Financial Assistance Scheme 16 September 2003 p1 DHSC0006217\_008. The briefing pack for the parliamentary answer was emphatic that people were not being compensated for a wrong done to them: "In carrying out NHS treatment, we have a duty to take every reasonable care to make it safe, using the processes available at the time. That is what we did." Briefing note for parliamentary question 2 September 2003 p10 DHSC0006217\_027
- 610 Hansard extract on Contaminated Blood Products: Hepatitis C 24 May 2006 p4 CBCA0000035. Lord Warner was Parliamentary Under-Secretary of State for Health between June 2003 and May 2005, from May 2005 to May 2006 he was Minister of State for National Health Services Delivery, and from May 2006 to January 2007 he was Minister of State for NHS Reform.
- 611 See the chapter Government Response to the Archer Inquiry.
- Briefing from Dr Rowena Jecock to Penelope Irving and Morven Smith 10 March 2009 p2 MHRA0024725
- 613 Email from Elizabeth Woodeson to Laura Hughes 22 May 2009 p2 DHSC5166878
- 614 Briefing from Dr Rowena Jecock to Dawn Primarolo 2 June 2009 p2 DHSC0041219 077

1991). This line began to be used in the 1990s: thus, for example, a November 1995 briefing for the Prime Minister, John Major, asserted that "As soon as reliable test became available (1991) all blood donations tested to prevent Hepatitis C infection."<sup>615</sup>

However, the particular significance of this line to take was its continued use following the judgment of Mr Justice Burton in A and Others v National Blood Authority. This was litigation under the Consumer Protection Act 1987 and thus did not concern negligence directly, but it is important to note that the case did not solely address the question of whether the infected blood was defective. It addressed also the question of whether the public at large would legitimately expect that different steps would have been taken by way of safety precautions (namely, the use of surrogate tests and the introduction of Hepatitis C screening earlier than September 1991), and the judge therefore considered whether it was reasonable to expect that these tests should have been adopted, taking into account all relevant circumstances. 616 His conclusions were that surrogate testing should have been introduced (which it never was), that this would have happened at the latest by March 1988, and that Hepatitis C screening should have been routinely introduced earlier than it was. This latter point was even partly accepted by the National Blood Authority, since it conceded that it should have happened by 1 April 1991 (although the judge himself went on to find that it should have been earlier than that). It is also relevant to note that the judge's background findings included that there was no "public understanding or acceptance of the infection of transfused blood by Hepatitis C. Doctors and surgeons knew, but did not tell their patients unless asked, and were very rarely asked. It was certainly, in my judgment, not known and accepted by society that there was such a risk".617 He said that "no warnings were given to the public or to patients or recipients about the risk from the receipt of transfused blood or in particular about the risk in question ... I am satisfied that neither the Defendants nor the Government nor the Press, insofar as either of the latter were relevant, gave any or any sufficient warning to the public of the risks".618

Although the Department of Health was not a party to the litigation, it had been well aware of its progress and knew full well what the judge had decided. It is to be presumed it knew of the concession which the National Blood Authority had made, as to there having been delay in introducing testing. A detailed brief to the Prime Minister, Tony Blair, about the case was provided on 27 March 2001. On 3 April 2001 Charles Lister sent a submission to Lord Philip Hunt, the Parliamentary Under-Secretary of State for Health in the House of Lords, whose responsibilities included blood and blood products, with a recommendation that an

Briefing for the Prime Minister: "no-fault" compensation for patients with Hepatitis C as result of NHS treatment p1 DHSC0042937\_075. There was a similar briefing for the Prime Minister in January 1995. Briefing for the Prime Minister – Hepatitis C Look-back Exercise and Compensation 31 January 1995 p1 DHSC0002552 011

<sup>616</sup> A and Others v National Blood Authority Judgment 26 March 2001 paras 106-107 PRSE0003333

<sup>617</sup> A and Others v National Blood Authority Judgment 26 March 2001 para 55 PRSE0003333

<sup>618</sup> A and Others v National Blood Authority Judgment 26 March 2001 para 100 vi PRSE0003333

<sup>619</sup> Fax from Jill Taylor to Christine Dora 26 March 2001 SBTS0000356\_037. A detailed submission was also sent on 26 March 2001 to Lord Hunt. Briefing from Charles Lister to Lord Hunt 26 March 2001 DHSC0016517

appeal should not be sought. That submission indicated that there were aspects of the judgment which counsel believed were open to challenge (including the finding regarding surrogate testing), but with only a 30% chance of success, which Charles Lister rightly characterised as "poor". It was "not proposed to challenge the Judge's finding that the Blood Service should have introduced the hepatitis C screening test as soon as it was available from 1 March 1990. This is not something we would wish to dispute nor would we stand any chance of success." The submission was widely copied within the Department of Health, including to Private Offices of the Secretary of State and the CMO, to the Deputy CMO and to special advisers. Ministers decided, unsurprisingly in light of the advice but with some reluctance, not to appeal. 621

On 14 November 2001 John Hutton, the Minister of State for Health, told the House of Commons that "Injecting drug misusers and those who received blood transfusions or blood products before screening and viral inactivation processes were introduced have been the main at-risk groups" and that "as soon as technology became available to render blood products safe, it was introduced."622 John Hutton's speech did not therefore go as far as later statements by asserting that the technology to render **blood** safe was introduced as soon as it was available. His reference to rendering **blood products** safe was no doubt a reference to viral inactivation and derived from the draft speech prepared by officials, which asserted that: "The technology to make blood products free from hepatitis C in sufficient quantities to treat all haemophiliacs in the UK was simply not possible prior to 1985. Once it was the NHS introduced it."623 Although unrelated to the issues covered by Mr Justice Burton, this was nonetheless incorrect: leaving aside the question of whether heat treatment was possible prior to 1985, the implication of the draft was that all people with haemophilia received blood products free from Hepatitis C from 1985 onwards. There was no acknowledgement of two facts – that many people with bleeding disorders continued to be treated until the late 1980s with commercial concentrates (which were not free from Hepatitis C), or of the fact that domestic product available in Scotland prior to 1988 continued to transmit Hepatitis C.624

This line to take concerning viral inactivation of blood products from 1985 then morphed into a line about the introduction of Hepatitis C screening in 1991. On 16 September 2003 Baroness Elizabeth (Kay) Andrews, emphasising that the financial assistance scheme for Hepatitis C was ex gratia and not compensatory, asserted that "there was no liability when this unfortunate event occurred. There was no test until 1991 for hepatitis C". 625 This was,

Submission from Charles Lister to Lord Hunt 3 April 2001 p1, p2, p4, p5 DHSC0004054\_012. Officials in Scotland were more keen on an appeal and Dr Aileen Keel regarded the Department of Health's decision not to appeal as "lamentable". Email from Christine Dora to Mairi Gibson and others 3 April 2001 p1 SCGV0000241\_055, Email from Dr Keel to Christine Dora 6 April 2001 SCGV0000241\_038

<sup>621 &</sup>quot;After discussion with Lord Hunt, SofS is inclined 'reluctantly' to agree with the advice not to appeal." Email from Charles Lister to Jill Taylor 5 April 2001 p1 DHSC0004741 024

<sup>622</sup> Hansard extract on Hepatitis C 14 November 2001 p16, p19 SCGV0000247\_035

Draft speech for Adjournment Debate: Hepatitis C 14 November 2001 p5 DHSC0043576\_058, Email from Vicki King to Jane Colman 13 November 2001 DHSC0043576\_053

<sup>624</sup> See the chapters on Viral Inactivation, Self-Sufficiency and Haemophilia Centres: Policies and Practice.

Hansard extract on Haemophiliacs with Hepatitis C: Financial Assistance Scheme 16 September 2003 p2 DHSC0006217\_008. Baroness Elizabeth (Kay) Andrews, responding on behalf of the Government

as a matter of fact, incorrect. Tests were available prior to 1991 – from 1989 onward, in fact. Her assertion was based on a briefing that asserted that "The NHS introduced measures to reduce the risk of transmitting Hep C in blood or blood products as soon as the technology existed to do so."626 Shortly afterwards campaigner Carol Grayson wrote to Baroness Andrews pointing out this error: "You must surely be aware of the whole-blood hepatitis C cases that were won where the judge stated that testing/screening of blood donors for hepatitis C should have been introduced prior to 1991, and that this country should have acted as other European countries did and adopted testing earlier, erring on the side of caution even if there were some false positive test results."627

Despite the correct position having been pointed out by Carol Grayson, 628 the line continued to be deployed. A briefing for an oral parliamentary question in January 2004 suggested the following answer to any call for a public inquiry: "Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time." Richard Gutowski, in his statement to the Inquiry, recognised that this and similar statements "could have better reflected the findings of the Court in A & others [2001] EWHC QB 446." 630

A brief by Scottish Executive officials for the meeting of Andy Kerr, the Minister for Health and Community Care with the Scottish Haemophilia Groups Forum on 1 February 2005 stated, in relation to the introduction of Hepatitis C screening in 1991, that this development was introduced "as early as [it] reasonably could be in the light of the current scientific knowledge and technical capabilities at that time." 631

An update for the Secretary of State for Health, John Reid, dated 29 March 2005 emphasised that "Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time." <sup>632</sup>

in her capacity as a Government Whip.

Briefing note for parliamentary question on Hepatitis C financial assistance scheme September 2003 p12 DHSC0006217\_027. The draft reply was drafted by Richard Gutowski and approved by Dr Vicki King. This is even more misleading, for the technology existed to use surrogate testing which would probably have reduced infections by Hepatitis C considerably. See the chapters on *Hepatitis C Surrogate Screening* and also *Viral Inactivation*.

<sup>627</sup> Letter from Carol Grayson to Baroness Andrews 21 September 2003 p1 WITN1055096

Though it should have been obvious that it had been authoritatively established by the judgment of Mr Justice Burton in any event, and the line should never have been used by the Department of Health after it decided that it had a poor chance of appealing the judge's conclusions and decided not to try to do so.

<sup>629</sup> Briefing note for parliamentary question 15 January 2004 p8 WITN5292050. This was drafted by Richard Gutowski and approved by Gerard Hetherington.

<sup>630</sup> Written Statement of Richard Gutowski p138 WITN5292016. This was something of an understatement. The line taken was incorrect.

Briefing from Sandra Falconer to the Minister for Health and Community Care 28 January 2005 p3 SCGV0000044\_024

<sup>632</sup> Minute from Gerard Hetherington to Helena Feinstein 29 March 2005 p2 DHSC5123255

The Secretary of State for Health writing to Andy Kerr on 4 April 2005, repeated this line (in the context of stating the Government's position that a public inquiry was not justified). <sup>633</sup> In his oral evidence to the Inquiry Lord Reid noted that the wording of this letter was based on the briefing received by officials and agreed that the line was "simply inaccurate." <sup>634</sup>

Two months later Caroline Flint, the Parliamentary Under-Secretary of State for Public Health, writing to Nick Harvey MP, repeated the same line.<sup>635</sup>

On 19 December 2005 the Department of Health's Customer Service Directorate told Carol Grayson that donor screening, introduced in 1991, "could not have been implemented before this time." 636

In January 2006 Lord Warner, speaking in the House of Lords, claimed that "the infection of people with hepatitis C was inadvertent. Nothing could have been done at the time with the technology available to assess the blood for that level of infection."<sup>637</sup>

In a letter to the Haemophilia Society on 8 February 2006, Caroline Flint repeated that "Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time." This was advanced as part of the rationale for rejecting a public inquiry. Later that same month, a minute to the Parliamentary Under-Secretary of State for Public Health set out the media handling plan for the publication of the report on Self-Sufficiency in Blood Products in England and Wales; the attached press release quoted the Minister as saying that "The review based on the available evidence, concludes that clinicians acted in the best interest of their patients in the light of the evidence available at the time. Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in technology, which could not have been implemented before this time." In her oral evidence to the Inquiry Caroline Flint, who was not aware of Mr Justice Burton's judgment, agreed that the press release should not have been drafted in these terms. She observed that "The briefings that I've obviously looked over in preparation for both my written statement and today and the answers I gave in

- 633 Letter from John Reid to Andy Kerr 4 April 2005 DHSC6264733
- Written Statement of Lord John Reid para 16.3 WITN0793001. During his oral evidence, Lord Reid was asked by counsel whether or not it was accurate to say that screening could have been introduced earlier than 1991. He said: "Not only may be said, it can be said. I didn't know this at the time. I can't recall being briefed at any time about the Burton decisions on this. My memory may be at fault but I just can't remember. So I would not have queried this at the time, but if you're asking me now, with what I know courtesy of the many thousand documents you were kind enough to send me, yes, this is an inaccurate statement." Lord John Reid Transcript 21 July 2022 p90 INQY1000232
- 635 Letter from Caroline Flint to Nick Harvey 7 June 2005 DHSC0004213\_083
- Email from Department of Health Customer Service Directorate to Carol Grayson 19 December 2005 WITN1055128. This same email also erroneously asserted that there was "no evidence that imported blood products carried a greater risk of transmitting hepatitis than those made in the UK."
- 637 Hansard parliamentary debates House of Lords Official Report 12 January 2006 p7 ARCH0000428
- 638 Letter from Caroline Flint to Margaret Unwin 8 February 2006 p1 HSOC0009247
- 639 Memo from Sophie Coppel to Caroline Flint 23 February 2006 p4 DHSC0200112. See, to the same effect, a document prepared as part of a briefing for a parliamentary question in the House of Lords in March 2006. Briefing note for parliamentary question 21 March 2006 p5 DHSC0200118

Parliament and elsewhere were very much sort of a 100 per cent suggesting that there was no testing that could have been done before 1991."640

In April 2006 an internal departmental document noted that *Wales on Sunday* was "doing a story on renewed calls for a public inquiry": the Department of Health's position in response was to be Caroline Flint saying – exactly as set out above – that "Donor screening for hepatitis C was introduced in the UK in 1991 and this test marked a major advance in microbiological technology, which could not have been implemented before this time." This statement was to be given to *Wales on Sunday*.<sup>641</sup>

The very same line to take appeared in a letter from the Secretary of State for Health, Patricia Hewitt, to Michael Connarty MP on 27 April 2006 in response to the request for a public inquiry.<sup>642</sup>

In September 2006 a Department of Health communications official wrote "I found the following line on a public inquiry on our CHIP systen [sic] and think it looks OK to use". The line to take was: "We are aware that some people would like the Government to set up a public inquiry into this issue. We have great sympathy for those infected with Hepatitis C and HIV and have considered the call for a public inquiry very carefully. However, the Government of the day acted in good faith, relying on the technology available at that time and therefore we do not feel a public inquiry would provide any real benefit to those affected."<sup>643</sup>

On 19 October 2006, writing to the Manor House Group, Caroline Flint again explained the rejection of a public inquiry by reference to the introduction of donor screening in 1991 "which could not have been implemented before this time." The same account was given to the Haemophilia Society on 24 October. 645

On 25 October 2006 the Department's Customer Service Centre wrote to campaigner Sue Threakall using the same line to take. A draft follow up letter to Sue Threakall in December 2006 contained a longer explanation:

"On the matter of holding a public enquiry about contaminated blood products, it may be helpful if I explain that Caroline Flint and her predecessors have considered a substantial published body of evidence on the developing understanding of non-A non-B hepatitis, later known as hepatitis C, and the emerging knowledge of the viral risks associated with pooled blood products ... In light of the substantial numbers of documents and reports available, the Government does not consider that a public inquiry would add significantly to the understanding of how the

- 640 Caroline Flint Transcript 16 September 2022 pp57-60 INQY1000241
- Department of Health Highlights 21 April 2006 p11 DHSC5068274
- 642 Letter from Patricia Hewitt to Michael Connarty 27 April 2006 p3 HSOC0009218
- 643 Email from Katie Robinson to Zubeda Seedat 15 September 2006 pp2-3 DHSC6696511. Zubeda Seedat's response was copied to William Connon.
- 644 Letter from Caroline Flint to Manor House Group 19 October 2006 p4 WITN1567016
- 645 Letter from Caroline Flint to Margaret Unwin 24 October 2006 HSOC0003591
- 646 Email from Department of Health Customer Service Centre to Sue Threakall 25 October 2006 DHSC0041155\_118

blood supply became infected with hepatitis C, or the steps needed to deal with problems of this kind now or in the future."

The points then listed included that "viral inactivation processes, heat treatment and screening tests were developed and introduced as soon as practicable." 647

On 19 February 2007 William Connon wrote to Dawn Primarolo, the Minister of State for Public Health and to Lord Hunt in response to media reports of an announcement of a public inquiry. The lines to take included "the Government of the day acted in good faith, relying on the technology available at the time" and "Donor screening for Hepatitis C was introduced in the UK in 1991 and this marked a major advance in microbiological technology, which could not have been implemented before this time." 648

The same line to take was relied on by Dawn Primarolo, Minister of State for Public Health, in July 2007 in telling the Manor House Group why the Government did not consider a public inquiry to be justified.<sup>649</sup>

Following the publication of the Archer report, a briefing provided to the Secretary of State for Health, Alan Johnson, and for Dawn Primarolo, in advance of a meeting with Lord Archer on 11 March 2009, asserted that "as soon as technologies (heat treatment and testing) were available to improve safety, they were introduced."<sup>650</sup> A briefing from the Secretary of State's Office for the Parliamentary Labour Party in May 2009 asserted that "Action was taken as soon as possible to introduce testing and safety measures for blood and blood products as these became available."<sup>651</sup> On 2 June 2009 a submission to Dawn Primarolo regarding the Government's response to the Archer report stated, as part of an explanation as to why the position in Ireland was different, that "as soon as blood screening tests were available they were implemented."<sup>652</sup>

- 647 Email from Department of Health Customer Service Centre to Sue Threakall December 2006 DHSC6483387. This was approved by Caroline Flint on 19 December 2006. Note from Jacky Buchan to Caroline Flint 15 December 2006 DHSC0041155\_113. "The knowledge that I acquired was incremental and when an issue or new briefing came to me, I would have been asking questions to understand what, if anything, had changed. This means that the documents, while very helpful, do not communicate the whole picture and also do not help me remember the whole picture." Written Statement of Caroline Flint para 3.2 WITN5427001
- 648 While the Government extended its greatest sympathy to those infected with Hepatitis C and HIV, the lines to take were such that "the Government of the day acted in good faith, relying on the technology available at the time and therefore we do not feel that a public inquiry would provide any real benefit to those affected." Memo from William Connon to Dawn Primarolo and Lord Hunt 19 February 2007 p1 DHSC0041155\_023
- 649 Letter from Dawn Primarolo to Manor House Group p2 DHSC6548424
- Briefing from Dr Rowena Jecock to Penelope Irving and Morven Smith 10 March 2009 p2 DHSC0041157\_052. The briefing was prepared by Dr Rowena Jecock and cleared by Dr Ailsa Wight.
- Government response to the Archer Inquiry from the office of Alan Johnson 27 May 2009 p4
  ARCH0001160. Alan Johnson, in his statement to the Inquiry, acknowledged that the High Court's
  2001 finding that the UK should have introduced screening or surrogate testing earlier should have
  been reflected in the briefing. Written Statement of Alan Johnson para 3.46 WITN7197001
- Briefing from Dr Rowena Jecock to Dawn Primarolo 2 June 2009 p2 DHSC0041219\_077. The briefing was prepared by Dr Rowena Jecock and cleared by Dr Ailsa Wight.

The repetition of this line to take at this stage is particularly incomprehensible because the Archer report had itself set out the facts regarding testing very clearly:

"The United Kingdom delayed testing until a specific test (as opposed to a surrogate test) became available. Even then, although such a test was in use in Japan in 1989, and in the USA, Australia and most European countries in 1990, the United Kingdom delayed introduction until the product had been approved by the Food and Drug Administration (FDA) in the USA, and it was not introduced into the United Kingdom until September 1991."

The Archer report then continued by referring to Mr Justice Burton's judgment and conclusions. No one reading the Archer report could have genuinely believed that "as soon as blood screening tests were available they were implemented."

#### "Inadvertent"

Numerous documents from the Department of Health in the time periods discussed above also referred to the infection of people with HIV or Hepatitis C from blood or blood products being "inadvertent". A handful of examples serve to illustrate the position (emphasis added):

"you have set out the case for immediate action to identify, counsel and treat those who may have been **inadvertently** infected with HCV by the NHS through blood transfusions." 654

"Dear Doctor ... I am sending this letter to inform you of the guidance and procedures for the look back exercise announced by Tom Sackville, Parliamentary Secretary of Health, on 11 January 1995, to trace, counsel and, if necessary, treat those people who may have been **inadvertently** infected with hepatitis C through blood transfusions." 655

655 Dear Doctor letter from Dr Kenneth Calman 3 April 1995 p1 NHBT0002764 001

The Archer Inquiry: Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 pp56-57 ARCH0000001

Letter from Tom Sackville to Lord Fraser QC 4 January 1995 p1 DHSC0032208 136. This letter 654 also demonstrates a desire to protect the line which had been adopted about having acted as quickly as possible on the basis of the best advice available, for it continues: "I have accepted the recommendations of the Advisory Committee on Microbiological Safety of Blood and Tissues for Transplantation [MSBT] and given the go-ahead for a look back programme to be undertaken in England as soon as possible. More particularly I have instructed Dr Jeremy Metters, DCMO [Deputy Chief Medical Officer], the chairman of the MSBT to set up without delay an ad hoc Working Party to draw up guidance on the counselling and treatment options. The working party will consider all actions which need to be taken to satisfy Ministers' duty of care towards the patients concerned and this may include good practice guidance on treatment, research etc. I want to see the look back exercise started as soon as possible ... I understand your wish to move quickly in Scotland to put in hand the look back exercise. I hope however you will recognise the overwhelming advantage of us moving forward on a UK wide basis. Any piecemeal approach, quite apart from giving all the wrong signals and causing confusion to the public, will seriously compromise the Government's defence that we have acted as quickly as possible on the basis of the best advice available and uniformly." Emphasis added. The line is regarded as a form of defence, rather than an impartial setting out of the truth as it is believed to be; the emphasis is on presentation rather than openness and transparency; and it is a poor reason to seek to delay a measure meant to benefit public health that it should have to wait in the interests of presenting government in a better light (or, here, a less bad one). Letter from Tom Sackville to Lord Fraser QC 4 January 1995 p1 DHSC0032208 136

"the Government have great sympathy with those who may have been **inadvertently** infected with hepatitis C through national health service treatment, but as no fault or negligence on the part of the NHS has been proved, we have no plans to make special payments." 656

"The needs of people whose condition results from **inadvertent** harm is met from benefits available to the population in general. On that basis, we have decided not to make an exception to the general rule in the case of haemophiliacs infected with hepatitis C." 657

"some people have **inadvertently** become infected with Hep C and some of them have become ill." 658

"As I have made clear repeatedly and repeat again today, the infection of people with hepatitis C was **inadvertent**." 659

"you express disappointment that the payment scheme has not been extended to dependants of those who have died following **inadvertent** infection with hepatitis C." 660

"Unfortunately, in the 1970s and early 1980's, before effective viral inactivation procedures had been developed, many patients with haemophilia were *inadvertently* infected with hepatitis C from contaminated blood products." <sup>661</sup>

"Whilst successive Governments acted in good faith, the serious infections inadvertantly [sic] contracted by these patients as a result of their treatment had tragic consequences, and we are deeply sorry that this happened." 662

Even the 2002 Hepatitis C Strategy for England stated that "*Prior to the introduction of viral inactivation of blood products in 1984, and before 1991 when the screening of blood donors was introduced, some recipients of blood and blood products were inadvertently infected." <sup>663</sup>* 

To suggest, in this context, that something was inadvertent is to suggest that it was accidental and unintentional. It hints at something that could not have been known about — a mishap, a chance by-product. Yet the risks of transmission of hepatitis were well known. Such transmission was not the purpose of the treatment, but that it might result was well recognised by clinicians and within government. It had been known for years in medical and public health circles. To characterise it as inadvertent is thus to downplay the significance of what happened.

- 656 Hansard written answer on Hepatitis C 12 March 1996 p1 DHSC0002533 113
- 657 Hansard written answer on Hepatitis C 28 July 1998 DHSC0006894 097
- From a briefing dated 8 September 2003 in respect of a parliamentary question. Briefing note for parliamentary question 2 September 2003 p10 DHSC0006217\_027. The draft reply was drafted by Richard Gutowski and approved by Dr Vicki King.
- Lord Warner speaking in the House of Lords. Hansard parliamentary debates House of Lords Official Report 12 January 2006 p7 ARCH0000428
- 660 Letter from Melanie Johnson to Roddy Morrison 25 March 2004 p1 HSOC0013726
- 661 Letter from Lord Warner to Lord Patrick Jenkin 10 March 2005 p1 ARCH0002570
- 662 Lord's Oral Questioning Briefing Pack, referring to Lord Archer's Inquiry p2 DHSC5562703
- 663 Department of Health Hepatitis C Strategy for England August 2002 p9 WITN6942004

Sir John Major, giving evidence to the Inquiry, drew gasps from many of those who had been infected and affected and had survived to hear his testimony when he described what had happened as "*incredibly bad luck*". The expression has similarities to it "being inadvertent". However, he went on to explain that though he had used words which he acknowledged could have been better chosen, he had thought the incidence of infection was "*completely random*".<sup>664</sup> It was plain from his testimony – and his reaction to the realisation that he was seen to have used an inappropriate phrase – that he personally disavowed the idea that it was appropriate to describe the infection as inadvertent.

# Commentary

The infection of thousands of NHS patients with HIV, Hepatitis C and Hepatitis B has (rightly) been described as the worst treatment disaster in the history of the NHS.<sup>665</sup> Announcing in July 2017 that there would, finally, be a public inquiry, the then Prime Minister, Theresa May, called "The contaminated blood scandal of the 1970s and 80s" an "appalling tragedy which should simply never have happened. Thousands of patients expected the world-class care our NHS is famous for, but they were failed."<sup>666</sup> How was it then that for years it was repeatedly and robustly asserted that those infected had received "the best treatment available"?

The factual basis (if any) which gave rise to the initial formulation and adoption of this line to take is unclear. There is, for example, no advice from the Chief Medical Officer to that effect. 667 It appears to have first been used by Charles Dobson in a submission to ministers in June 1989 in relation to the HIV litigation. 668 Charles Dobson worked to Strachan Heppell, Deputy Secretary, who then expressed himself in a similar fashion, as did the Prime Minister, Margaret Thatcher. None is recorded as querying it. Lord Horam, in his oral evidence to the Inquiry, acknowledged that he was repeatedly told by civil servants in the documents prepared for him that people had received the best available treatment at the time. 669 His expectation was that there would have been a proper evidential basis for that assertion — that officials would have investigated the matter so as to be able to assert that everyone was treated with the best treatment available at the time. He did not question the basis for this confidently asserted line to take but trusted their judgement. 670 Sir John Major also confirmed that, if he had been told that there were question marks about the best treatment available,

- 664 Sir John Major Transcript 27 June 2022 p43, p163 INQY1000219
- 665 Hansard extract on Haemophiliacs and Hepatitis C 5 June 1998 p1 HSOC0003171, Letter from Karin Pappenheim to Ray Michie 9 November 1998 p4 HSOC0026374, Hansard extract on Blood Products: Effects of Contamination 30 March 2000 p1 HSOC0011775
- 666 Infected Blood Inquiry Briefing Pack p2 DHSC0050189
- The line emerged during the course of litigation, and so one source might in theory have been the expert evidence obtained by the Department of Health for the purposes of that litigation. However, not only is there no evidence to indicate that this was in fact what gave rise to the line, but even a short moment of self-reflection should have been sufficient for the Department of Health to appreciate that expert witness reports from the very reference centre directors whose actions and advice were under question would not be the most promising source of impartial analysis.
- Memo from Charles Dobson to Alan Davey 26 June 1989 pp1-3 MHRA0017681. For a fuller account see the chapter on the *HIV Haemophilia Litigation*, where the use of the phrase is also considered.
- 669 Lord John Horam Transcript 29 June 2022 p21 INQY1000217
- 670 Lord John Horam Transcript 29 June 2022 pp113-116 INQY1000217

or whether patients had been given proper information about risks, or whether there was a delay in the introduction of screening, he would have asked to have that information, the details of what was not done and the effects of that, so that he was in a position to make a judgement based on facts.<sup>671</sup>

The reality is that this use of this blanket line to take – sometimes applied to the position of people with bleeding disorders, sometimes to all those infected with Hepatitis C from blood or blood products – was inappropriate. It was wrong. It was a statement of perfection - asserting that there was nothing better that could have been done. The use of such a statement should always be approached with considerable caution. There was no recognition of anything that might balance the absolutist claim that the treatment was simply the best. It took no account of whether there were steps that could have been taken to reduce the risks of viral transmission (eg not using prison blood; improving donor selection; improving donor screening practices; earlier testing of blood). It took no account of the alternatives to treatment with factor concentrates, which did exist. It took no account of whether patients may have been over-treated (whether with blood or blood products). It took no account of whether commercial concentrates, carrying a known greater risk of hepatitis, should have been licensed. It took no account of how government looked the other way as pool sizes increased and increased when manufacturing NHS concentrates, to the extent that the theoretical benefit of small pool sizes was lost, and the risk of infection increased. It took no account of what if any information about risks had been provided to patients about the treatment. It thus took no account of whether those treated had given informed consent. It took no account of how clinicians, faced with uncertainty as to whether non-A non-B Hepatitis was benign or a serious disease with significant long-term consequences, assumed the former unless there was more proof of the latter, thus failing to give safety priority. It took no account of whether there were particular cohorts of patients (eg children, people with mild haemophilia, obstetric patients) who could or should have been treated differently. It took no account of delays in introducing heat treatment into NHS production which (as it transpired) would have been effective against hepatitis, and would in almost all cases have prevented HIV. It appears to have been based in part on the erroneous belief that treatment with factor concentrates was necessary for the survival of people with bleeding disorders as a cohort.<sup>672</sup>

In short, adopting the line amounted to blindness. Adopting it without realising it needed to have a proper evidential base, and they did not know what it was, was unacceptable.

The line, which was wrong from the very outset, then became entrenched for around twenty years: a dogma became a mantra. It was enshrined. It was never questioned. No one stopped

<sup>671</sup> Sir John Major Transcript 27 June 2022 pp146-148 INQY1000219. He added that he did not ask those questions because he was not advised that there might have been question marks about the treatment received by patients. He, like other ministers, was told that patients had received the best treatment available in light of medical knowledge at the time. See for example Briefing for the Prime Minister: "No fault" compensation for patients with Hepatitis C as result of NHS treatment DHSC0042937 075

This was Lord Clarke's view. He suggested in his evidence to the Inquiry that the best treatment available line would have been a reflection of the fact that "more people would be damaged, and the quality of life of haemophiliacs very badly damaged, if we stopped giving them the Factor VIII." Lord Kenneth Clarke Transcript 28 July 2021 pp172-174 INQY1000142

to ask "What's the evidence for the apparently extraordinary claim that treatment which has killed over a thousand people with bleeding disorders was the best available treatment in the light of medical knowledge at the time?" It quite clearly fed into decisions not to provide financial support to those infected with Hepatitis C.<sup>673</sup> It influenced the repeated refusal to hold a public inquiry. As the Haemophilia Society observed in its written submission to the Archer Inquiry, "Without an independent review of its validity, no minister can be sure that the best treatment was given ... at best, the Ministers' responses have been complacent".<sup>674</sup>

Stephen Dorrell acknowledged, in relation to this line to take, that it was "clearly open to ministers and officials to enquire whether there was any evidence of negligent or unprofessional care associated with the HCV cases" and that "this specific question does not appear to have been asked."675 In relation to Hepatitis C, Ministers took on faith what civil servants said; civil servants took on faith what the files said. No one stood back and reflected. No one asked questions – could this really be right? How could the best treatment available lead to the infection of so many?

The line that the screening of blood for Hepatitis C was introduced as soon as possible was untrue. It must have been known to be untrue by the Department of Health, given the judgment in *A and Others v National Blood Authority*. In any event, it had been recognised within the Department of Health even before that case was heard that the UK might well be criticised for being so late by comparison with other countries. There has been no explanation as to how the line came to be formulated in the first place or why it was parroted without question for years. Poor corporate memory is not an adequate answer, though it explains why use of the line persisted for so long.

It is clear that the claim that the screening of blood for Hepatitis C was introduced as early as it could have been influenced the decision-making of successive Governments. In particular: it influenced the decision as to whether there should be a payment scheme for those infected with Hepatitis C; it was advanced as a reason as to why no such scheme

As explained by Tom Sackville in his written statement to the Inquiry, the thinking was that "Blood and blood products were provided to patients on the reasonable understanding that they were safe. It was felt that the NHS had the best scientific evidence available at the time ... In essence, treatment was provided in accordance with the best medical knowledge at the relevant time and the policy was that no-fault compensation payments should not be made to those who had, albeit very unfortunately, become infected with Hepatitis C." Written Statement of Tom Sackville paras 8.65-8.66 WITN5249001. See also the Written Statement of Sir John Major para 4.2.6 WITN5284001

<sup>674</sup> Submission of Haemophilia Society to the Archer Inquiry p35 ARCH0001232

Written Statement of Stephen Dorrell para 2.125 WITN5290001. He suggested, however, that both ministers and officials were "clearly looking, over a protracted period, for possible lines of argument which could be used to justify payments to the HCV cases" and that had there been an argument based on negligent or unprofessional practice it would have been "strongly advanced by the main bodies" (such as the Haemophilia Society). The evidence does not, however, suggest that ministers and officials were looking for arguments to justify payments: on the contrary.

should be established.<sup>676</sup> It influenced the response to the Archer report. It influenced the decision not to hold a public inquiry.<sup>677</sup>

Dr Rowena Jecock, in her oral evidence to the Inquiry, described long standing lines as becoming "embedded ... almost hard wired into your mindset" and accepted that there were "occasions when we should have been more critical of that than we were." Jeremy Hunt, a former Secretary of State for Health, described in his oral evidence "a kind of memory illusion, but at a departmental level, where the people collectively try to remember things as they would like them to have been, rather than as they actually were." Both were right, but the problem was a deeper one still. As Andy Burnham put it:

"embedded deep within the Civil Service psyche, over not just a few years in question but a number of decades, I would say, the response to this particular issue was primarily driven by a fear of financial exposure. That, in my judgement, describes ... all of the responses, the lines, everything, kind of came from that feeling originally. And so these letters, I think, are drafted with that primarily in mind. Not with the kind of needs of people who ... through absolutely no fault of their own, had their lives utterly ruined." 680

#### I agree.

Not only must the Civil Service ensure that information provided to, and promulgated by, ministers is accurate, but ministers must probe and query the evidential basis for any lines to be taken, particularly when they are historical in nature and prone to the malleable corporate memory of the Civil Service,<sup>681</sup> and make bold claims that what was done was the very best that was possible. This simply was not done, again and again.

- See, for example, the statement of Hazel Blears, Parliamentary Under-Secretary of State for Health between June 2001 and May 2002 and Parliamentary Under-Secretary of State for Public Health between May 2002 and June 2003: "The rationale for not setting up a compensation scheme for those with Hepatitis C was that there had been no fault on the part of the NHS, action had been taken to screen blood products as soon as the technology became available and there was no precedent for accepting liability without fault." Emphasis added. Written Statement of Hazel Blears para 2.50 WITN6658001. The drafting of statements and briefings was a collaborative process that followed the hierarchy of the team. As set out in the written statement of Debbie Webb: "The branch was hierarchical. The Division was headed by the Director (initially Ms Liz Woodeson and then Ms Clara Swinson), then the Branch Head (Dr Ailsa Wight), then the Grade 6 (Dr Rowena Jecock) and then finally, me. There were various junior support staff, but I am afraid I cannot now remember all their names." Written Statement of Debbie Webb para 2.12 WITN7409001
- 677 See the relevant sections of this chapter.
- 678 Dr Rowena Jecock Transcript 13 July 2022 pp57-58 INQY1000226
- 679 Jeremy Hunt Transcript 27 July 2022 pp38-39 INQY1000235
- 680 Andy Burnham Transcript 15 July 2022 pp27-28 INQY1000228. Andy Burnham was Minister of State for Delivery and Reform, Department of Health, 2006-2007 and Secretary of State for Health 2009-2010.
- Asked about groupthink, Alan Milburn said: "I think what happens is that some things do just get set in stone, history, which is malleable because it is subject to interpretation, it somehow or other at some point becomes set in stone and that may be for good reasons, maybe because actually the history is not contested. The problem here is that the history was contested." Alan Milburn Transcript 14 July 2022 p48 INQY1000227. Alan Milburn was Minister of State for Health 1997-1998 and Secretary of State 1999-2003.

The cruelty, for those infected and affected, of hearing, over and over, that they had received the best treatment available, that testing had been introduced as soon as possible, that they had been inadvertently infected, should not be underestimated.

Professor Ian Kennedy in his 1980 Reith Lectures *Unmasking Medicine* observed that "*it is a basic moral principle of our society that we should tell the truth.*"<sup>682</sup> That is as applicable to government ministers and officials as it is to clinicians.<sup>683</sup> Unhappily, in their repeated use of these lines to take, successive governments were more concerned about reputational damage than openness and honesty; more defensive than candid; more interested in avoiding financial exposure than in admitting shortcomings.

The basic point to be made is elementary. Part of the responsibility of government is to provide a reliable source of information: to be trusted to be open and to tell the whole truth, not just the part of it they might prefer to relate. Not to do so sacrifices trust, and trust is essential.

The development of a line to take, which when adopted is echoed across government, is not in itself wrong. If different departments or government politicians express differing views on an issue the listener may see confusion, and lose trust. A settled line avoids that. However, the Nolan principles of public life are paramount. They emphasise that those holding public office are expected to behave with objectivity, openness and honesty. They were articulated by Lord Michael Nolan in 1995 as representing well settled principles. Yet this was, at a time when for six years an over-confident line with no proper evidential foundation had been repeated by civil servants, adopted by them as having the status of a "given" through a form of groupthink, and was to go on being used.

Openness and honesty are compatible with a line to take: but only if those drafting, repeating, or using the line in public pronouncements take care to ensure that if in truth there are uncertainties about the position the line reflects it and says so. If there are doubts, it must express them as qualifications to the main message. Government should never feel that it has to know everything; politicians should not feel they always have to have an answer so that they give one, for the sake of it, when the truth is they simply do not yet know. Admitting to some ignorance is not easy: but is an essential part of deserving the trust of the public. Ministers and civil servants should be astute to recognise where there may be uncertainties, and be particularly wary about seeming to ignore these when expressing reassurance or certainty: both the lines of "no conclusive proof" used in 1983 in respect of

<sup>682</sup> Professor Ian Kennedy Reith Lectures Transcript 26 November 1980 p3 RLIT0000620

As was clear from the evidence of the expert group on Public Health and Administration, the attributes of integrity, honesty, objectivity and impartiality form the bedrock upon which the Civil Service was built; and ministers were expected to behave with objectivity, openness and honesty, even before Lord Michael Nolan articulated those principles as part of the seven principles of public life. Public Health and Administration Expert Panel Transcript 3 October 2022 pp6-9 INQY1000251. Expert Report to the Infected Blood Inquiry: Public Health and Administration August 2022 pp8-12 EXPG0000047. The seven principles are: (1) Selflessness (requiring holders of public office to act solely in the public interest); (2) Integrity; (3) Objectivity; (4) Accountability; (5) Openness; (6) Honesty; and (7) Leadership.

whether an infectious agent caused AIDS,<sup>684</sup> and "best available treatment" were obvious communication traps for someone alert to them.

When considering the Government response, it must be acknowledged that civil servants may have adopted some of their approach from clinicians who were falsely reassuring patients. However, this does not justify adopting the lines to take in the first place; holding to them without question for as long as occurred; sticking to them in the face of evidence to the contrary; and being prepared to ignore inconvenient truths established by objective third parties (such as the courts) in order to do so. It is also difficult to avoid a conclusion that when politicians began to query the position in the 2000s civil servants still sought to advance that which they had come to regard as sacrosanct truth – the line – on the basis that it was acknowledged truth, though in fact there was no adequate basis for it.

684 See the chapter on Role of Government: Response to Risk.

# 7.4 Delay in Holding a Public Inquiry

This chapter explores continuing calls for a public inquiry and successive governments' resistance to holding one. It considers the reasoning which underpinned the reluctance and examines how pressure from campaigners and parliamentarians helped overcome it.

## **Key Dates**

**October 1989** option of a Commission of Enquiry included in ministerial submission. **June 1990** Prime Minister Margaret Thatcher refuses Haemophilia Society's and Alf Morris MP's request for an inquiry into compensation for people with haemophilia who had been infected with HIV.

October 1998 Haemophilia Society calls for a public inquiry.

June 1999 Prime Minister Tony Blair declines the request for public inquiry.

**December 1999** a petition calls on the Scottish Parliament to hold an inquiry.

**July 2001** advice to the Parliamentary Under-Secretary of State for Public Health sets out options, including a public inquiry.

**September 2003** Scottish Executive position remains that no public inquiry should be held.

**December 2003** the Government maintains that it does not consider a public inquiry is justified.

**February 2006** Self-Sufficiency in Blood Products in England and Wales: a Chronology from 1973-1991 is published.

June 2006 Scottish Government concludes there is no basis for a public inquiry.

**May 2007** Review of Documentation Relating to the Safety of Blood Products 1970-1985 (Non A Non B Hepatitis) is published.

April 2008 Scottish Government announces a public inquiry will be held in Scotland.

February 2009 Archer Inquiry publishes report.

March 2015 Penrose Inquiry publishes report.

**September 2016** Prime Minister Theresa May rejects further calls for an inquiry.

April 2017 Andy Burnham calls for a public inquiry.

7 July 2017 six opposition party leaders write to the Prime Minister calling for an inquiry.

10 July 2017 Diana Johnson MP secures an emergency debate on a public inquiry.

11 July 2017 announcement of Infected Blood Inquiry.

#### **People**

**Andy Burnham** Secretary of State for Health (2009 - 2010), Shadow Secretary of State for Health (2011 - 2015)

Malcolm Chisholm Minister for Health and Community Care, Scotland (2001 - 2004)

William Connon Head of Blood Policy, Department of Health (2004 - 2008)

**Susan Deacon** Minister for Health and Community Care, Scotland (1999 - 2001)

**Caroline Flint Minister of State for Public Health (2005 - 2008)** 

**Jeremy Hunt** Secretary of State for Health (2012 - 2018)

**Diana Johnson** Member of Parliament (since 2005)

**Andy Kerr** Minister for Health and Community Care, Scotland (2004 - 2007)

**Alf Morris** MP (1964 - 1997), member of House of Lords (1997 - 2012)

**Bob Stock** head of Ancillary Services branch, Health Planning & Quality Division, Scottish Executive (2001 - 2004)

On 11 July 2017 the Prime Minister, Theresa May, made this announcement:

"The contaminated blood scandal of the 1970s and 80s is an appalling tragedy which should simply never have happened ... Thousands of patients expected the world-class care our NHS is famous for, but they were failed ... At least 2,400 people died and thousands more were exposed to Hepatitis C and HIV, with life-changing consequences ... The victims and their families who have suffered so much pain and hardship deserve answers as to how this could possibly have happened ... While this government has invested record amounts to support the victims, they have been denied those answers for too long and I want to put that right ... As Prime Minister, I am determined to stand up for victims and confront injustice and unfairness in our society at every turn ... We will work with the victims and their families to decide what form this inquiry should take so their voices are heard and they finally get the answers and justice they have spent decades waiting for." 685

Why did it take until 2017 for a national public inquiry to be established into "the worst treatment disaster in the history of the National Health Service"?<sup>686</sup>

## The 1980s

By 1986 the Government can have been under no illusion about the scale of what had happened to people with haemophilia – many had been infected with HIV, a virus with an exceptionally high mortality rate for which there was no known treatment, and sufferers experienced public hostility.<sup>687</sup> The Government knew that the direct cause of this disaster was the treatment which they had received from the National Health Service. Public inquiries were not unknown in the 1980s.<sup>688</sup> Yet there is no documentary evidence to show that it occurred to anyone within Government before 1989<sup>689</sup> either that there might be an important public interest in investigating and understanding precisely how this had occurred, or that those whose lives had been devastated in this way might deserve answers as to how and

<sup>685</sup> UK Government Press Release *PM Statement on Contaminated Blood Inquiry* 11 July 2017 p2 RLIT0001168

<sup>686</sup> Hansard extract on Blood Products: Effects of Contamination 30 March 2000 p1 HSOC0011775

See for example the briefing from Dr Alison Smithies to Bernard Hayhoe, the Minister of State for Health on 18 August 1986, in light of articles in the *Daily Telegraph* and the *Times*. Dr Smithies noted a survey of haemophilia centre directors from August 1985 which had (at that stage) reported there were 896 people with Haemophilia A infected with HIV. Dr Smithies also recorded the figures from the Communicable Disease Surveillance Centre on 1 August (18 haemophiliacs with AIDS, 17 of whom had died), and that as at April 1986 109 were reported to have HIV-related disease, the majority of whom were expected to "progress to the full-blown syndrome". The newspaper articles reported the possibility of legal action for compensation; this was characterised by officials as "sabre rattling" by David Watters of the Haemophilia Society "in an effort to draw comments". Briefing from Dr Smithies to Michael O'Connor 18 August 1986 DHSC0001025

Examples include the inquiry into the King's Cross Underground Fire, the inquiry into the Clapham Junction Railway Accident, the inquiry into the Piper Alpha Disaster and Lord Justice Peter Taylor's Hillsborough Stadium Disaster inquiry.

<sup>689</sup> It should be noted that Lord Norman Fowler, who was Secretary of State for Health and Social Security prior to June 1987, has urged that it took far too long for this Inquiry to be held, and has himself criticised the prevarication over it being held.

why it had happened. It ought to have been clear that there were lessons to be learned for the future if something similar were not to recur.

In October 1989, during the Department of Health's involvement in the HIV litigation, a submission to the Minister of State for Health, David Mellor, set out various options in relation to the ongoing litigation. One was the establishment of a "Commission of Enquiry", which could either "assess the government's record over the relevant period" or "consider the case for an ex-gratia payment" or both. However, the submission noted that such a course of action could set a precedent and ministers were advised to continue to "strongly defend the Court action." 690

A further submission from officials concerning the HIV litigation was sent to David Mellor's successor, Virginia Bottomley, on 24 July 1990, following Mr Justice Ognall's invitation to consider an out-of-court settlement. This again referred to the alternative option of a Commission of Enquiry, but suggested this might be no quicker than allowing the litigation to take its course. There was also a concern that it might be precedent-setting. All the options were described in the submission as "fairly unpalatable ... There is clearly no certainty that any of the options outlined ... would be effective in "ring-fencing" any further special treatment for the haemophiliacs ... Ministers will need to judge whether the political costs of maintaining the present line outweigh the risks of setting an expensive precedent if some further easement is offered."692

By this time the Department of Health was aware that most people with bleeding disorders who received unheated concentrates had been infected with non-A non-B Hepatitis.<sup>693</sup>

Submission on HIV/Haemophilia Litigation 26 October 1989 pp9-11 WITN5292079. The submission recorded that this was an option mooted by a haemophilia centre director. It is likely that this was Dr Peter Jones. See the minute from Dr Andrzej Rejman reporting on a UK Haemophilia Centre Doctors' Organisation ("UKHCDO") meeting on 9 October: "Dr Jones, off the record, in private suggested to me that one possible way out of the difficulty would be the setting up of a Royal Commission to investigate the problem of HIV and haemophilia". Memo from Dr Rejman to Dr Hilary Pickles 11 October 1989 DHSC0006279\_031

Memo from Strachan Heppell to ministers and the Chief Medical Officer 24 July 1990 DHSC0046964\_003; enclosing a paper from Charles Dobson: Haemophiliacs: AIDS Litigation July 1990 DHSC0004360\_147. In his covering memo Strachan Heppell observed that "Mr Dobson rightly lays out a range of possible choices" and expressed his "own view" that "the choices boil down to two": continuing firmly to resist the present action or seeking a settlement out of court. Memo from Strachan Heppell to ministers and the Chief Medical Officer 24 July 1990 p1 DHSC0046964\_003. In her written statement to this Inquiry, Baroness Bottomley suggested that: "as matters stood in 1990 the option of holding a public inquiry was not attractive because: (i) it was unlikely to report quickly enough to deal with the immediate calls for greater financial help for those infected; (ii) there was concern that it may trespass outside of the question of payments to the infected haemophiliacs and into wider issues of compensation for medical (and even other types of) accidents." Written Statement of Baroness Virginia Bottomley para 8.11 WITN5289001

<sup>692</sup> Emphasis in the original. Haemophiliacs: AIDS Litigation July 1990 p8 DHSC0004360 147

<sup>693</sup> Memo from John Canavan to Dr Elizabeth Smales and Mary Delfgou 21 December 1990 p6 PRSE0004667

## The 1990s

In 1990 the Haemophilia Society, together with Alf Morris MP, sought "a special inquiry into the compensation issue of those with Haemophilia infected with the HIV virus." <sup>694</sup> The Prime Minister, Margaret Thatcher, refused the request on 4 June 1990, suggesting that "the basic question whether there should be compensation is still at issue in the haemophiliacs case. It is a matter normally settled through the litigation process." <sup>695</sup>

Following the settlement of the HIV litigation, and for much of the 1990s, campaigning activities, from the Manor House Group and then the Haemophilia Society, focused principally on the absence of any financial assistance for people with haemophilia who had been infected with Hepatitis C.<sup>696</sup> The Government's failure to heed repeated requests for assistance led to a day of action on 22 July 1998, with representatives delivering a petition and white lilies to Downing Street.<sup>697</sup>

By October 1998, the Haemophilia Society was calling for a public inquiry.<sup>698</sup> The Society's calls followed on from the announcement of Frank Dobson, the Secretary of State for Health, that financial recompense in relation to Hepatitis C would not be given.<sup>699</sup>

On 26 February 1999, the Society's chief executive, Karin Pappenheim, wrote to Frank Dobson seeking his support for a full public inquiry:

"It is shameful that 13 years after this tragedy, described by many clinicians as one of the greatest treatment disasters in the history of the NHS, there has been no public inquiry into how it took place, whether more could have been done to prevent the infection at an earlier stage, and the full impact of HIV and hepatitis C on the lives of haemophilia patients ... Those who were infected feel largely

- 694 Victims of HIV infected blood products will not waiver on the cause for fair settlement 7 June 1990 HSOC0004574, Letter from David Watters to Margaret Thatcher 1 June 1990 HSOC0004581
- 695 Letter from Margaret Thatcher to Alf Morris 4 June 1990 HSOC0004580. In Parliament on 9 May 1990, Stephen Dorrell, Parliamentary Under-Secretary of State for Health, responded to another MP raising the question of an inquiry by differentiating the situation of those with haemophilia from those injured from thalidomide because the issue in the latter situation was one of corporate liability and involved issues of causation by the defendant's products. Hansard extract on Haemophilia 9 May 1990 p3 DHSC0000290
- 696 Letter from Chris Hodgson to Frank Dobson 4 September 1997 HSOC0014285, Meeting with Health Secretary on Hepatitis C 10 September 1997 DHSC0041199\_059, Written Statement of David Tonkin WITN1567008
- 697 Haemophilia Society Press Release *Haemophilia Society Day of Action for Hepatitis C Victims* 20 July 1998 HSOC0009365, Letter from Karin Pappenheim to the Editor of The Times 22 July 1998 p1 HSOC0014086
- 698 Haemophilia Society Press Release Haemophilia Society Calls for Inquiry into Hepatitis C Infection of the UK Haemophilia Population 21 October 1998 HSOC0014014 008
- Letter from Karin Pappenheim to Mark Fisher 5 November 1998 DHSC0046034\_098. In late 1998 the Haemophilia Society sought, without success, to persuade the Health Select Committee to undertake an inquiry looking into "the safety issues posed by blood borne viruses, including HIV, hepatitis C and other strains of hepatitis in the past, and the continuing concerns about transmission of CJD, for which there is no screening test, and recently discovered TTV and parvovirus, both of which appear to escape viral inactivation processes ... Two central themes would be to establish the facts about how patients came to be treated in the '70s and '80s with contaminated blood products and to find out what preventative steps were taken at the time." Letter from Karin Pappenheim to Dr Peter Brand 16 December 1998 HSOC0019684

forgotten. Their appeal for financial assistance has been rejected by Government. The fact that there has still been no public recognition of their plight, and no full public investigation of this NHS tragedy only adds to the sense of injustice. We believe a full inquiry is long overdue, not only for the sake of those who have lost their lives or health through contaminated blood, but in the interests of public health to be certain this cannot happen again." <sup>700</sup>

At a meeting on 17 March 1999 of the All-Party Parliamentary Group on Hepatitis C Karin Pappenheim explained that the Society's campaign was not just calling for financial assistance: "it is also about truth and social recognition. A public enquiry is needed to investigate how and why the contaminated blood products came to be used, whether enough was done at the time to prevent the infection of patients and what the full impact has been on those infected."<sup>701</sup>

Lord Alf Morris wrote to the Prime Minister, Tony Blair, on 11 May 1999 seeking a meeting with him, along with representatives of the Haemophilia Society, about "the case for a public inquiry", 702 and on 24 May he asked Baroness Helene Hayman, the Parliamentary Under-Secretary of State for Health in the House of Lords, "when can we expect a response to the Haemophilia Society's urgent request for a public inquiry?" Her response was that "we concluded that a public inquiry was not the way forward". 703

The Prime Minister responded on 23 June 1999, declining the request for a public inquiry: "Though I recognise that people with haemophilia and their families feel a sense of injustice, I am not convinced that a public inquiry would provide greater insight into the problem or pave the way for any further improvements in the safety controls which are now in place."<sup>704</sup> In his statement to this Inquiry, Sir Tony Blair expressed confidence that "investigations would have been undertaken at that time, in order for me to state that within my reply."<sup>705</sup> There is, however, no evidence of any such investigations being undertaken. A further letter

- 700 Letter from Karin Pappenheim to Frank Dobson 26 February 1999 p1 HSOC0001741
- 701 Minutes of All-Party Parliamentary Group on Hepatitis C meeting 17 March 1999 p4 HSOC0014513. She also wrote to the *British Medical Journal* setting out the Society's call for a public inquiry, observing that whilst the Irish Government was holding an inquiry and had set up a compensation scheme, and the Canadian Government had set aside 1.1 billion Canadian dollars to compensate an estimated 20,000 people following a four year long public inquiry, in the UK "the government has failed even to hold an inquiry." Letter from Karin Pappenheim to the British Medical Journal 3 July 1999 HSOC0016859
- To Letter from Lord Morris to Tony Blair 11 May 1999 p1 HSOC0014459. Alfred Morris had become a peer in October 1997.
- 703 Hansard extract on Hepatitis C Infection 24 May 1999 p1 HSOC0023993. She added that an inquiry "would not help prevention of future transmission. That has been covered by advances in screening and the ability to make blood products safer." Baroness Hayman was Parliamentary Under-Secretary of State for Health between July 1998 and July 1999. Written Statement of Baroness Helene Hayman para 2.5 WITN5523001
- Total Letter from Tony Blair to Lord Morris 23 June 1999 p2 HSOC0002041. It is unclear what if any personal consideration was given to the issue by the Prime Minister. The letter from Lord Morris had been forwarded by the Prime Minister's Assistant Private Secretary to the Department of Health, with a request for the latter to "provide a draft reply for the Prime Minister's signature."

  Letter from Janice Richards to Heather Rogers 17 May 1999 WITN5523011
- 705 Written Statement of Sir Tony Blair para 2.12 WITN7199001

from the Prime Minister dated 6 August 1999 suggested that "it is best to take steps that are positive and which look to the future."<sup>706</sup>

# Calls for an inquiry in Scotland 1999 - 2000

The Haemophilia Society's calls for a public inquiry in the UK, were echoed by campaigners in Scotland, 707 and were taken up with Susan Deacon, Minister for Health and Community Care in the Scottish Executive. 708 The inquiry which the Scottish Executive decided to undertake, however, was neither a full inquiry nor a formal or public one. Rather it was to be an internal review. The focus of the investigation concerned the introduction of heattreated Factor 8 concentrates in Scotland and "whether or not patients in Scotland with haemophilia were exposed to the risks of HCV longer than they should have been given the state of knowledge at the time"; consideration might also be given to allegations that patients were not given sufficient information about the risks of contracting Hepatitis C from blood products, which the Scottish Executive might examine "from a wider policy perspective ... to see what general policy issues they may raise." 709

The Haemophilia Society's submission to the internal review in December 1999 pressed the case for a wider and independent public inquiry, noting that "the process of gathering full information on all relevant aspects of the contaminated blood tragedy must examine the actions of a number of bodies beyond the SNBTS [Scottish National Blood Transfusion Service]. This should include the various committees with responsibility for blood safety in the UK and Scotland, and the haemophilia clinicians' organisation."710 During her oral evidence to this Inquiry, Susan Deacon was asked if this prompted her to consider that a public inquiry, as opposed to an internal review, would be more appropriate. She responded that she could not envisage circumstances "in those first few years of devolution where I would have reached for a public inquiry as a means to progress an issue ... the complexity of the issues involved here and the degree to which they took place before devolution and the extent to which they involved a complexity of UK-wide issues ... for me that absolutely tipped the balance that we could not move this issue forward through that vehicle."711

On 7 December 1999, the Health and Community Care Committee of the Scottish Parliament met and discussed the Haemophilia Society's call for a full public inquiry. The Convenor noted that when they had met the Haemophilia Society prior to the Committee's meeting, the Convenor had told the Society that the Committee was not the way to pursue further investigations, "given our workload, our limited resources and because the Minister for

<sup>706</sup> Letter from Tony Blair to Lord Morris 6 August 1999 p1 HSOC0002110

<sup>707</sup> Letter from Anon to Karin Pappenheim 10 September 1999 HSOC0020449

For example: Haemophilia Society Press Release *Society calls for urgent action on Hepatitis C in Scotland* 6 August 1999 HSOC0001738, Letter from Karin Pappenheim to Susan Deacon 23 September 1999 HSOC0011792\_007

<sup>709</sup> Letter from Susan Deacon to Karin Pappenheim October 1999 pp2-3 SCGV0000170 011

<sup>710</sup> Haemophilia Society's Response to the Scottish investigation December 1999 pp2-3 PRSE0001404

<sup>711</sup> Susan Deacon Transcript 29 July 2022 p53, pp117-122 INQY1000237

Health and Community Care and her department are undertaking an internal review." The Committee agreed to await the internal report before considering any further inquiry.<sup>712</sup>

On the same day, a petition was lodged with the Scottish Parliament (PE 45) calling on the Parliament "to hold an independent inquiry into hepatitis C and other infections of people with haemophilia contracted from contaminated blood products in Scotland and to consider providing financial assistance for people with haemophilia affected by HCV similar to that already provided for people with haemophilia infected with HIV."<sup>713</sup>

Bill Wright described this petition as "pivotal" to what happened next in Scotland: "We'd had complete intransigence within Westminster. We were getting nowhere in London. Philip Dolan<sup>714</sup> ... was trying very hard to get some movement. We were writing to MPs and our voice was not being heard."<sup>715</sup>

The petition was considered by the Health and Community Care Committee in January 2000 and it was agreed again to await the outcome of the Executive's internal review.<sup>716</sup> A request by the Health and Community Care Committee in June 2000 for the internal review to be extended to cover Hepatitis C infection arising from blood transfusions was rejected by Susan Deacon.<sup>717</sup>

The report of the Scottish Executive's internal investigation was published in October 2000.<sup>718</sup> At the Health and Community Care Committee on 25 October 2000, Susan Deacon stated, in response to a question from Nicola Sturgeon MSP asking if she would consider the case for a "public inquiry, which has been supported by a significant number of members of this Parliament, so that evidence can be taken and conclusions formulated independently and openly", that "I do not believe that it would be appropriate to have further investigation of what happened 10, 15 or 20 years ago. We have set out the facts … I am not aware of anybody challenging the substantive facts in this case. What is crucial is that we all think

<sup>712</sup> Health and Community Care Committee Convener's Report 7 December 1999 p2 MACK0001929 016

<sup>713</sup> Petition to the Scottish Parliament calling for an independent inquiry into contaminated blood 7 December 1999 WITN2287022

<sup>714</sup> Philip Dolan was a leading campaigner in Scotland who became Convener of the Scottish Infected Blood Forum. Written Statement of The Scottish Infected Blood Forum paras 26-30 WITN7165001. He gave evidence to the Archer Inquiry. Philip Dolan Archer Inquiry Transcript 4 June 2007 pp58-77 ARCH0000005

<sup>715</sup> William Wright Transcript 10 June 2021 pp20-21 INQY1000127. William Wright is chair of Haemophilia Scotland, having been chair of the Scottish committee of the Haemophilia Society. Written Statement of William Wright para 2.1 WITN2287019

<sup>716</sup> Health and Community Care Committee meeting Transcript 26 January 2000 p2 MACK0001929\_017

<sup>717</sup> Letter from Susan Deacon to Margaret Smith 13 June 2000 p1 SCGV0000171\_010. The request was triggered by a further petition (PE 185) which called on Parliament to take the necessary steps to establish a scheme of compensation to assist people in Scotland who had contracted Hepatitis C as a consequence of infected blood transfusions. Letter from Margaret Smith to Susan Deacon 7 June 2000 p1 SCGV0000171\_005

<sup>718</sup> The process of investigation and the substance of the report are considered in the chapter on *Scotland*.

about what we can do in future, not just for the haemophiliacs who have been infected with hepatitis C, but for the growing number of Scots who are infected with it."<sup>719</sup>

The response to the report from campaigners was one of disappointment, with the Haemophilia Society describing it as a "very thin, incomplete piece of work". The Society's request for a meeting with the Minister to discuss the need for a wider inquiry was declined. The Scottish Executive's line to take was that there was no need for a further inquiry. However, the Health and Community Care Committee met on 12 December 2000 to consider the report and the Convenor explained "Frankly, I do not believe that the committee will be able to carry out a full inquiry into the haemophilia and hepatitis C situations; we do not have the research resources to take on that task" but she anticipated that once they had heard further evidence, the Committee would be able to say whether the report was adequate, should be amended or whether a full public inquiry was required.

#### 2000 - 2001

In Westminster, the Department of Health continued to take the line that no public inquiry was warranted. On 7 March 2000 John Denham, Minister of State for Health, responded to a Westminster Hall debate about people with haemophilia who had been infected with Hepatitis C: "In preparation for the debate and in discussion with my colleagues, I have seen no evidence that would persuade me of the need for a public inquiry or further examination of the history of the matter."<sup>724</sup>

In April 2000 campaigner Carol Grayson wrote to the Secretary of State, Alan Milburn, concerning the need for a public inquiry: "How can the Government justify this decision on what was described in the Lords as 'the worst treatment disaster in the history of the NHS', with more deaths than the 'Marchioness', Southall and Paddington disasters combined, and set to go on claiming lives for many years to come?" She pointed to the importance of there being an **independent** perspective, rather than the Government repeating that there was no evidence of negligence. She challenged the line to take regarding the introduction of heat treating in 1985 "as if technology is the only means of harm reduction." She pointed too to a number of issues that cried out for examination: these included the importation of factor concentrates known to be a high hepatitis risk; the failure to achieve self-sufficiency;

<sup>719</sup> Health and Community Care Committee Convener's Report: Transcript discussing Hepatitis C 25 October 2000 pp3-4 MACK0001929 021

<sup>720</sup> Letter from Karin Pappenheim to Susan Deacon 27 October 2000 p1 HSOC0011980

Letter from Karin Pappenheim to Susan Deacon 15 November 2000 SCGV0000180\_090, Letter from Susan Deacon to Karin Pappenheim 5 December 2000 HSOC0011976

<sup>722</sup> Memo from Sandra Falconer to Minister for Health and Community Care 7 December 2000 p2 SCGV0000173\_031, Letter from Susan Deacon to Angus MacKay 12 December 2000 p1 SCGV0000180 053

<sup>723</sup> Health and Community Care Committee Convener's Report 12 December 2000 p8 MACK0001929 024

<sup>724</sup> Hansard extract on Haemophiliacs 7 March 2000 p24 SCGV0000170\_224. He was responding to the question: "Does that mean the Minister is quite certain that all the necessary investigations have already taken place to rule out the possibility that there was negligence on the part of the Department of Health or NHS in the matter?"

the failure to make use of the facilities at the PFC; knowledge of non-A non-B Hepatitis in the 1970s; the failure to revert to cryoprecipitate or other measures ("This country ... did not adopt these damage limitation measures and encouraged home treatment at any cost"); the failure to ensure that patients were informed of the risks of AIDS; and delays in testing people for Hepatitis C.<sup>725</sup> Carol Grayson wrote a few days later to the Prime Minister enclosing her letter to Alan Milburn and pressing the case for a full and open public inquiry.<sup>726</sup>

A lengthy briefing was prepared in preparation for a Lord's unstarred question<sup>727</sup> on 1 November 2000 about the plans of the Government to improve the care and treatment of patients with Hepatitis C. It included the line to take regarding the need for a public inquiry: "information on research into hepatitis C and the inactivation of the virus in blood is already in the public domain. I therefore do not believe that a public inquiry would add to what is already well established ... The important thing now is to look to the future and ensure that haemophiliacs with Hepatitis C receive the best treatments we can provide."<sup>728</sup>

The position that a public inquiry was not necessary was affirmed by Lord Philip Hunt on 27 November 2000.<sup>729</sup>

Versions of this line to take continued to be trotted out during 2001:

"The technology to make blood products free from HIV and hepatitis C, in sufficient quantities to treat all haemophilia patients in the UK was not available until the mid 1980s. Once it was, the NHS introduced it. All this information is

<sup>725</sup> Letter from Carol Grayson to Alan Milburn 9 April 2000 WITN1055046. Alan Milburn did not personally see this letter. Alan Milburn Transcript 14 July 2022 p175 INQY1000227. He did not recall being asked to consider establishing a public inquiry during his time in office. Written Statement of Alan Milburn para 22.2 WITN6942001

Letter from Carol Grayson to Tony Blair 12 April 2000 WITN1055047. A letter from Lord Philip Hunt to Jim Cousins in July 2000 attempted to respond to some of these points. Two parts of the response show assumptions being made by the Department of Health in favour of doctors. "I hear from haemophilia doctors and others who worked with haemophiliacs that though it was known that there was an element of risk from undefined viruses, the balance, assessed at that time, was in favour of blood products and their perceived benefits." "I think we should assume that as part of their professional care for a patient, haemophilia doctors would have reached out to contact those who they might otherwise see infrequently." Letter from Lord Hunt to Jim Cousins 31 July 2000 p2, p3 WITN1055057. This skates over the whole question of informed consent and assumes doctors would have done no wrong, without any investigation. The assumption underpinning the response is a ministerial expectation that doctors would have done things the proper way. Campaigners on the other hand have sought to point out that, whatever doctors were expected to do, there was evidence that they had not done it, and that was one of the reasons why it needed to be looked at. Carol Grayson Transcript 8 July 2022 pp125-6 INQY1000223

<sup>727</sup> In the House of Lords a Member may ask a question at the end of the day's business, or during the dinner break, and allow a short debate ending with a government reply. These were called "unstarred questions" prior to the 2006-07 session.

Lord's unstarred question on what plans the Government have to improve the care and treatment of patients with hepatitis C 1 November 2000 p24 DHSC0004183\_009

<sup>&</sup>quot;We are all extremely sorry that people with haemophilia were exposed to bloodborne viruses before it was possible to inactivate them in blood products on a large production scale ... we have to bear in mind that twenty or thirty years ago relatively little was really known, much less safety technology was available and that as a consequence lesser requirements would have been in place." Letter from Lord Hunt to Anon 27 November 2000 p1 DHSC0042298\_121. Lord Hunt had ministerial responsibility for blood policy between July 1999 and June 2001.

in the public domain and I do not believe that anyone's interest would be best served by a public inquiry." 730

"The Government understands that haemophiliacs infected with hepatitis C want to know how it happened and why it could not have been prevented, however, all the information is in the public domain and the Government does not believe that anybody's interest would be best served by a public inquiry." <sup>731</sup>

Similar lines to take were adopted in a number of responses from different ministers to letters seeking a public inquiry, with an added expression of sympathy.<sup>732</sup>

In response to a Lords oral question from Lord Alf Morris dated 15 October 2001, Lord Hunt responded that:

"the Government have great sympathy with haemophilia patients who were infected with hepatitis C before the means existed to remove the virus from blood products. We have given careful consideration to the call for a public inquiry but do not believe that that is the way forward. The facts have been set out clearly on many occasions in debates in both Houses, in meetings with Ministers from the Department of Health and in correspondence." 733

When questioned further, Lord Hunt responded: "I believe that all the facts have been produced in various debates in your Lordships' House and in the other place ... As soon as the technology became available to make blood products free from hepatitis C, it was introduced by the National Health Service." These responses followed the lines to take in the briefing prepared by civil servants.<sup>734</sup>

Lord Hunt told this Inquiry that:

- 730 Hansard written answer on Public Inquiry into the Infection of People with Haemophilia, HIV and Hepatitis through Contaminated Blood Products 22 January 2001 p3 DHSC5299323. Whilst those infected were being told that their interests were not best served by a public inquiry, they were of course campaigning for that very thing: see for example the demonstration in Whitehall in April 2001. People living with Haemophilia and related bleeding disorders on Demonstration at Whitehall 3 April 2001 WITN1055076
- 731 Early Day Motion Line to Take on Haemophilia 9 April 2001 p1 DHSC0004294 017
- 732 Letter from Lord Hunt to Clive Soley 12 April 2001 DHSC0006562\_198, Letter from Hazel Blears to Jim Dobbin 6 August 2001 DHSC0038520\_191, Letter from John Hutton to Marion Roe 23 August 2001 DHSC0038520\_067, and Letter from John Hutton to Jim Dobbin 17 September 2001 DHSC0038521 173
- 733 Hansard written answer on Hepatitis C 15 October 2001 p1 DHSC0020742\_093. Answers were based on a briefing provided by officials which asserted that the failure to achieve self-sufficiency was caused by "the massive increase in demand for clotting factors at the time not to any failure to implement Ministerial initiatives." Briefing on calls for a public inquiry 15 October 2001 p12 DHSC0020742\_093. This rather missed the point that there was a failure properly to plan for the increased demand for concentrates.
- Hansard written answer on Hepatitis C 15 October 2001 p1 DHSC0020742\_093. A similar answer was given by John Hutton: Letter from John Hutton to Joyce Quin 18 January 2002 DHSC0006983\_257. Carol Grayson, a tireless writer of letters to ministers, rightly described the experience as "from very early on, a standard line was taken, and that was that nobody was negligent, that the best possible treatment was given at the time, and there was a whole series of these statements that we used to joke that they were copy and pasted into every single letter. And no matter what evidence you presented, they wouldn't budge from that line." Carol Grayson Transcript 8 July 2022 p108 INQY1000223

"It was my understanding that the default position in government was to resist the many calls for various public inquiries unless there were compelling reasons to do so ... while a breach of Lord Owen's commitment to self-sufficiency was said by the campaign and interest groups to justify an inquiry, the information officials were providing to us suggested that that the funds allocated for this had been properly invested in self-sufficiency; that the revised production target had been met, and that the problem was that demand had risen much further than anticipated when the funds had been allocated." 735

Now "with the benefit of hindsight and more fulsome information and knowing something of the many strands being investigated by the current Inquiry, I do believe the calls for a public inquiry were justified."<sup>736</sup>

In Scotland, on 14 March 2001, the Health and Community Care Committee met and heard from the Scottish National Blood Transfusion Service ("SNBTS") and the Haemophilia Society, with the latter renewing its call for a "full independent Public Enquiry ... Only in this way will we get the transparent process required to uncover how this tragedy was allowed to happen and learn what we need to prevent similar events in the future."<sup>737</sup> On 26 April 2001 a debate was held in the Scottish Parliament on Hepatitis C. It focused on compensation but Nicola Sturgeon also referred to the internal report of the Scottish Executive and asked the Executive to reflect on the need for a public inquiry.<sup>738</sup> The Executive's position remained, however, that "We remain unconvinced that a full public inquiry would add substantially to the findings of the report or that a public inquiry would represent the appropriate way for us to move forward."<sup>739</sup>

In November 2001, the Health and Community Care Committee produced their report on Hepatitis C. Whilst the Committee was "not persuaded of the case for a further, independent inquiry into all the concerns raised by the Haemophilia Society and others, if that were to focus mainly on exploring questions of alleged fault", it recommended that financial and practical support should be provided to all NHS patients who had contracted Hepatitis C from blood transfusion or blood products.<sup>740</sup> This led, in due course, to the appointment of

- 735 Written Statement of Lord Philip Hunt para 5.4 WITN4680008
- 736 Written Statement of Lord Philip Hunt para 5.13 WITN4680008
- Health and Community Care Committee 17th Report Annexe B Submission by the Haemophilia Society February 2001 p2 SBTS0000390\_022, Official Report of Health and Community Care Committee meeting 14 March 2001 pp6-29 WITN2287027
- 738 Scottish Parliament Official Report 26 April 2001 p2 SBTS0000357 013
- Letter from Malcolm Chisholm to Iain Gray 19 July 2001 SCGV0000182\_078, Letter from Malcolm Chisholm to Dennis Canavan 4 July 2001 p2 SCGV0000182\_099
- 740 Health and Community Care Committee 17th Report on Hepatitis C 2001 pp25-27 MACK0001929\_001. The formal response from the Scottish Executive welcomed "the report and, in particular, its conclusion that a further, independent enquiry is not desirable. We are also pleased that the Committee concluded that there was no negligence in relation to the introduction of screening or heat treatment and no policy to deliberately withhold information on risk from patients." Report on Hepatitis C Response from Scottish Executive p1 SCGV0000044\_012. However, the Committee considered that this was not a wholly accurate statement of its findings: "Our view is that further investigation would be necessary to conclusively determine whether or not there was negligence by the SNBTS or by any other NHS body ... It is also somewhat misleading to state without

an expert group under Lord Ross. Its work, the response to the expert group's report, and the eventual establishment of the Skipton Fund, are considered elsewhere in this Report.<sup>741</sup>

In the summer of 2001, there had been media coverage of Lord Owen's statements that failure to become self-sufficient in blood supplies had led to unnecessary and avoidable infection. This resulted in questions and letters from MPs, and members of the public, to the Department of Health, including "whether this alters your response to the repeated calls for a public enquiry into the events surrounding what remains one of the most tragic episodes in the history of the NHS." In response, the Department of Health said that they were "looking into points raised by Lord Owen" and would write again once that examination of documents was complete. A briefing sent to Yvette Cooper, the Parliamentary Under Secretary of State for Public Health, on 2 July 2001 noted there was "considerable parliamentary concern on this issue. Lord Morris ... and a number of backbench MPs regularly raise questions in both Houses." It also referenced the "high profile" campaign by the Haemophilia Society that was "calling again for a Public Inquiry."

The briefing to Yvette Cooper was accompanied by a list of options for ministers following the judgment of Mr Justice Michael Burton in *A and Others v National Blood Authority*. An option was to hold a public inquiry alongside the provision of a lump sum and hardship fund. Arguments put forward against this option stated that the relevant facts were largely established and that information was in the public domain. Further arguments against an inquiry included the length of time a public inquiry would take and the concern that a "*Public Inquiry would raise the profile of potential no fault compensation at a time when litigation in the NHS is an increasing problem.*"<sup>746</sup> Yvette Cooper has told this Inquiry that the statement about the facts being established and in the public domain was wrong; she did not, however, see evidence of that until her return from maternity leave in January 2002.<sup>747</sup>

An email from Bob Stock to Susan Deacon on 5 April 2002 explained that the former had

"received a warning yesterday from my opposite number in DH(E) [Department of Health (Ireland)] that they are under a lot of parliamentary pressure to hold a

elaboration ... that the Committee concluded 'that a further, independent enquiry is not desirable' ... Since we had become persuaded by what we classified as the 'moral argument' for awarding financial assistance on the basis of need, our view was that a further lengthy inquiry focusing on questions of fault would achieve little useful purpose ... In short, while the Committee did not recommend that there be an independent inquiry this was not because we were certain that there was no negligence, or that nothing significant would emerge from such an inquiry." Letter from Margaret Smith to Malcolm Chisholm 19 December 2001 p3 SCGV0000248\_109

- 741 See the chapters on Scotland and Government Response to Hepatitis C Infections.
- 742 BBC News Haemophiliac HIV tragedy 'needless' 3 August 2001 RLIT0001233, Guardian Unlimited Haemophiliac infections 'due to broken promises' 3 August 2001 PMOS0000260\_205
- 743 Letter from Paul Goggins to Alan Milburn 29 August 2001 DHSC0014992\_161
- 744 Letter from Yvette Cooper to Paul Goggins 11 February 2002 p1 ARCH0002964\_002. See also: Letter from Lord Morris to Tony Blair 22 August 2001 p1 WITN4680002, Letter from Lord Hunt to Lord Morris 12 November 2001 p1 LDOW0000118
- 745 Memo from Briony Enser to Yvette Cooper 2 July 2001 pp1-2 DHSC0041379 177
- 746 Options for haemophiliacs infected with hepatitis C through blood products p3 DHSC0020756 025
- 747 She was on maternity leave from July 2001 to January 2002. Written Statement of Yvette Cooper paras 4.4-4.5 WITN7187001

public enquiry into the circumstances surrounding contamination of blood with HCV in the 1980s. This is partly being fuelled by pressure from the Haemophilia Groups Forum but also from Lord Owen ... DH(E) are giving consideration to setting up some lesser status enquiry (maybe internal or independent external) in an attempt to avoid being forced into a public enquiry." <sup>748</sup>

According to Yvette Cooper, it had become clear that "there were a series of unanswered questions about events in the 1970s – mid 1980s or so, which required further investigation." She commissioned an internal review, which would, she said, "have been the precursor to any further consideration of the issue or any decision to call a public inquiry."<sup>749</sup>

# The Department of Health's responses to requests for a public inquiry during the preparation of the self-sufficiency report: 2002 – February 2006

Although the self-sufficiency review was commissioned in May 2002, it was not published by the Department of Health until February 2006. Throughout it remained the Government's position that a public inquiry was not warranted.

Thus in a letter to campaigner Mary Grindley in July 2002, the Department of Health's Blood Policy Team asserted that: "The Government has considered the call for a public inquiry very carefully and the issue has been debated in the House of Parliament many times and in meetings with Ministers and voluntary organisations also calling for a public inquiry. The Government decision is that all the information is already in the public domain and they do not think it is the way forward." The same position was maintained in Parliament: Lord Filkin, speaking on behalf of the Government in his capacity as a government whip, told the House of Lords on 12 March 2002 that "In essence, the Government's position ... is that there is nothing of fundamental significance that we do not know about a public inquiry that would be brought out by it ... I do not believe that there is benefit to anyone from a public inquiry, and the Government therefore do not support that." The Department of Health's Blood Policy Po

T48 Email from Bob Stock to Susan Deacon 5 April 2002 SCGV0000175\_018. Bob Stock was Head of Ancillary Services Branch, Health Planning & Quality Division, Scottish Executive.

<sup>749</sup> Written Statement of Yvette Cooper paras 4.5-4.6 WITN7187001. This review, initially undertaken by Peter Burgin and eventually published by the DH as *Self-Sufficiency in Blood Products in England and Wales: a Chronology from 1973 to 1991* 2006 DHSC0200111, is considered elsewhere in this Report. On 15 May 2002, Yvette Cooper and Charles Lister met with campaigners and MPs Sylvia Heal and Paul Goggins: Minutes of meeting at NHS London 15 May 2002 HSOC0010634\_093. In her evidence to the Inquiry, Yvette Cooper disputes the official DH minute of this meeting, which records her as saying: "it was not believed that anyone's interest would be best served by a public inquiry." Minutes of Parliamentary Under-Secretary of Public Health and Manor House Group meeting 15 May 2002 p3 WITN4505279. She says: "I do not believe that is the language I would have used, and it is not reflected in the Manor House Group minutes who I believe would have found that language provocative and would have recorded it." Written Statement of Yvette Cooper para 4.19 WITN7187001

<sup>750</sup> Letter from Jill Taylor to Mary Grindley 23 July 2002 DHSC0020811\_141. See also Letter from Hazel Blears to Paul Goggins 20 August 2002 ARCH0002964\_004 and Letter from Hazel Blears to Greg Pope 15 January 2003 DHSC0004029 233

<sup>751</sup> Hansard – House of Lords Official Report 12 March 2002 p47 HSOC0009293

In April 2003, concern was expressed within the Department of Health that there was increasing pressure in Scotland for a public inquiry to take place. Charles Lister, in an email to the Office of the Deputy Prime Minister, noted that "Just prior to the Election the outgoing Parliamentary Health Committee expressed some support for continuing demands from Scottish haemophilia patients with hepatitis C for a public inquiry. Those same demands are being made here ... Should Scottish Ministers concede on this under Parliamentary pressure, we will inevitably find ourselves dragged in despite our Ministers determination to resist an inquiry."<sup>752</sup> Charles Lister, in his evidence to the Inquiry, explained that "Ministers were always very clear in their minds that an inquiry, in their view, was not warranted. And that applied to successive ministers, so it was very much an established government position which, as a civil servant, it was my responsibility to maintain."<sup>753</sup>

It became a repeated refrain, both in communications from the Department of Health to individuals and MPs and in Parliament, that the Government "does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified." This was often allied with the assertion that "Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time."<sup>754</sup> In December 2003 Lord Warner, the Parliamentary Under-Secretary of State for Health, told the House of Lords that: "I have to make it as clear in as gentle a way as I can that the Government does not accept that any wrongful practices were employed, and do not consider that a public inquiry is justified".<sup>755</sup> This was recorded as the Blood Policy Team's line to take in June 2004.<sup>756</sup>

Following a request from Scottish officials in March 2005, William Connon sent Scottish health official, Sylvia Shearer, an email providing background on the UK Government's decision not to hold a public inquiry, confirming that: "the ministerial line has consistently been that a public enquiry is not justified." 757

- 752 Email from Charles Lister to Peter Thompson 16 April 2003 p2 DHSC5320612
- 753 Charles Lister Transcript 8 June 2022 pp30-31 INQY1000212
- 754 Letter from David Reay to Anon 9 October 2003 DHSC6701738. The repeated (inaccurate) line that screening for Hepatitis C could not have been implemented before 1991 is considered in the chapter on *Lines to Take*.
- 755 Hansard extract regarding ex gratia payment scheme for people with Hepatitis C 11 December 2003 p57 HSOC0003140. Lord Warner continued by repeating the assertion that donor screening for Hepatitis C could not have been implemented before 1991.
- 756 Blood Policy Hepatitis C Ex-Gratia Financial Assistance Scheme 22 June 2004 p5 DHSC0041181\_002. In June 2004, Melanie Johnson, Parliamentary Under-Secretary of State for Public Health, responded to Lord Morris who had forwarded a letter from campaigner Carol Grayson and stated that, in relation to a public inquiry particularly into the sourcing of plasma, "I believe it is important to stress that the Government does not accept that any wrongful practices were employed and does not consider a public enquiry is justified, as we do not believe that any new light would be shed on this issue as a result." Letter from Melanie Johnson to Lord Morris 1 June 2004 p2 CGRA0000834
- 757 Email from William Connon to Sylvia Shearer 2 March 2005 p1 DHSC0041217\_056. See further: Letter from John Reid to Andy Kerr 4 April 2005 DHSC6264733, Submission from William Connon to Sir Nigel Crisp April 2005 p3 WITN3996010, Suggested response by Lord Warner to Lord Morris' parliamentary question regarding a public inquiry p23 DHSC0004213\_115, Hansard written answers on Hepatitis C and Blood Products 26 May 2005 p3 HSOC0012574; all of which repeated the DH's line to take.

In late 2005 and early 2006 the line remained that the Government did not accept that any wrongful practices were employed and considered that there was no justification for a public inquiry.<sup>758</sup>

# The position in Scotland 2003 - 2006

In early 2003 the line to take in Scotland was to refer to the internal Executive report commissioned by Susan Deacon and state that the Executive did "not believe that a public inquiry into this would provide significantly more or that it would be in the interest of those involved".<sup>759</sup> By March 2003 the line was echoing the Department of Health's by asserting that there was "No reason to believe anyone acted wrongly in the light of the facts that were available to them at the time." As for a public inquiry, "Given the passage of time, gathering reliable evidence would be a difficult, lengthy and expensive process" and would be likely to involve investigating bodies outside Scotland.<sup>760</sup>

A Scottish election was to be held on 1 May 2003 and, in advance of that, Bob Stock updated the Department of Health in England that he perceived that demands for a public inquiry would "be renewed with some vigour ... with a good deal of support from the Scottish Parliament."<sup>761</sup>

On 9 September 2003, Malcolm Chisholm, the Minister for Health and Community Care, who had announced a financial support scheme for those with Hepatitis C, was asked about holding a public inquiry. He responded that he was not persuaded that an inquiry should be held:

"the area is very complex. The reality is that a specific screening test was not introduced until 1991 and that although people knew about what was called non-A, non-B hepatitis, they might not have known about its exact longer-term effects. There were many issues to address. In fact, a critical issue was that doctors had to make a choice about giving certain blood products, because the alternative might well have meant death for the particular patient ... If new evidence emerges, I am happy to consider it with an open mind." 762

By way of comment, the reasoning in this statement is unconvincing. To say that an area is not merely complex but "very complex", and that there "were many issues to address" should be good reasons in favour of holding an inquiry, rather than reasons against doing so. The only other reason given for deciding not to have a public inquiry was the difficulty of the choice in relation to blood products, unhappily linked with a view that the choice was that of the doctor rather than that of the patient illuminated by the professional knowledge

<sup>758</sup> Memo from Sophie Coppel 13 December 2005 DHSC0041162\_049, Email from Sophie Coppel to Kim Norman 13 December 2005 p2 DHSC6702956, House of Lords Official Report 12 January 2006 p6 ARCH0000428

<sup>759</sup> Email from Bob Stock to Sandra Falconer 26 February 2003 p2 SCGV0000252\_012

<sup>760</sup> Email from Bob Stock 19 March 2003 p3 DHSC5541661

<sup>761</sup> Email from Charles Lister to Peter Thompson 16 April 2003 p3 DHSC5541783

<sup>762</sup> Scottish Parliament – Health Committee Official Report 9 September 2003 p5 SCGV0001116 066

of the doctor. This merely emphasises an aspect of complexity rather than gives any reason against an inquiry – and it might have been thought that the complexity of a subject made it more, rather than less, appropriate that an inquiry should examine it in public.

On 19 September 2003, the Health and Community Care Committee wrote to Malcolm Chisholm asking when, in light of further evidence provided by campaigners, he would be "in a position to comment on whether or not you consider this evidence to be sufficient to hold a public inquiry?"<sup>763</sup> The response rejected the contention that there was new evidence necessitating a public inquiry. He stated that the material he had been provided with "does confirm that haemophilia directors and the Department of Health and Social Security were aware of such a link,"<sup>64</sup> but I am afraid that this does not constitute new evidence" and referred to the "numerous published articles in eminent medical journals" in the 1970s and 1980s. It was asserted too that information regarding the risk of transmitting hepatitis had been available to "the substantial proportion of patients who were practising home therapy". <sup>765</sup>

The line to take provided by officials for the purposes of a meeting between the Minister and Philip Dolan in autumn 2003 was: "Not convinced that there are any lessons to be learnt that have not already been learnt. Nowadays risk management and the precautionary principle are key issues for the Health service. And we are committed to better communication between clinicians and patients – especially on risk."<sup>766</sup> Writing in October 2003 Bob Stock reiterated that:

"As regards NHS Scotland operations we do not believe that there are any lessons to be learnt that have not already been learnt. Some of the campaigners don't agree with that ... Basically they cannot accept that such a large number of people could have been harmed without someone being at fault (in the negligence rather than the CPA sense). So ... I think the enquiry would be based around discovering maladministration. But there are issues about procedures too – notably in terms of providing risk information to patients to enable them to make choices. We would contend that, whilst this might not be completely fixed, there

<sup>763</sup> Letter from Christine Grahame to Malcolm Chisholm 19 September 2003 SCGV0001093 110

<sup>764</sup> ie a link between factor concentrates and non-A non-B Hepatitis.

Letter from Malcolm Chisholm to Christine Grahame 6 October 2003 SCGV0000256\_075. See also the letter dated 4 November 2003 from Sandra Falconer in which the same line to take is used. Letter from Sandra Falconer to Robert Mackie 4 November 2003 MACK0000600. In one of the briefings dealing with Malcolm Chisholm's response, Ian Gordon, director of Service Policy and Planning, Scottish Executive, stated that: "we should be careful not to claim more than we know about what was understood at the time; conversely, we need to help the Committee to recognise that the case for a public enquiry cannot be based solely on hindsight, but has to include some evidence of wrong or mistaken behaviour at the time (in the light of what was known at the time)." His advice not to claim more than they knew was wise. Devolution issues were also a concern if the Scottish Executive initiated a Scottish inquiry: "The devolution settlement was not intended to prevent such enquiries across the devolved/reserved boundary, but much depends on the willingness of the UK authorities to co-operate. We would have to base our case on the inappropriateness of a Scottish enquiry when the critical issue is clearly within the competence of a UK Government Department, but 'inappropriate' is rarely a convincing adjective." Email from Ian Gordon to Minister for Health and Community Care 30 September 2003 pp1-2 SCGV0000256\_102

<sup>766</sup> Emphasis in the original. Hepatitis C – Public Enquiry Issues etc: Lines to Take for Dolan Meeting 6 October 2003 p4 SCGV0000255\_004

is already a major drive throughout Scotland to change culture and procedures around this issue ... The reality is, given the extremely emotive nature of all this, that Ministers could be steam rollered into accepting the need for an enquiry even though convinced and advised that there would be no real benefit in doing so." <sup>767</sup>

In January 2004, the Minister for Health and Community Care asked for an analysis of the strengths, weaknesses, opportunities and threats (a "SWOT analysis") in relation to a possible public inquiry and this was produced by the Health Planning and Quality Division. It noted that: "The essential case for an inquiry is that it would allow a full examination in public of all the issues and provide a better-informed view of what happened to allow Hepatitis C infection to take place through blood and blood products. On the other hand, it is not clear that it would provide significant new evidence or lead to lessons being learned for the future." A decision from the Lord Advocate as to whether to establish a Fatal Accident Inquiry to investigate a number of Hepatitis C related deaths was awaited.<sup>768</sup>

In November 2004 Andy Kerr, Minister for Health and Community Care, addressed the question of a public inquiry stating that it "has been considered by Ministers. It is our view that there is nothing to be learned from a public inquiry that has not already been learned. We have, however, stated that should any new evidence come to light that this would be reconsidered."<sup>769</sup>

Sylvia Shearer, head of the blood and rehabilitation branch, told this Inquiry that, on taking up her post, her understanding of why the Scottish Executive was refusing an independent public inquiry was:

"One was that lessons had been learned and there was no new evidence forthcoming to support the need for a public inquiry. The other was concern at Ministerial level that a precedent would be set in relation to NHS treatment and this could result in large sums being paid in compensation claims which would impact on the Health budget and thereby the efficacy of the NHS to provide treatment free at the point of delivery."

She thought that the latter "was mostly responsible for the official 'line to take' as directed by Ministers."<sup>770</sup>

On 1 February 2005 a meeting took place between the Minister, Andy Kerr, and representatives of the Scottish Haemophilia Forum, at which the Minister:

"advised that he remains unconvinced of the added value or outcomes that an enquiry would bring. He felt that the history of the issue was well known and that the lessons learned and considerable action taken means that the enquiry would

<sup>767</sup> Emphasis in the original. Email from Bob Stock to Patrick Layden and Jan Marshall 9 October 2003 SCGV0000262 119, Written Statement of Robert Stock paras 32-38 WITN7078001

<sup>768</sup> Advice to Minister for Health and Community Care February 2004 p1 SCGV0001080 040

Letter from Andy Kerr to Murray Tosh 5 November 2004 p2 SCGV0000040\_194. See also: Letter from Andy Kerr to Euan Robson 11 November 2004 MACK0002352\_002

<sup>770</sup> Written Statement of Sylvia Shearer para 6.1 WITN7489001

deliver little. The Minister was confident that all possible steps had been taken in terms of tracing and notification ... and was clear that those involved had acted in the interests of the patients and on the best information available at that time." 771

In March 2005, Sylvia Shearer wrote to William Connon at the Department of Health in London that:

"The issue of a public inquiry is being revisited on 10 May ... Due to FOI [Freedom of Information], the line that there is no new evidence to suggest holding a PI [public inquiry] is becoming increasingly difficult to defend. I know you have responded that your Ministers are not deviating from that, but I would still like to know whether, if we were to go ahead, they would be supportive in terms of co-operating with one held in Scotland. If that is a categoric 'no' then we need to advise our Minister accordingly." 772

She has told this Inquiry that it became evident that "there had been pressure from DH (UK Government) at the time on the SHHD [Scottish Home and Health Department]/Secretary of State for Scotland, to hold the line of no PI." Her understanding was that the main concern "was around precedent and the financial implications of compensation rather than any suspected malpractice." She felt that this was "not necessarily sufficient justification for not holding a PI as holding it would have clarified the scientific and medical decisions taken at the time based on the knowledge base at the time." It was obvious to her that "UK Government were in control of the lines to take prior to and even after Devolution."<sup>773</sup>

On 15 April 2005 Andy Kerr sought a meeting with the Lord Advocate about the "position of your current thinking" on whether to hold a Fatal Accident Inquiry and whether a decision would be made in advance of his scheduled appearance before the Health Committee on 10 May.<sup>774</sup> Prior to his appearance before the Committee, a letter to submit as written evidence<sup>775</sup> and a speaking note<sup>776</sup> were prepared for the Minister which continued to hold

<sup>771</sup> Minutes of Scottish Haemophilia Forum meeting 1 February 2005 p1 SCGV0001080\_052. This latter point echoed the DH's line to take that patients had received the "best treatment available" in light of medical knowledge at the time. Following the meeting, Andy Kerr requested that a literature review be considered to establish what materials in relation to Hepatitis C could be released into the public domain. Memo from Sylvia Shearer to Minister for Health and Community Care 22 February 2005 p3 SCGV0000262\_002. Initial investigation indicated that there were 150 files that had been stored and were to be considered.

<sup>772</sup> Email from Sylvia Shearer to William Connon 7 March 2005 p1 DHSC0004520 045

<sup>773</sup> Written Statement of Sylvia Shearer para 10.1(d) WITN7489001

<sup>774</sup> Email from Minister for Health and Community Care to Lord Advocate 15 April 2005 p3 SCGV0001080\_011

The reasoning included that the Minister was not convinced that any officials or NHS staff acted wrongly in the light of the facts that were available to them at the time; the resource implications of holding a public inquiry were high; the fact that many people involved at the time were either dead or retired; and that it would be difficult to conduct an inquiry at this distance in time. Written evidence from Minister for Health and Community Care 10 May 2005 pp3-4 SCGV0000263 097

<sup>776</sup> Call for Public Inquiry in Relation to Haemophilia Treatment Health Committee Appearance 10 May 2005 SCGV0000263\_076

the line that a public inquiry was not justified.<sup>777</sup> Ultimately, the Minister did not give evidence to the Committee.<sup>778</sup> A decision from the Lord Advocate regarding a Fatal Accident Inquiry was still awaited, and petitions for judicial review were lodged on 9 May 2005 by Thompsons Solicitors on behalf of their clients, arguing that an inquiry was required by virtue of Article 2 of the European Convention on Human Rights. The line to take became: "Due to court proceedings which are pending we are limited in the response we can provide at this time."<sup>779</sup>

Meanwhile, a trawl of files was conducted in response to a Freedom of Information request from Robert Mackie, and the Minister was asked to agree to the publication of a number of documents. It was noted that some documents were sensitive mostly because of "the tone used, often between the medical advisers of the day, rather than any specific failure in policy. The Minister may wish to consider whether the ensuing embarrassment, should some comments be taken out of context by the media, outweighs the need to be seen as 'open and transparent." The Minister's position was that whilst wanting to be "as open as possible" he did not consider it appropriate to release "advice to ministers". Subsequently, William Connon, of the Department of Health, appears to have expressed frustration that the documents were being released when he would have denied the request. Sylvia Shearer noted that this was not an option as the Minister had agreed with the Scottish Haemophilia Forum that they would be released.

In August 2005, the Convenor of Health Committee wrote to Andy Kerr asking if he could attend at a reconvened session. Sylvia Shearer prepared a draft briefing on the calls for a public inquiry to assist his decision-making regarding whether to provide evidence to the Committee. The briefing included a note that: "Embarrassment and eventual claims for compensation could result from the release" of documentation held by the branch. In her covering email, Sylvia Shearer explained that she had originally been asked to provide an off-the-record briefing "but on reflection over the weekend, I felt it was necessary to formally respond. I realise this Minute is lengthy, but then the issues are complex and I think should be on record." She did not want substantive amendments to the briefing: "It is my assessment of the situation from my perspective and I would welcome the opportunity

- 778 Letter from Andy Kerr to Roseanna Cunningham 10 May 2005 SCGV0001081\_058
- 779 Email from Jan Marshall to Julie Grant and others 31 May 2005 p1 SCGV0000263\_033
- 780 Memo from Sylvia Shearer to the Minister for Health and Community Care 6 May 2005 p1 SCGV0001081\_066. Robert Mackie has given evidence to the Inquiry about his and his wife Alice's research into the circumstances that led to infections from blood products in Edinburgh. Written Statement of Robert Mackie para 1 WITN2190001, Written Statement of Alice Mackie WITN2189005
- 781 Email from Lindsay Blakemore to Sylvia Shearer 9 May 2005 p3 SCGV0001081 053
- 782 Email chain between William Connon and Sylvia Shearer November 2005 p2, p4 DHSC5394925
- 783 Letter from Roseanna Cunningham to Andy Kerr 10 August 2005 SCGV0001081 027

<sup>777</sup> In his written statement, Andy Kerr states that: "I always made it clear to officials that if we felt that the position being adopted on the matter of a public inquiry was wrong then we should acknowledge that and move to a public inquiry, for example, if there was evidence that actions were wrong and covered up then we should acknowledge that and move to a public inquiry." Written Statement of Andy Kerr para 53 WITN5753003. Sylvia Shearer, however, in her written statement states that: "I am unaware of him having expressed any opinion to me at any time other than to continue to hold the line to take as agreed with the UK Government 'As there is no new evidence and lessons have been learned there is no need for a Public Inquiry." Emphasis in the original. Written Statement of Sylvia Shearer para 11.1(c) WITN7489001

to present it to the Minister as such."<sup>784</sup> She was, however, asked to make the briefing "more neutral and factual" and "not as the views of the 'branch head' however sensible and well informed these may be!"<sup>785</sup> Officials advised that the Minister should attend the Health Committee to give evidence but not stray into issues that could affect the judicial review and this was conveyed to the Committee.<sup>786</sup>

The Executive's tranche of documents was released on 12 December 2005 with a covering letter which noted that: "Whilst we fully appreciate that this material will be perceived as 'new' to the public, the Executive maintains the position that there is no new evidence contained within these files, which were available to officials and previous Ministers, to warrant a public inquiry into this issue."<sup>787</sup>

A briefing paper dated 21 December 2005 to the Deputy Minister for Health and Community Care noted that there had been a series of FOI requests and the documents placed "the Minister in a potentially difficult position. It is a matter of interpretation whether the 'evidence' presented will be viewed by MSPs as sufficient 'new evidence' and provide a reason to support a public inquiry. The Minister is advised to consider how he wishes to manage this situation. Going on past experience, there will be considerable public and media interest in this event. It is an emotive issue and requires a sensitive but firm response." It was also noted that the UK Government did not support an inquiry and Department of Health officials had expressed "considerable concern about holding a public inquiry ... whilst the formal line is that the SoS [Secretary of State] does not support a public inquiry ... should Scotland hold one, they would feel obliged, albeit with considerable reluctance, to co-operate as not to do so would be seen as untenable." 188

The Minister, Andy Kerr, appeared before the Health Committee on 31 January 2006. His opening statement set out his view that he was unconvinced of the benefits of a further inquiry, the events having taken place mainly between 20 and 30 years previously "when there was not an understanding of the basic science involved."<sup>789</sup> In his written statement to this Inquiry, he stated that: "The civil service provided briefing and advice and I took the position that the advice was persuasive. I asked questions as to whether the new evidence would change the position on the call for a public inquiry. I had little option but to rely on that advice, the advice was from many sources which included special advisors."<sup>790</sup>

<sup>784</sup> Email from Sylvia Shearer to Andrew MacLeod and Jan Marshall 22 August 2005 p1, p3 SCGV0000263 020

<sup>785</sup> Email from Andrew MacLeod to Sylvia Shearer 22 August 2005 p1 SCGV0000263\_016. Sylvia Shearer explains in her statement to this Inquiry that she "felt exposed being asked to give an 'Off the record' briefing and, on reflection, wanted a formal record of my actions and advice. You will note my draft was withheld by Mr Mcleod so Mr Kerr will have been correct in saying he did not receive it." Written Statement of Sylvia Shearer para 13.1 WITN7489001

<sup>786</sup> Email from Sylvia Shearer to Andrew MacLeod and Jan Marshall 17 August 2005 SCGV0000263\_024, Letter from Andy Kerr to Roseanna Cunningham August 2005 SCGV0001081\_030

<sup>787</sup> Letter from Sylvia Shearer to Robert Mackie 12 December 2005 MACK0001194 001

Advice to Ministers: Call for Public Inquiry in Relation to Hemophilia Treatment parliamentary debate 21 December 2005 pp4-5 SCGV0001082 018

<sup>789</sup> Health Committee Official Report on Hepatitis C 31 January 2006 p28 MACK0001200 002

<sup>790</sup> Written Statement of Andy Kerr para 71 WITN5753003

On 18 April 2006 the Health Committee met and discussed the case for a public inquiry. A motion was put by Shona Robison, Shadow Minister for Health and Social Justice, that a call should be made for an independent judicial inquiry. The Committee voted in favour of calling for "an independent public inquiry" with the Convenor casting the deciding vote.<sup>791</sup>

The Committee's decision was not welcomed by the Scottish Executive. <sup>792</sup> Sylvia Shearer notified William Connon and counterparts in Wales and Northern Ireland, advising: "The Minister is keen that we advise whether we think we can still robustly claim there is no new evidence and therefore no need for a public inquiry. Having talked to Andrew [MacLeod], Deputy CMO [Deputy Chief Medical Officer] Dr Aileen Keel and SNBTS we are of the view we can retain that line." <sup>793</sup> This was said to be reassuring to Department of Health ministers. <sup>794</sup>

In June 2006 Andy Kerr was advised that the Lord Advocate had decided that no Fatal Accident Inquiry would be held. It was recommended that the letter to the Health Committee indicating that the Minister was not minded to hold a public inquiry should be sent at the same time as the Lord Advocate's letter to Thompsons Solicitors about not holding a Fatal Accident Inquiry. On 16 June 2006 the Minister wrote to the Health Committee setting out his conclusion that there was no basis for a public inquiry. The reasons included the fact that it would be a major and time-consuming exercise which would depend on the recollection of witnesses ("This would make it difficult to construct a clear and detailed picture of what took place"); it would not add significantly to understanding of how the blood supply became infected with Hepatitis C, or the steps needed to deal with problems of this kind now or in the future; transmission of Hepatitis C took place at a time when there was limited knowledge about the condition and its outlook; and communication between professionals and patients had changed significantly since the 1980s.

Health Committee Official Report on Hepatitis C 18 April 2006 p13 HSOC0002983. The Health Committee's decision to call for a full public judicial inquiry was communicated to the Minister on 19 April 2006. Letter from Roseanna Cunningham to Andy Kerr 19 April 2006 SCGV0001083 017

The Executive was said to be examining "the validity of a vote in the Scottish Parliament Health Committee in support of a public inquiry. It is understood that the casting vote of the Chairman may be disallowed" and the advice from Scottish Executive officials was "very strongly against holding a public inquiry." Memo from Gerard Hetherington to Becky Spavin 26 May 2006 para 7 DHSC0041159\_205. See also: Memo from Andrew MacLeod to Minister for Health and Community Care 26 May 2006 SCGV0001083\_010

<sup>793</sup> Email from Sylvia Shearer to William Connon and others 19 April 2006 p3 DHSC5293683. The email was passed on by William Connon to Caroline Flint's private secretary, noting it would be very difficult for the DH to "hold the line that there are no grounds for a public enquiry in England if the Scots were to hold an enquiry. This is not least because this all happened pre-devolution, therefore the papers, people and issues would inevitably have to be sourced through this department or at least they would all relate directly to DH." Email from Sylvia Shearer to William Connon and others 19 April 2006 p2 DHSC5293683

<sup>794</sup> Memo from Andrew MacLeod to Minister for Health and Community Care 26 May 2006 p2 SCGV0001083\_010

<sup>795</sup> Memo from Sylvia Shearer to Minister for Health and Community Care 12 June 2006 SCGV0001083\_003

<sup>796</sup> Letter from Andy Kerr to Roseanna Cunningham 16 June 2006 pp5-6 PRSE0000167

# The Department of Health's response to continuing calls for a public inquiry from February 2006 to December 2006

The report entitled *Self-sufficiency in Blood Products in England and Wales: A chronology from 1973-1991* was published on 27 February 2006.<sup>797</sup> The media briefing before publication anticipated criticisms of the report from pressure groups who had campaigned for compensation and a public inquiry, and it was recognised that continued demands for a public inquiry were likely.<sup>798</sup>

At a meeting between officials, Lord Warner (Minister of State for National Health Services Delivery) and Caroline Flint (Minister of State for Public Health) in May 2006 it was recorded that ministers felt that it was becoming increasingly difficult to resist holding a public inquiry. On 2 June 2006, Hugh Taylor, the Permanent Secretary at the Department of Health, asked for more information about what was "driving the pressure" for a public inquiry. He was informed by Gerard Hetherington, the head of health protection, that the "key factor" behind the request for an inquiry was a belief of campaigners that a finding of culpability would "lead to higher compensation payments and a settlement of some kind for the families of those who have died." 801

In a briefing to ministers on 26 June 2006, the "considerable pressure" for a public inquiry was noted and that "patient groups continue to press for higher levels of compensation and believe an inquiry could help to achieve this by demonstrating the Department was culpable". The Department's assessment of the pros and cons of a public inquiry were set out. The advice of officials was that, on balance, "we consider an inquiry to be disproportionate and not justified in the circumstances."<sup>802</sup>

A suggestion was made by Lord Warner that rather than a public inquiry the powers under the National Health Service Act 1977 could be used "to commission a review of ALL the documents (new ones, old ones and if possible Scottish ones) with a view to producing an

- 797 See the chapter on the Self-Sufficiency Report.
- 798 Memo from Sophie Coppel to Permanent Secretary for Public Health 23 February 2006 p2 DHSC0200112
- 799 Memo from Gerard Hetherington to Becky Spavin and Jacky Buchan 25 May 2006 p2 DHSC5106722
- 800 Email from Gregory Hartwell to Gerard Hetherington 2 June 2006 p1 WITN7498002
- 801 Email from Gerard Hetherington to Gregory Hartwell 8 June 2006 DHSC5416837
- Memo from Gerard Hetherington to Rebecca Spavin and Jacky Buchan 26 June 2006 DHSC0041159\_204. In his statement to the Inquiry Sir Hugh Taylor suggested that "With the benefit of hindsight, however, it is clear that, in this case, there were some limitations on the conventional process of Ministerial challenge and indeed challenge from senior officials to the established position in relation to events that had occurred decades before. An official line had been developed much closer to the events in time and then over successive government administrations. Officials briefing Ministers at this time could say in good faith that no fundamentally new evidence had emerged which justified bringing these lines into question. But none of the officials working in the Department at this time had direct experience of the events; and their capacity to interrogate conclusively all the assumptions and evidence behind decisions taken and conclusions drawn at the time was necessarily limited. In the end, that was always the case for some sort of dedicated inquiry." Written Statement of Sir Hugh Taylor para 4.28 WITN7498001. He further observed that "it is certainly my impression that, during the period when I was Permanent Secretary [March 2006 to July 2010] the Government placed a very high bar on holding public inquiries, higher than perhaps it has become in recent years." Written Statement of Sir Hugh Taylor para 4.31 WITN7498001

independent legal/judicial commentary on them and putting all these into the public arena."803 He thought a retired judge or Queen's Counsel ("QC") could do this with an administrative support team. Caroline Flint thought this a sensible way forward.804

Patricia Hewitt, the Secretary of State, left the decision to Caroline Flint: "SofS has seen your/ Lord Warner's note and commented that if you really believe an independent commentary is worth it and affordable, then [the Secretary of State] is content. However, she feels that it will fuel rather than deflect calls for a public enquiry — which we are absolutely right not to do."805 Lord Warner indicated that it was Caroline Flint's call because it was her policy area and that he did "not think the calls for a public inquiry will go away whatever we do but thinks an independent commentary on all the papers available will help to resist a public inquiry — he still thinks the commentary is worth doing if the money is available."806

In her statement to this Inquiry, Caroline Flint explained that she supported Lord Warner's suggestion because she was "obviously very aware of calls for a public inquiry, the understandable concerns about missing and destroyed documents, and the breakdown in trust in successive governments. I did come to believe that DH needed to do more to reassure the public about what documents were available and what they said."807

However, instead of a review by a QC or judge, it appears that in July 2006 a Grade 6 civil servant, Linda Page, had been tasked with undertaking a review of existing papers. Caroline Flint, in her statement, could not say with confidence "why progress was not made with an independent external review of the documents. It would appear that [by] the end of July 2006, a DH official had already started an internal document review and I do not recall if we thought it best to await the outcome of that. That was completed in February 2007 and, of course, Lord Archer announced his inquiry in February 2007 also. That may then have overtaken things but I do not think the possibility of an independent review was abandoned altogether."

On 23 November 2006, in a written answer to a question from an MP, the Minister used a broadly similar line to take as before: "The Government has great sympathy for those infected with hepatitis C and has considered the call for a public inquiry very carefully. However, as previously stated, the Government does not accept that any wrongful practices

A number of inquiries had previously been set up using powers under the National Health Service Act 1977, including the Allitt Inquiry, the Bristol Royal Infirmary Inquiry, and the Royal Liverpool Children's Hospital Inquiry.

Email from Jacky Buchan to Dr Ailsa Wight 11 July 2006 p5 DHSC0015764. This suggestion was added to the note that was sent to the Secretary of State in July. Letter from Becca Spavin to Jacky Buchan DHSC0041159\_251, Memo from Minister of State to the Secretary of State July 2006 p4 DHSC0041159\_201, Memo from Caroline Flint and Norman Warner to the Secretary of State 24 July 2006 p2 DHSC0103399 003

Letter from Jennie to Patricia Hewitt 24 July 2006 DHSC0041306\_038, Letter from Caroline Flint to Jacky Buchan 4 August 2006 DHSC0041159 139

<sup>806</sup> Letter from Caroline Flint to Jacky Buchan 4 August 2006 DHSC0041159 139

<sup>807</sup> Written Statement of Caroline Flint para 3.152 WITN5427001

<sup>808</sup> Memo from William Connon to Chief Medical Officer 4 December 2006 p4 DHSC5069877

Written Statement of Caroline Flint para 3.153 WITN5427001, Memo from Elizabeth Woodeson to Minister of State 24 April 2007 para 11 DHSC0041193\_026

were employed and does not consider that a public inquiry is justified. Donor screening for hepatitis C was introduced in the United Kingdom in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time."810

In a letter dated 1 December 2006, Caroline Flint responded to Roddy Morrison, chairman of the Haemophilia Society, who was calling for a public inquiry: "In light of the substantial numbers of documents and reports available, the Government does not consider that a public inquiry would add significantly to our understanding of how the blood supply became infected with hepatitis C or the steps needed to deal with problems of this kind now or in the future."811

On 4 December 2006, a lengthy briefing was provided to the Chief Medical Officer ("CMO") dealing with the need for a public inquiry in anticipation of a meeting with ministers. The briefing note set out the background and noted that the work by Linda Page would be completed by January 2007 and had "found no new evidence that identifies any culpability of the Department". The briefing noted that the review "will conclude that, on balance, taking account of the content of all available documentation relating to NANBH [non-A non-B Hepatitis], that a careful and proper approach was taken to the issues of blood safety. With regard to a Public Inquiry, the Government has never agreed that any wrongful practices were employed, and does not consider that a Public Inquiry is justified."812

# The review by Linda Page

The report by Linda Page titled *Review of Documentation Relating to the Safety of Blood Products 1970-1985 (Non A Non B Hepatitis)* was published in May 2007.<sup>813</sup> It had been sent to ministers in April 2007, under cover of a submission which stated that the report "concludes that the documents provide no new information that challenges the Department's position. The papers reviewed support the view in the 1970s and early 1980s that NANBH (hepatitis C) was a mild disease, a view widely shared at the time. CMO has commended the report's rigorous analysis and agreed its conclusions."<sup>814</sup>

- 810 Parliamentary written answer on blood products 23 November 2006 p1 DHSC0006197\_036
- Letter from Caroline Flint to Roddy Morrison 1 December 2006 p1 HSOC0003594, Letter from Roddy Morrison to Caroline Flint HSOC0029809
- 812 Letter from William Connon to Chief Medical Officer 4 December 2006 p3, p5 DHSC5069877. The meeting with the CMO did not in fact take place. Email chain between Rebecca Lloyd and others 12 December 2006 DHSC5447475
- Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 PRSE0000642. A briefing pack was produced alongside it: Review of Documentation Relating to the Safety of Blood Products 1970-1985 (Non-A, Non-B Hepatitis) DHSC0103399\_092. Linda Page had no medical or legal training. In the four years prior to her taking on this review she was a project manager in the DH's Electronic Staff Record Project, which concerned the development of an electronic record of all NHS staff. Written Statement of Linda Page para 1.3 WITN7269001
- Memo from Elizabeth Woodeson to Minister of State 24 April 2007 p1 DHSC0041193\_026. Emphasis in original. Email chain between Linda Page and Richard Kelly 9 February 2007 DHSC0050752. Caroline Flint explained in her statement, by reference to this report, that she "was not provided with information that would have led me to revisit the government's established policy position. I was also

The background to the review was described in an email from Dr Ailsa Wight, the Department of Health's deputy director of general health protection in June 2006. This referred to there being "considerable Parliamentary and patient group interest" and "an urgent need to assess the evidence relating to previous Government policy on the safe use of imported and domestic blood products, and to advise Ministers accordingly ... The end result will be a report to Ministers to establish the facts and make recommendations on future handling in the light of public interest requirements."815 The report itself explained that the need to assess the extent and content of documents held by the Department of Health in relation to non-A non-B Hepatitis was "prompted by calls for a Government backed public inquiry and the return of documents, previously considered missing, from a firm of solicitors."816

A project board oversaw the work and at a board meeting on 4 September 2006 it was decided that the period of interest should not be extended to 1991 when donor screening was introduced and that the focus was an assessment of documentation in relation to the viral inactivation of blood products "rather than the broader remit of the safety of blood".817 Accordingly it was decided that the timescale 1970-85 remained the appropriate timescale for the project.818 The end point of 1985 reflected the point in time at which the Blood Product Laboratory's ("BPL") concentrate 8Y became available;819 the report did not, therefore, address the usage of commercial factor concentrates during the second half of the 1980s, which continued to transmit non-A non-B Hepatitis. Nor did the report address any issues relating to HIV.

Even within its own limited terms, the report was flawed.820

reassured by the view of the CMO. Releasing the documents that had been reviewed was important to the transparency of the process and provided evidence behind the NANBH Document Review Report's findings." Written Statement of Caroline Flint para 3.197 WITN5427001

<sup>815</sup> Job/Project Task Description on Blood Safety: Haemophiliacs Infected with HIV and Hepatitis C WITN7269003, Email from Dr Wight to William Connon 26 June 2006 WITN7269002

Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p3 PRSE0000642

<sup>817</sup> Notes of Project Board meeting 5 September 2006 p2 WITN7269005. Whilst the remit of the report remained the period up to 1985, it is notable that it nonetheless repeated the departmental line about screening: "The DH is of the view that only after the virus had been identified was it feasible to develop a screening process for hepatitis C. Screening of blood donations for hepatitis C was introduced in 1991: prior to this no reliable and validated assays for hepatitis C antibody were available." Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p7 PRSE0000642. As discussed elsewhere in this Report, this ignores the findings of Mr Justice Burton regarding both surrogate testing and Hepatitis C testing.

Notes of Project Board meeting 5 September 2006 p2 WITN7269005. The suggestion of widening the scope of the work had been made by Dr Hugh Nicholas, a senior medical officer in the DH. Email from Dr Nicholas to Linda Page 8 August 2006 DHSC0004232\_053. Dr Nicholas undertook a "Quality Assurance function" in relation to aspects of the report. Written Statement of Linda Page para 2.13.1 WITN7269001

<sup>819</sup> Written Statement of Linda Page para 2.48 WITN7269001

This is not intended as a criticism of Linda Page. The criticism is of the Department of Health, for reasons apparent in the text, and of the reliance that was subsequently placed by the Department of Health on the report.

Firstly, it was flawed because Linda Page (as she had been asked to do) looked only at documents actually held by the Department of Health.<sup>821</sup> She was not asked to consider medical literature more widely. The consequence was that, in a report which bought into the idea that non-A non-B Hepatitis was understood to be a mild and benign condition, there was no reference at all to the 1978 Sheffield study, published in *The Lancet*,<sup>822</sup> and described to this Inquiry as an "absolutely key moment".<sup>823</sup> and "one of the great sea change moments".<sup>824</sup>

Secondly, it was flawed in its focus on evidence of mortality, rather than an understanding that the real problem was chronic liver disease. This is illustrated by the report's discussion of what was said to be the United Kingdom Haemophilia Centre Directors Organisation ("UKHCDO") Hepatitis Working Party's 1978 report: attention was drawn by Linda Page to the fact that "no further fatalities directly due to acute hepatitis had been reported".825 In fact the document referred to was the Hepatitis Working Party's 1979 report.826 The 1978 report of the Hepatitis Working Party (which, although in the possession of the Department of Health,827 was not discussed) recorded that there were patients in several haemophilia centres thought to have evidence of chronic liver disease and reported on Dr John Craske's recent visit to a leading US hospital which had carried out almost 100 liver biopsies on patients who had been treated with commercial Factor 8 concentrates, nearly 50% of which showed histological changes compatible with cirrhosis, chronic active or chronic persistent hepatitis.828 This was important information, which was omitted.

Thirdly, it was flawed in its conclusion that "The treatment of NANBH in the correspondence and notes of meetings gives no indication that NANBH was considered a life threatening disease over the period to which this review relates i.e. 1970 to 1985."829 This conclusion was flatly at odds with a document which Linda Page did consider, namely Dr Diana Walford's minute of 15 September 1980 in which she wrote that "This form of hepatitis can be rapidly fatal (particularly when acquired by patients with pre-existing liver disease) or can lead to

Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p4, p29 PRSE0000642

<sup>822</sup> Preston et al *Percutaneous Liver Biopsy and Chronic Liver Disease in Haemophiliacs* The Lancet 16 September 1978 PRSE0003622

<sup>823</sup> Dr Mark Winter Transcript 1 October 2020 p58 INQY1000059

B24 Dr Mark Winter Transcript 1 October 2020 p59 INQY1000059. In her written statement Linda Page acknowledges that the Preston article was "sufficiently relevant and important to the subject matter of the project" that she would have included it in the report if she had come across it in the course of her work on the project. "Lawyers assisting me in preparing this statement have not been able to locate this article on the DH's 'Iron Mountain' or 'Preservica' systems, and it does not appear in the inventories of documents reviewed. I do not know why this is the case." Written Statement of Linda Page paras 2.74-2.75 WITN7269001

Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p13 PRSE0000642. It is to be noted that the focus in this remark was on "acute" hepatitis: whereas the real problem was chronic disease.

<sup>826</sup> Report of Haemophilia Centre Directors Hepatitis Working Party 1979 p5 HCDO0000135 023

<sup>827</sup> Report of Haemophilia Centre Directors Hepatitis Working Party 1978 DHSC6887757\_102

<sup>828</sup> Report of Haemophilia Centre Directors Hepatitis Working Party 1978 20 August 1978 pp5-6 DHSC6887757 102

Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p29 PRSE0000642, Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p14 PRSE0000642

progressive liver damage. It can also result in a chronic carrier state, thus increasing the 'pool' of these viruses in the community."830 As to why the conclusion was so at odds with what the contemporaneous document showed:

- (a) It is apparent that Linda Page identified the minute as relevant: she highlighted it in her progress report of 16 August 2006<sup>831</sup> and in the project board's meeting minutes of 4 September 2006 it was agreed that Dr Walford should be advised that the 1980 minute had been released under the Freedom of Information Act ("FOIA").<sup>832</sup>
- (b) Following the release of the document under FOIA the Haemophilia Society appears to have noted its significance and raised it in correspondence. The Department of Health's response to the Society was as follows:
  - "You have drawn attention to comments in the note from Dr Walford (dated 15 September 1980) about reports of fatal complications following the administration of Factor IX concentrates. She may have been referring to a report in the Lancet in March 1979. This reported three fatalities in jaundiced patients (who did not have haemophilia) subsequently shown to have severe cirrhosis due to either alcohol (2) or Wilsons disease (1), who were given Factor IX concentrate to correct clotting abnormalities prior to liver biopsy. The circumstances were thus rather different from those that might be expected in patients receiving factor concentrates for haemophilia, and the finding is not born [sic] out by our current knowledge of acute hepatitis C infection in patients without underlying liver disease." 833
- (c) This ex post facto "explanation" of Dr Walford's minute plainly came to the attention of Linda Page: it appears in a briefing from William Connon for the CMO in December 2006 (copied to Linda Page) which describes the minute as a document "that required a detailed explanation on its release."<sup>834</sup>

<sup>830</sup> Memo from Dr Walford to John Harley 15 September 1980 p1 WITN0282008. The review also failed to pick up on the warnings of severity at the Glasgow international symposium in September 1980 on unresolved problems in haemophilia treatment. Linda Page characterised it and related reports as not reporting "to any extent upon the severity" of chronic hepatitis, yet the first paper of the symposium warned: "It seems likely that some patients will develop severe chronic liver disease over the next 10 years." Another contributor said "it is in 10 years time that we shall see the problems. Bearing in mind the proportion of the patients that are infected, or have persistent abnormal liver function tests, anything from 60 to 80 per cent, it will be an enormous problem when it happens." Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 pp15-16, p34 PRSE0000642, Forbes and Lowe Unresolved problems in Haemophilia 1982 p19, p58 RLIT0001242

Review of Documentation Related to the Safety of Blood Products: 1970-1985 16 August 2006 p1 DHSC0004232 059

Notes of Project Board meeting 5 September 2006 p1 WITN7269005

<sup>833</sup> Letter from Caroline Flint to Margaret Unwin 31 October 2006 p1 ARCH0002323

Memo from William Connon to Chief Medical Officer 4 December 2006 p5 DHSC5069877. The same phrase is in an undated draft submission referred to in Linda Page's statement. Memo from Linda Page to Caroline Flint and Lord Warner p5 DHSC5228443, Written Statement of Linda Page para 2.82 WITN7269001

In her statement Linda Page has suggested that the letter to the Haemophilia Society "provided an explanation that put Dr Walford's comments in context" and that she probably concluded that they were consistent with the conclusion in the report.835 However, the difficulty with the explanation that the Department of Health came up with is threefold.836 Firstly, it is inconsistent with the terms of the minute itself, in which Dr Walford was at pains to emphasise the seriousness of non-A non-B Hepatitis in the context of the production of blood products and the potential take over of BPL by industry. Secondly, it offers an explanation for only one part of Dr Walford's minute (her reference to rapid fatality): her reference to progressive liver damage was equally, if not more, significant and is simply glossed over. Thirdly, it does not appear that anyone thought to ask Dr Walford herself what had underpinned her thinking.837 Had they done so, no doubt she would have told the Department of Health what she told the Inquiry: that she had a sense that not everyone within the Department of Health and Social Security ("DHSS") was as conscious as she was that non-A non-B Hepatitis could potentially give rise to severe chronic disease, that this was one of the reasons she spoke about it "really quite forcibly" in her minute and also why she deliberately copied it "pretty widely" to others more senior within the DHSS.838

When asked whether, in his view, the review fulfilled its objective, in his written evidence to the Inquiry Sir Hugh Taylor states that it:

"could be said to have met its, inevitably limited, objectives. However, reflecting on this question now, there is a limit to how far an internal Departmental review of this kind was likely to assuage public concern, given its limitations. The review rehearsed rather than re-examined the Department's previous analysis of the history, which the new documentation did not appear to undermine, but which was still being challenged by campaigners. It was not resourced to put the original decision making on these issues under the microscope in the way that, given the passage of time that had already elapsed, only a statutory inquiry with the power to call witnesses and with the resources and expertise to apply an objective forensic analysis to the evidence could do." 839

I agree with these observations, which, coupled with both the review's limited scope and its flawed approach (as described above) meant that it did not provide the assessment of the evidence relating to previous government policy on the safe use of imported and domestic blood products with a view to making "recommendations on future handling in the light of

Written Statement of Linda Page para 2.84 WITN7269001. And see: Review of Documentation Relating to the Safety of Blood Products between 1970-1985 (Non A Non B Hepatitis) May 2007 p14 PRSE0000642

The documents indicate that it was others in the Department of Health and not Linda Page who came up with this explanation.

Although Dr Walford no longer worked at the Department of Health by this time, she was the principal of Mansfield College, Oxford, and would have been readily traceable.

<sup>838</sup> Dr Diana Walford Transcript 19 July 2021 pp109-113 INQY1000136

<sup>839</sup> Written Statement of Sir Hugh Taylor para 4.17 WITN7498001

public interest requirements" – which was what had led to the review being conducted.<sup>840</sup> This suggests it was meant to play a part in Government decision-making about an inquiry. However, the evidence of the Permanent Secretary of the Department of Health at the time, Sir Hugh Taylor, was that he doubted (from the documents he had seen) that the document review itself was a significant factor in the Government's stance on the issue of a public inquiry, though he qualified this by saying: "although as I have said I was never close to Ministerial thinking on this at the time." <sup>841</sup>

Certainly, as it stood, it should never have been relied on as a reason not to hold a public inquiry (if it was), though perhaps the more important point is that if it had, for instance, drawn attention more accurately to the risks of which Dr Walford spoke, rather than attempt to explain them away, and had focussed upon the worrying prediction made at the Glasgow symposium which had been shown over the time since to have been well-founded, it would actually have provided material that would have been persuasive toward having an inquiry. The opportunity (if it truly was one) was missed.

# **Engagement with the Archer Inquiry**

On 16 February 2007, Lord Peter Archer wrote to the Secretary of State for Health, Patricia Hewitt, informing her that he had agreed to chair an independent inquiry. He asked "if someone from the Department can be available, on a mutually agreed date, to say what its position has been and is; and to lay before us any further facts, of which you think we should be aware." William Connon was anxious that "we do not become involved in an inquiry 'through the back door' given that ministers across the UK have consistently declined requests for an inquiry." He considered that, given the Department of Health's stance that an inquiry was not required, "it would be difficult to justify becoming involved in any form of inquiry." He suggested sending a copy of the Page report to Lord Archer and that, together with the release of as many documents as they could, would mean "we have done all we can." Advice from Jonathan Stopes-Roe, head of strategy and legislation, suggested that "MS(PH) [Minister of State for Public Health] should offer to meet Lord Archer in due course, if he would care to call" and "no-one from DH should attend as a 'witness'". Advice is

<sup>840</sup> Job/Project Task Description on Blood Safety: Haemophiliacs Infected with HIV and Hepatitis C WITN7269003

Written Statement of Sir Hugh Taylor para 4.18 WITN7498001

<sup>842</sup> Letter from Lord Archer to Patricia Hewitt 16 February 2007 DHSC0041193\_056

Email chain between Michelle Lucas, William Connon and others 19 February 2007 p4 DHSC6700786. His views were further apparent from an email, in which he emphasised that "we have certainly not agreed to cooperate with the Inquiry. The UK has always maintained that there is no need for an inquiry therefore to 'cooperate' with this one, particularly when the terms of reference, status and funding are far from clear, could be misinterpreted. It could also lead to difficulties once the inquiry reports if the recommendations were to be critical of Government. This is the line we are planning to take". Email from William Connon to John Brunton and others 20 February 2007 p2 DHSC5458301

<sup>844</sup> Email from William Connon to Simon Rodgers and others 20 February 2007 DHSC5264793

Email from Jonathan Stopes-Roe to William Connon and others 20 February 2007 p2 DHSC5458185, responding to: Email chain between Michelle Lucas, William Connon and others 19 February 2007 DHSC6700786

that we should not become involved in Lord Archer's Inquiry at all" and "I would not advise that we make any contact with those launching the inquiry to request further details."846

Caroline Flint's view was that "not co-operating in any way was not sustainable and DH needed to strike a balance in how involved it should become in the inquiry."847 On 21 March 2007, the Secretary of State, Caroline Flint and the special advisors met to discuss how to respond to Lord Archer's request for cooperation. They considered that "the response needs to be more cooperative regarding the inquiry and officials should give evidence and papers should be made available."848 This stance was challenged by William Connon: "by cooperating with the Inquiry the department and ministers will be in a potentially very difficult situation if the Inquiry concludes that the Government of the day or the department was in any way at fault."849 These concerns were reiterated in a minute from Elizabeth Woodeson to Hugh Taylor and she sought agreement that the reply to Lord Archer would not include an offer for officials to give evidence. Her draft reply offered for officials to meet with members of the Inquiry team "to discuss the exact terms of your Inquiry in more detail and identify how the department may be able to assist you."850

By way of comment, the stance articulated by William Connon (that co-operating could create difficulties if the Inquiry concludes that either the government of the day "or the department" was in any way at fault) demonstrates why an independent inquiry, capable of hearing all sides of a question, and reaching an objective conclusion was needed, for his stance was effectively one which was not prepared to contemplate fault. The way to deal with shortcomings, whether governmental or personal, must be to be prepared to acknowledge them, apologise where needed, and rectify them. This stance was the opposite. The possibility that there may have been shortcomings was the basis for the Archer Inquiry; rather than government being embarrassed by the true facts (whatever they were or are) being revealed, the establishment of an objective truth should be welcomed by a body with the public interest at heart. This stance took the opposite view.

The submission that went to Caroline Flint from William Connon did offer a meeting with officials. It also set out the reasons why officials should not give evidence including the "considerable scope for embarrassment" in relation to document destruction, the lack of clear legal framework for the Inquiry, the "vast amount of preparation that would be required", the possibility that ministers might be asked to give evidence, that inevitably there would be pressure to "release documents without any redaction – and to release submissions" and "While none of these policy documents gives rise to any real concerns over liability, some

<sup>846</sup> Email from William Connon to Jacky Buchan and others 21 February 2007 pp2-3 DHSC5460426

<sup>847</sup> Written Statement of Caroline Flint para 3,236 WITN5427001

Email from Jacky Buchan to William Connon and others 21 March 2007 p2 DHSC5463411, Email from Dani Lee to Jacky Buchan 14 March 2007 WITN5427017

<sup>849</sup> Email from William Connon to Elizabeth Woodeson 22 March 2007 p1 DHSC5463453

Memo from Elizabeth Woodeson to Hugh Taylor 23 March 2007 p3 DHSC5046267. Hugh Taylor agreed with Elizabeth Woodeson's stance. Email from Gregory Hartwell to William Connon and others 26 March 2007 p1 DHSC6510543

are sensitive in respect of potential for criticism or embarrassment of former ministers and senior officials."851 None of these amounted to good reasons.

On 30 March 2007, the Secretary of State for Health responded to Lord Archer's initial letter requesting cooperation with the Inquiry, offering a meeting with officials and provision of the Page report once completed.<sup>852</sup>

On 25 April 2007, officials from the Department of Health met Lords Archer and Leslie Turnberg and Judith Willets and others from the Inquiry team. William Connon wrote afterwards that the meeting went well and that "It has not been agreed that DH will appear before the inquiry but ministers are keen that we are as helpful as possible, without actually participating in the inquiry."853 What was said to be a chronology on screening was sent to the Archer Inquiry on 10 May 2007 and the Inquiry team was directed towards the NHS Blood and Transplant ("NHSBT") website for further information.854 The Page report and supporting references were later provided.855

- 851 Memo from William Connon to Caroline Flint and others 28 March 2007 DHSC0041307\_142. His concerns were said mainly to "arise from the suggestion that officials should agree to appear as witnesses." The reasons were that:
  - "• There is no evidence of any negligence or wrongdoing on the part of the department during the period in question (1970-1985). Nevertheless, given the subsequent destruction and loss of a number of files there is considerable scope for embarrassment for the department if officials are asked to appear before the inquiry.
  - With official Government Inquiries there is a clear legal framework under which to operate in the case of an inquiry under the Inquiries Act 2005 and in the case of non-statutory inquiries there are established principles and guidelines. These would not apply to a non-government inquiry such as Lord Archer's one and it is unclear exactly what departmental involvement may entail. For example, would officials be asked to attend?
  - Colleagues are also naturally worried about the vast amount of preparation that would be required to prepare themselves if they were called to give evidence and answer questions about over 6000 documents.
  - If it is agreed that officials should give evidence, this may in turn raise the possibility of ministers themselves being asked to give evidence.
  - We will inevitably be pressed to release documents without any redaction and to release submissions. While none of these policy documents gives rise to any real concerns over liability, some are sensitive in respect of potential for criticism or embarrassment of former ministers and senior officials. It may be much harder to maintain the line that we are only prepared to release documents under FOI principles if officials are asked to defend this line publicly in front of the inquiry.
  - Sol have pointed out that the inquiry will not have any statutory powers therefore civil servants, ministers or others could not be compelled to attend or provide evidence. However, if it is suggested that they should do so, then no doubt the inquiry would draw adverse inferences from any refusal to do so.
  - There is also a question whether the inquiry would offer legal indemnities to officials against the possibility of legal proceedings being instituted against them as a result of their evidence to the inquiry.
  - Sol's view is that we should avoid becoming in any way directly involved." Memo from William Connon to Caroline Flint and others 28 March 2007 pp2-3 DHSC0041307\_142
- 852 Letter from Patricia Hewitt to Lord Archer 30 March 2007 DHSC0041193 048
- 853 Email from William Connon to Terry Male and others 26 April 2007 p2 DHSC5469319
- 854 Email from William Connon to Vijay Mehan and others 10 May 2007 pp2-3 DHSC5472679. The "chronology" provided merely gave the dates on which certain tests of blood donations were introduced. Chronology on Testing of UK Blood Donors for Evidence of Transfusion-Transmissible Infections DHSC5471708
- These were released between June and October 2007. Email from Linda Page to Vijay Mehan and others 15 June 2007 p1 DHSC5477388, Email from Patrick Hennessy to Vijay Mehan and others 25 October 2007 DHSC5493642

Alan Johnson, who was now Secretary of State for Health, was briefed ahead of an appearance at the Health Select Committee in July 2007. His briefing included that "Officials have advised, following advice from SOL, that … any direct involvement of the Department with the current independent and private inquiry would be inappropriate and undesirable."

On 19 September 2007, a meeting between the Archer team and the NHSBT took place. Before the meeting, the secretary to the Archer Inquiry, Vijay Mehan, informed Lord Archer and Judith Willetts that he had "tried to put [the Department of Health] off inviting [William Connon] along, as he probably is the clog in the wheels ... we have met with Mr Connon before and although he did not come across as particularly obstructive, he was not exactly forthcoming with offers of help."857 At the meeting, it appears that William Connon agreed to "clarify the position regarding Government policy and funding of the initiative to become self-sufficient in blood products in the 1970's." However, after the meeting he simply directed the Inquiry to the self-sufficiency report, which Vijay Mehan described as "Getting easy information out of [William Connon] is like getting blood out of a stone."858

On 8 May 2008 in emails concerning a request from the Archer Inquiry to meet with officials because "Lord Archer has a list of questions, which he would like to put to the department/NHSBT, before publishing his final report", William Connon felt that "we should try and discourage the Archer Team from entering into further, detailed discussions about the issues, at this late stage (eg BPL). There are clearly some questions outstanding and I have already asked Mr Mehan to submit these questions, in advance of the meeting. This should minimise detailed discussions about minutiae, on the day and allow for a more structured discussion on 'where next, when and the impact of the Scottish inquiry'."859 When the questions were received, officials were critical of them and the apparent lack of knowledge of the Archer Inquiry team and this criticism was repeated after the meeting with the team on 12 June 2008.860

It is clear that the Department of Health was at pains to distance itself from, and avoid endorsing, Lord Archer's Inquiry. It provided documents but not full access to the departmental

Written Statement of Alan Johnson para 2.7 WITN7197001. Alan Johnson was Secretary of State for Health from June 2007 to June 2009.

<sup>857</sup> Email from Vijay Mehan to Judith Willetts and others 12 September 2007 ARCH0001026. For a period of 10 days from the end of July to early August 2007, letters were sent out to MPs and individuals from the DH that appeared to suggest that the Archer Inquiry had ignored requests by the DH for a meeting. Letter from Morven Smith to Anon 14 August 2007 HSOC0013877. The Archer Inquiry team objected to this as no meetings had been requested by the Department. Letter from Lord Archer to William Connon 4 September 2007 ARCH0001628. Clarification letters were subsequently issued in November 2007, following an explanation in answer to a question from Lord Patrick Jenkin. Lord Ara Darzi's Response to parliamentary question from Lord Jenkin 23 October 2007 HSOC0012728\_007, Email chain between Patrick Hennessy and Julia Scott and others 20 November 2007 DHSC6615818

<sup>858</sup> Email from Vijay Mehan to Lord Archer 20 September 2007 p1 ARCH0000787

<sup>859</sup> Email from William Connon to Patrick Hennessy and others 8 May 2008 p5, p1 DHSC5518489

Email from William Connon to Patrick Hennessy and others 10 June 2008 p1 DHSC5524730, Email from William Connon to Dr Wight and others 17 June 2008 pp1-2 DHSC5526400, Questions to Blood Transfusion Service from Lord Archer 6 June 2008 ARCH0000841

files.861 No consideration was given to the need for the inquiry to have access to as much information as it required to understand how events unfolded. The Department of Health did not offer witnesses or waive legal professional privilege. Further, as the Department of Health well knew, the Archer Inquiry lacked the powers available to a statutory inquiry, or the resources necessary to conduct a full investigation. As a result its conclusions were always likely to fall short of a full picture of what had happened, and why. Reflecting on the extent of the Government's engagement with the Archer Inquiry, Alan Johnson accepted "that it would have been theoretically open to me (as the new Secretary of State) to change our approach to the Archer Inquiry. In practice, however, the approach of co-operating with the Inquiry by providing the relevant historic documents did not strike me as inappropriate. Nor have I seen any submission to me positively suggesting that a change of approach might be advisable."862 However, the problem with the departmental response was that everything was viewed from the perspective of what impact there might be on the Department of Health and its officials, and not from the perspective of those who had been infected and their families and their need for answers. In short, the Department of Health's engagement with the Archer Inquiry was both disappointing and inadequate, and (in its apparent concern to avoid a position in which uncomfortable but accurate facts might be revealed) troubling.

Whilst the Department of Health's line remained firmly that no public inquiry was warranted, the new Scottish Government's position in line with their manifesto commitment was "that a public inquiry is the best way forward". 863 At a meeting between the Scottish Executive and the Scottish Haemophilia Forum in August 2007, it was confirmed that a separate Scottish inquiry would be held, but that "the right thing to do was to wait for the outcome of the Archer Inquiry, before deciding what still needed to be done in instigating a properly focused Scottish inquiry."864

# **Establishment of the Penrose Inquiry**

The inquiry in Scotland that became known as the Penrose Inquiry was formally announced on 23 April 2008.865

- The Department of Health ultimately shared over 5,000 documents from the period 1970-1985, linked to the release of the documents from the Self-Sufficiency Report (for which see the chapter on the Self-Sufficiency Report) and Linda Page's further Review. Memo from Linda Page to Jacky Buchan 13 June 2007 DHSC6341171, Letter from Dawn Primarolo to Lord Archer
  - 7 April 2009 ARCH0000061. After the Archer Inquiry published its report, the Department of Health undertook a further review. Lord Archer thanked the Department of Health for "trying to ensure that as much information as possible is in the public domain." Email from Morven Smith to Marc McGonagle 3 March 2009 DHSC6120809, 23 April 2009 Letter from Lord Archer to Dawn Primarolo DHSC0041240\_082
- He explained that the Departmental approach had already been established when he became Secretary of State in June 2007. Written Statement of Alan Johnson para 2.5, para 2.10 WITN7197001
- Letter from John Brunton to William Wright 21 June 2007 WITN2287064, Note of meeting between Scottish Executive, Philip Dolan and others 16 August 2007 p2 DHSC5221267
- Note of meeting between Scottish Executive, Philip Dolan and others 16 August 2007 p2 DHSC5221267
- Scottish Government Press Release Scottish Government confirms Inquiry for those infected with Hepatitis C and HIV through NHS Treatment with blood and blood products in Scotland 23 April 2008 MACK0001174, Statement by Nicola Sturgeon to Scottish Parliament 23 April

The Department of Health had been informed of the intention to establish an inquiry in Scotland and on 28 February 2008 Dr Ailsa Wight set out a variety of options "in order of commitment":

- "- watch events in Scotland, with many of our documents already in the public domain (but can we pass those that aren't eg on HIV to Scotland, if they are ours, or do we have to go through them ourselves?)
- co-operate in the low key way we have with Archer (paper evidence only to the inquiry, working closely with the Scottish Gov)
- acknowledge from the start that we would consider whatever recommendations come out to apply to us as well
- actively sign up to the Inquiry (which is likely to commit us to oral evidence and which also as it is a different Gov may not be what our ministers wish)" 866

The decision of the Minister, Dawn Primarolo, was "for now we should hold our line. We are not to join Scottish Enquiry. Officials must keep events under close scrutiny – and report back regularly so that I can keep our position under review." In a further submission on 28 March 2008, the Minister was advised "maintain the position that an inquiry in England is unnecessary"; the advantages and disadvantages of joining and staying out of the Scottish inquiry were outlined, with a summary given that:

- "The very limited advantage of joining does not justify the considerable disadvantages, including:
- Loss of control on whether and how to give evidence.
- Fewer option [sic] in terms of policy on final recommendations.
- Cost." 868

2008 MACK0001175. On 5 February 2008, the Court of Session had quashed the decisions of the Lord Advocate and of Scottish ministers refusing to hold Fatal Accident Inquiries: it was held that they had acted in a manner incompatible with the European Convention rights of the deceased. Petitions seeking judicial review of these decisions had been raised by the relatives of two people who had died following infection with Hepatitis C. Opinion of Lord Donald Mackayon petitions by Anon and Anon for judicial review of Lord Advocate and Scottish Ministers decisions 5 February 2008 DHSC5040661

866 Email from Dr Wight to Patrick Hennessy and others 28 February 2008 p2 DHSC5508756

Email from Patrick Hennessy to Zubeda Seedat 13 March 2008 DHSC5510515

868 Memo from Patrick Hennessy to Hugh Taylor and the Minister of State for Public Health 28 March 2008 pp3-4 DHSC5003293

Emphasis in the original. Note from Dawn Primarolo to Ian Bishop 13 March 2008 WITN5494020. Her reasoning for keeping the matter under review was that "At this point I needed to be sure that none of the reasons previously given by the Government for not holding a Public Inquiry had changed as a result of new relevant information becoming available." Though she was a Minister who probed the advice she was given, she said that: "as the Minister I was caught between arguments which were said to justify a public inquiry and my Department's rebuttal of those arguments, without (as it seems to me now) an adequate tool and means to identify objectively whether the threshold for calling a public inquiry was met." Written Statement of Baroness Dawn Primarolo paras 3.35, 5.14, 5.16 and 5.19 WITN5494001

This was broadly the line to take throughout the Penrose Inquiry.869

Throughout the Penrose Inquiry, the campaign for a public inquiry in England did not cease. The Department of Health's position remained that no public inquiry was required.<sup>870</sup>

# Response to the publication of the Penrose report in March 2015

Campaigners continued to press for a UK-wide inquiry. In February 2014 a submission to the Prime Minister, David Cameron, from his senior special adviser on health, Nick Seddon, referred to the continuing pressure and advised that "Doing nothing is no longer an option." The "next moment to do something" would be when the Penrose Inquiry reported.<sup>871</sup> The submission explained that "The victims are seeking some form of truth-revealing exercise because they believe that DH is yet to tell the full story, followed by an apology." Reference was made to the Archer and Penrose Inquiries: "Neither were full Public Inquiries and no DH officials have submitted themselves for questioning. However, all papers from this period have been published (>5,000 documents up to 1985), and, without a Public Inquiry that compels ex-officials to submit to questioning, progress here is unlikely."<sup>872</sup>

Nick Seddon advised that there was probably little to be gained from a new inquiry. The central parts of this advice were:

"**To recap:** The NHS introduced blood screening tests for blood transfusions when sensitive and reliable tests became available; this was in 1985 for HIV, and in 1991 for hepatitis C. Before these tests were introduced, however, thousands of NHS patients were exposed to Hep C and HIV infections ...

#### 869 The line to take collated in November 2008 was:

- "The decision to convene an inquiry was a decision by the Scottish Government in response to a judicial decision that applied to Scotland and not to the rest of the UK. In line with the Inquiries Act, it must be confined to Scottish matters.
- The Department has said that it will aim to be helpful to the Scottish inquiry, e.g., by making relevant documentation available, where this is not already in the public domain. However, we do not accept that the inquiry should be extended to other parts of the UK, and will contest any attempt to do so.
- As we have previously stated, we have great sympathy for those affected, but the Government, as
  with previous administrations, sees no justification for a public inquiry into these matters in England
  after all this time.
- The facts are known and measures have been in place to deal with the risks of contamination by HIV or Hepatitis C for many years (screening for HIV and heat-treatment of blood products since 1985, and screening for hepatitis C since 1991). Ex gratia payment schemes for those affected are in place.
- More than 5000 relevant official documents on this subject were released in line with FOI in 2007. There is no significant new information to be gleaned from an inquiry.
- The Government believes that the significant costs which an inquiry in England would involve should be directed at providing health care and not diverted to an unnecessary inquiry."

Public Inquiry in Scotland into Contamination of NHS Blood and Blood Products: Lines to take on the inquiry and on current actions on Hepatitis C 20 November 2008 pp2-3 DHSC0041307\_111

- 870 House of Commons debate on Hepatitis C 29 March 2013 RLIT0001612
- Anticipated in the submission to be April/May 2014.
- 872 Memo from Nick Seddon to David Cameron 6 February 2014 p3 WITN3903009, Written Statement of Lord Cameron para 33 WITN3903007

Liability has never been established or accepted. Haemophilia patients initiated litigation against the Government over HIV infections in the late 1980s, which was settled out-of-court in 1991; we have paid out to all those eligible. We have never been taken to court over the Hep C infections and have no similar out-of-court settlement to cover these infections; this indicates that legal advice to the claimants has been that they would be unlikely to win ...

There is probably little to be gained from a new Inquiry. All the papers are published, it is not clear that the government was substantially at fault (if it was then we would have been successfully sued) and all the lessons were learnt years ago." 873

These do not stand up as good reasons. "*All*" the papers were not published (and, as the submission itself acknowledged, Department of Health officials had never been questioned). The judgment in *A and Others v National Blood Authority* held that blood screening tests should have been introduced earlier than they were, so it was wrong to say they were introduced "*when available*".<sup>874</sup> The assertion that the absence of successful litigation meant that the government could not have been substantially at fault lacked logic and insight,<sup>875</sup> considered neither the case of *A and Others v National Blood Authority* (in which the blood services had been taken to court over Hepatitis C and had lost) nor the judicial review Andrew March brought<sup>876</sup> and failed to recognise that it may only be through an inquiry that the presence or absence of fault is established. So far as Hepatitis C was concerned, it took no account of the fact that the waiver anyone wishing to benefit from the Macfarlane Trust following infection with HIV in England or Wales had to sign precluded legal action. The belief that lessons had been learnt years ago was also facile: without identifying where things have gone wrong – one of the central purposes of an inquiry – it cannot sensibly be concluded that lessons have been learnt.<sup>877</sup>

On 25 March 2015, the Penrose Inquiry report was published.<sup>878</sup> It is no part of this Inquiry's role to review the conclusions of the Penrose Inquiry. This Inquiry has a wider geographical remit, different terms of reference, and documents and evidence that were not available to the Penrose Inquiry.

On the same day the Prime Minister, David Cameron, gave an apology:

"While it will be for the next Government to take account of these findings, it is right that we use this moment to recognise the pain and suffering experienced by

<sup>873</sup> Memo from Nick Seddon to David Cameron 6 February 2014 pp2-3 WITN3903009

<sup>874</sup> Implying "as soon as". *A and Others v National Blood Authority* Judgment 26 March 2001 para 172 PRSE0003333

There may be a number of reasons why a government is not successfully sued: the costs of attempting to do so may be prohibitive; legal defences may be available that are not to be equated with an absence of fault; the poor health of those who would otherwise sue may also be a factor.

<sup>876</sup> R (March) v Secretary of State for Health Judgment 16 April 2010 DHSC0003819 011

Lessons could possibly have been learnt another way, but it seems unlikely that the author could have pointed to any.

<sup>878</sup> The Penrose Inquiry Final Report March 2015 PRSE0007002

people as a result of this tragedy. It is difficult to imagine the feelings of unfairness that people must feel at being infected with something like hepatitis C or HIV as a result of a totally unrelated treatment within the NHS. To each and every one of those people, I would like to say sorry on behalf of the Government for something that should not have happened." 879

The Secretary of State for Health, Jeremy Hunt, laid a written ministerial statement as an interim response to the report. In Parliament on 26 March 2015, Andy Burnham stated: "The 2010 to 2015 Parliament will be remembered for some extraordinary work to right historical wrong—on Bloody Sunday, on Hillsborough, on child abuse—but as it comes to an end this Parliament has not made enough progress on perhaps the greatest injustice of them all: the loss and ruination of many thousands of lives through the use of contaminated blood." He asked for "a further process of Inquiry in the next Parliament". Jane Ellison, Parliamentary Under-Secretary of State for Public Health, replied that: "The Government's initial reaction is that another inquiry would not be in the best interests of sufferers and their families as it would further delay action to address their concerns. The strong message I have had is that it is time for action".881

Reflecting on this period in his statement to the Inquiry, Andy Burnham states: "It is clear from my speech that I believed that the Penrose Inquiry had left many questions unanswered and that far more needed to be done for those affected by contaminated blood". 882

Jeremy Hunt, who was Secretary of State for Health between 2012 and 2018, told the Inquiry that it was made clear to him when he became Secretary of State for Health that "the Treasury would not support an inquiry because of the potential cost to the taxpayer which (taking into account any decisions on financial support which might follow, such as a recommendation for a compensation scheme similar to that in place in Ireland) could amount to billions of pounds." He did not therefore pursue the issue and followed the official Government "line" in correspondence with all campaigners. He wrote to the Prime Minister on 30 June 2015: "Should there be calls for a further inquiry in England, I recommend that they be rejected, as all our documentary evidence will be in the public domain very shortly, and further inquiries would hinder scheme reform."884

#### 2016 - 2017

In response to a written parliamentary question from Stephen Kinnock MP in January 2016, asking "the Secretary of State for Health, if he will commission an inquiry into contaminated blood in England and Wales", Jane Ellison pointed to "the thoroughness of Lord [George]

<sup>879</sup> Email from Naomi Balabanoff to Dr Rowena Jecock and others 25 March 2015 pp1-2 DHNI0000703, Written Statement of David Cameron para 5 WITN3903001

<sup>880</sup> Written Ministerial Statement on Infected Blood 25 March 2015 MACF0000022 045

House of Commons debate on Penrose 26 March 2015 pp3-4 RCPE0000281\_011

Written Statement of Andy Burnham para 20.4 WITN7060001

Written Statement of Jeremy Hunt paras 0.4-0.5 WITN3499001

<sup>884</sup> Letter from Jeremy Hunt to David Cameron 30 June 2015 p4 CABO0000163 003

Penrose's report" and explained that "our view remains that there is no need for a further public inquiry in England." Another inquiry was said not to be in the best interests of sufferers and their families "as it would be costly and further delay action to address their concerns and significantly delay plans to reform existing payment support schemes."885

During Prime Minister's Questions on 14 September 2016, Diana Johnson asked for a "review" similar to the Hillsborough Independent Panel. Theresa May responded that she would "take it away and consider it." On 30 September the Prime Minister responded by declining to hold an inquiry. It was said that "Lord Archer of Sandwell and Lord Penrose have already separately undertaken thorough, independent inquiries within the last decade. Neither inquiry found the governments of the day to have been at fault and did not apportion blame." The relevant documents were said to have been published on the Department of Health and the National Archive websites and it was unlikely that a public inquiry would provide further information. "Given all of this, the Government does not believe that another inquiry would be in the best interests of sufferers and their families as it would further delay action to address their concerns, and would curtail plans to reform the existing support schemes." 887

In response to a further push from Diana Johnson for an independent panel, Jeremy Hunt suggested that an independent panel would not add to current knowledge about how infections happened or the steps taken to deal with the problem, and reiterated the line that this would "detract from the work we are doing to support sufferers and their families."888 He told this Inquiry that he "had to defend the public 'line', even though it did not reflect how I felt personally about the importance of improving support offered to victims of the scandal, something most likely to be achieved by a public inquiry."889 He reiterated that it had been made clear to him that "the Treasury would not accept a public inquiry in any circumstances, because of the risk it would recommend a multi-billion pound settlement."890

On 25 April 2017, Andy Burnham made his final speech in the House of Commons and used it as an opportunity to call for a public inquiry, stating: "this is a speech made with a sense of guilt in that all of us here are collectively culpable of failing to act on evidence that is there before us if only we cared to look and, by extent, failing thousands of our fellow citizens who are the victims of perhaps the greatest untold injustice in the history of this country." 891

<sup>885</sup> Hansard written answer on Blood Contamination 22 January 2016 RLIT0002231

<sup>886</sup> Contaminated Blood Campaign parliamentary actions 2010-2020 p3 WITN2050081

<sup>887</sup> Letter from the Prime Minister to Diana Johnson 30 September 2016 p1 HSOC0029779

Letter from Diana Johnson to Theresa May 12 October 2016 HSOC0029780, Letter from Jeremy Hunt to Diana Johnson 10 November 2016 p1 HSOC0029781

Written Statement of Jeremy Hunt para 43.4 WITN3499001

<sup>890</sup> Written Statement of Jeremy Hunt para 42.2 WITN3499001

<sup>891</sup> Hansard parliamentary debate on Contaminated Blood 25 April 2017 p1 RLIT0001578

On 4 July 2017 the *Daily Mail* reported on its front page the Group Litigation Order for which Collins Solicitors had applied as a result of their meeting with Jason Evans at a meeting organised by Andy Burnham in Parliament in January 2017.<sup>892</sup>

On 7 July 2017 the leaders of the six opposition parties wrote to the Prime Minister calling for an inquiry: "it is now time for all political parties to come together, and give those affected by this scandal a basic right they have long been denied: the right to answers."893

Ministers requested further information on the possibility of holding a public inquiry and on 7 July 2017 a submission was sent by the Department of Health's Infected Blood Policy Team.<sup>894</sup> This noted the letter from the leaders of opposition parties had sent a letter to the Prime Minister calling for a public inquiry<sup>895</sup> and that pressure to hold an inquiry had increased because of recent events "including the announced inquiry into the Grenfell Tower fire and recent media articles on infected blood". It concluded with a recommendation that the Government announce its intention to establish an inquiry.<sup>896</sup>

Diana Johnson wrote to the Speaker of the House on 10 July 2017 seeking an emergency debate on an independent public inquiry, which was granted.<sup>897</sup> Given the lack of an overall majority following the recent general election,<sup>898</sup> and the support of other parties for an inquiry, it was, as Jeremy Hunt acknowledged in his evidence to the Inquiry, likely that the Government would lose a vote if the matter was put to the test. Indeed, in pinpointing the turning point for the Government's stance, Jeremy Hunt told the Inquiry that: "I think the real thing that caused, if I can put it this way, the goal to be open, was the threat of losing a vote in Parliament which was subsequent to this when the Speaker said that he would allow a debate. And I think that was really what allowed me to go to Theresa May and say, 'Look, I think this is the right thing to do and this is the moment to do it." <sup>899</sup> He informed the Prime

- 893 Letter from Jeremy Corbyn and others to Theresa May 7 July 2017 WITN2050080
- Written Statement of Jeremy Hunt para 42.3 WITN3499001, Infected blood payment scheme options on additional funding and inquiry 7 July 2017 DHSC0050028
- 895 Letter from Jeremy Corbyn and others to Theresa May 7 July 2017 WITN2050080
- 896 Infected blood payment scheme options on additional funding and inquiry 7 July 2017 p4 DHSC0050028
- 897 Letter from Diana Johnson to John Bercow 10 July 2017 HSOC0029867
- 898 The Government had a confidence and supply agreement with the Democratic Unionist Party of Northern Ireland, but its leader, Nigel Dodds, was a co-signatory to the letter of 7 July calling for an inquiry.
- 899 Jeremy Hunt Transcript 27 July 2022 p131 INQY1000235

Daily Mail Online NHS tainted blood shame: Secret files reveal health bosses knew for FIVE years patients were being infected with deadly contaminated samples 3 July 2017 MDIA0000184 (this is the online copy published the night before); Written Statement of Jason Evans paras 21-24, para 141 WITN1210008. The Daily Mail article made reference to Dr Howard Thomas at the Glasgow symposium of 1980 having predicted an "enormous problem when it happens"; Dr Craske saying at the same meeting that "There is a high risk from the use of Factor VIII or IX concentrate that the patients will contract non-A, non-B hepatitis, and a 20-30 per cent chance of resultant chronic hepatitis"; it alleged that Dr Walford had known of the concerns. These were regarded as significant – and underscores the comment made in the chapter that the document review by Linda Page could have provided earlier persuasive material in favour of an inquiry if the significance of what was being looked at had been fully appreciated.

Minister on 10 July that he was minded to hold an inquiry and sought to consult her.<sup>900</sup> The establishment of this Inquiry was announced on 11 July 2017.<sup>901</sup>

Cabinet Office lines to take following announcement of the Infected Blood Inquiry included:

"Why has the Government changed its mind about holding an inquiry?

- This Government has recognised the concerns that the previous inquiries and release of documents about this tragedy did not go far enough to provide the answers wanted by those affected.
- In light of these concerns, and of reports of new evidence, the Government has decided to set up an independent inquiry."902

The reality, however, is that none of this should have been new to the Government. The concerns expressed in 2017 were largely the same concerns that had been voiced by campaigners and others (including parliamentarians) for the previous two and a half decades.

# The position in Wales

The line to take on a public inquiry in Wales followed that of the Department of Health. Thus, for example, Jane Hutt, Minister for Health and Social Services, responded to a campaigner in February 2000: "I do not believe that a public inquiry at this time would ease the plight of haemophiliacs infected with hepatitis C in this way. The important point now is that they receive the best treatment, advice and support we can provide and current work in these areas outlined below aims to achieve this."903 A letter from an official within the Welsh Health Services Division in August 2000 explained that this decision was made "in consultation with officials and health professionals."904 It is unclear which health professionals had been consulted (or why).

A debate in the Welsh Assembly on 8 March 2001 referred to the ongoing refusal of the Department of Health in Westminster to hold a public inquiry and included a call for a full Health and Social Services investigation into the issues discussed. The response from the Minister was that "I understand that people infected with hepatitis C want to know what happened and why it could not have been prevented. It is a global problem linked to the development of science and technology. It is not confined to the UK or linked to some local

<sup>900</sup> Email from Private Secretary to the Secretary of State for Health to Government officials 10 July 2017 CGRA0001119

<sup>901</sup> Government Press Release PM statement on contaminated blood inquiry 11 July 2017 RLIT0001168

<sup>902</sup> Infected Blood Inquiry - briefing pack p1 DHSC0050189

<sup>903</sup> Letter from Jane Hutt to Jan Wallace 3 February 2000 HSSG0000140\_047. Jane Hutt had been briefed in December 1999 on calls for compensation and a public inquiry. The advice, echoing the line taken by the DH, was that the technology to produce heat-treated products for people with haemophilia in sufficient quantities to prevent infection was not available prior to 1985 and that an inquiry would not "serve any useful purpose to ease the plight of haemophiliacs who have become infected." The line to take more generally was the same as in England: "they received the best available treatment at the time." Memo from Sue Paterson to J Gregory and others 20 December 1999 pp3-4 HSSG0000140\_074, Written Statement of Jane Hutt para 46 WITN7293001

<sup>904</sup> Letter from Sue Paterson to Jan Wallace 25 August 2000 GLEW0000520

breakdown in blood product development. Therefore, a public inquiry would probably not provide a satisfactory answer."905

The view of Jane Hutt was that relevant to any consideration by the Welsh Assembly Government of the case for holding a public inquiry was that events predated devolution and that any public inquiry would need to be a UK inquiry.<sup>906</sup>

On 6 November 2003, Department of Health official David Reay provided a Q&A document to Welsh health official, Caroline Lewis, in advance of a meeting with representatives of Haemophilia Wales.<sup>907</sup> He described it as "our Q&A for 'difficult' questions!" In respect of calls for a public inquiry, it contained the standard line: "The Government does not accept that any wrongful practices were employed and does not consider a public inquiry justified."<sup>908</sup>

In a letter dated 22 December 2004, the Minister for Health and Social Services wrote to campaigner Haydn Lewis, declining the call for a public inquiry, stating "I can fully understand your desire to understand how, in the past, people have come to be infected through NHS blood and blood products and why it could not have been prevented. I am satisfied, however, that all the information available is already in the public domain and that a public inquiry would not provide any additional information. I therefore remain of the view that a public inquiry is not justified."909

A nearly identical line was taken in April 2005 by Brian Gibbons, the Minister for Health and Social Services, when he responded to a request from Assembly Member Jenny Randerson for a public inquiry. He stated that:

"UK health administrations accept that, regrettably, a number of people were infected with HIV and/or Hepatitis C as a result of NHS blood or blood products prior to the development and introduction of viable screening processes to prevent the transmission ... Whilst I can understand why there have been requests for a public inquiry to be held, I am satisfied that all information available is already in the public domain. A public inquiry would therefore not provide any additional information, and I remain of the view that a public inquiry is not justified."

<sup>905</sup> Short debate on Compensation for Haemophiliacs Infected with Hepatitis C 8 March 2001 pp3-4 GLEW0000437\_002. The same statement appeared in a paper prepared for the Health and Social Services Committee for its meeting on 13 March 2002. Paper on Safety of Blood and Blood Products 13 March 2002 p5 GLEW0000568

<sup>906</sup> Written Statement of Jane Hutt paras 47, 49 WITN7293001

<sup>907</sup> Email from David Reay to Caroline Lewis 6 November 2003 p2 DHSC5328404

<sup>908</sup> Hepatitis C Financial Assistance Scheme Q&A p9 SCGV0000256 049

Letter from Jane Hutt to Haydn Lewis 22 December 2004 p2 GLEW0000143, responding to Haydn Lewis' call for a public inquiry: "I personally feel that the death of over 1000 people with Haemophilia which on average works out at one for every week that has passed, deserves a full explanation! Instead we have received vague and unsubstantiated Ministerial comments of 'inadvertent' or some kind of 'systematic failure' ... I would be most grateful if all Assembly members would support our request for a Full Public inquiry into this as yet unexplained tragedy." Letter from Haydn Lewis to Welsh Assembly member 18 November 2004 GLEW0000393. Gaynor Lewis provided an account of her late husband's campaigning. Written Statement of Gaynor Lewis WITN2368019

This was followed by the assertion that the Welsh Assembly Government did not believe that there were any lessons to be learned that had not already been learned and that "None of the available evidence indicates that anyone in Wales acted wrongly in the light of the facts that were available to them at the time."910

A meeting took place between officials of the Department of Health, the Welsh Assembly Government and the Scottish Executive on 17 March 2005, at which William Connon requested that Scottish ministers liaise with ministers and special advisers in the other administrations before any decision was taken to hold a public inquiry.<sup>911</sup>

On 8 February 2006 there was a short debate in the Welsh Assembly on Hepatitis C in which Assembly Member Jocelyn Davies asked if a public inquiry was supported by the Administration. John Griffiths, Deputy Minister with Responsibility for Older People, responded that:

"The Welsh Assembly Government's position has been quite clear on this: it remains our view that there is no need for a public inquiry. All the relevant information on Wales is already in the public domain and has been the subject of reports to the Health and Social Services Committee by the former Minister for Health and Social Services, and ministerial replies to correspondence. The Welsh Assembly Government's view is that there is nothing to be gained from a public inquiry given that all the information is already in the public domain." 912

In spring 2006 Jenny Randerson sought to persuade Caroline Flint that a national inquiry should be held on behalf of some of her constituents. The Minister's response was that "the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified."<sup>913</sup>

Jenny Randerson also posed the question of a public inquiry to Welsh First Minister Rhodri Morgan during a debate in the Welsh Assembly on 3 May 2006. The First Minister appears to have provided a standard response, namely that all relevant information was already in the public domain. Commenting afterwards, she emphasised that, "A public enquiry is the only real way of finding out who knew what ... These are people whose health has been severely restricted through no fault of their own, they deserve a public enquiry, not so we can play the blame game but so they can understand how they were infected which I think is their right."<sup>914</sup>

<sup>910</sup> Letter from Brian Gibbons to Jenny Randerson 11 April 2005 GLEW0000382

<sup>911</sup> Note of DH(E) and Welsh Assembly colleagues meeting 17 March 2005 p2 SCGV0001087\_047. A representative of the DHSS Northern Ireland ("DHSS NI") had been invited but sent his apologies.

<sup>912</sup> Short debate on Hepatitis C - The Forgotten Illness 8 February 2006 p12 MACK0002537

Letter from Jenny Randerson to Caroline Flint 4 April 2006 GLEW0000388\_002, Letter from Caroline Flint to Jenny Randerson 11 May 2006 GLEW0000387. The Minister's letter included the erroneous assertion that donor screening for Hepatitis C could not have been introduced before it was.

<sup>914</sup> Randerson demands public enquiry 3 May 2006 p1 HSOC0003614

On 20 May 2009, the Welsh Minister for Health and Social Services, Edwina Hart, published the Welsh Assembly's response to the Archer Report, coinciding with publication of the UK Government's response.<sup>915</sup>

On 23 October 2013, the Minister for Health and Social Services, Mark Drakeford, met with members of Wales' Cross Party Group on Haemophilia and Contaminated Blood and the Haemophilia Society. Following up on this meeting, he wrote to Assembly Member Julie Morgan, Chair of the Cross Party Group: "I confirmed that Wales would not be holding its own Public Inquiry into contaminated blood given by the NHS to patients. However, I will be discussing the Penrose Report with the Northern Ireland and Scotland Minister when it is published. I will also make a statement for Wales at that time." 916

In the days leading up to publication of the Penrose Report on 25 March 2015, officials within the Department of Health liaised with counterparts in Wales and Northern Ireland in respect of the provisional UK Government response. Jenny Thorne, Head of Healthcare Associated Infections & Blood Safety Branch, Welsh Assembly, shared her Government's proposed lines:

- "Wales will not be holding its own Public Inquiry into NHS supplied contaminated blood/blood products to patients.
- We are keen to learn lessons from Scottish experience so the Penrose Inquiry findings and recommendations will be considered carefully.
- Wales will work closely with the other UK health departments in improving the arrangements to support affected patients." 917

Lynne Kelly, chair of Haemophilia Wales, told the Inquiry that the Welsh Government had been "briefed by Westminster so they didn't feel there was any need for a public inquiry. You know, the usual thing, Archer Inquiry had said there was no fault, there would be no benefit in having another inquiry."918 She described how then there were more and more meetings, with key politicians, who understood the strength of feeling in Wales, heard "the personal stories" and began to "veer away from Westminster." It was, she said, "a battle all the way", culminating in the Welsh Government voting, on 25 January 2017, in favour of a public inquiry - which was "a real breakthrough."919

<sup>915</sup> Written Statement by the Welsh Assembly Government 20 May 2009 GLEW0000328

<sup>916</sup> Letter from Mark Drakeford to Julie Morgan 27 November 2013 p3 WITN3988002

<sup>917</sup> Email from Jenny Thorne to Lynsey Lauder 23 March 2015 p1 DHNI0000697

<sup>918</sup> Lynne Kelly Transcript 10 June 2021 pp82-83 INQY1000127. She described the obstacles faced in campaigning for the Government in Westminster to agree to a public inquiry: "the Government kept saying that there was no fault, and then, when we had the Lindsay Tribunal, obviously in Ireland they compensated on moral grounds, and they took responsibility but the Government changed that line and the Government kept saying that the situation in Ireland was different. Therefore that was repeated and repeated and repeated, so obviously all the civil servants over the years were briefed and everybody kept saying the same thing ... the same was said in Welsh Government. They just repeated the mantra, really, that it was different and there would be no – there was no fault, the circumstances were different." Lynne Kelly Transcript 10 June 2021 p91 INQY1000127

<sup>919</sup> Lynne Kelly Transcript 10 June 2021 pp82-83 INQY1000127

Reflecting that change of position, Vaughan Gething (Cabinet Secretary for Health, Wellbeing and Sport) wrote to Jeremy Hunt on 20 December 2016 in support of the call for a public inquiry. He had met with affected individuals and their families, as well as representatives of Haemophilia Wales and noted that "The families seek closure and clarity about what has happened to them."920

In March 2017, Julie Morgan also wrote to Jeremy Hunt calling for a UK-wide public inquiry. She emphasised that people infected and their families "deserve to have a public inquiry so that they can find out all the answers to their questions, hear the reasons why they have had to suffer for most of their lives, and after all this time finally get an apology and compensation that they so dearly deserve." The Parliamentary Under-Secretary of State for Health, Lord James O'Shaughnessy, replied. Pointing to the "thorough, independent" Archer and Penrose Inquiries, he said that they had not found the Government at the time to be at fault and added that a public inquiry would be unlikely to provide further information and would not be in the best interests of sufferers and their families. 922

Three months later the Government reversed its position.

# The position in Northern Ireland

Such limited evidence as there is indicates that the position in Northern Ireland was to follow the Department of Health line. As campaigner and chair of Haemophilia Northern Ireland Simon Hamilton told the Inquiry, "Our Department of Health would have responded to the guide and direction from central Government, from the Department of Health in England. So that was the process, by and large."923 John Breen, a civil servant in the Health Promotion branch of Department of Health, Social Services and Public Safety for Northern Ireland ("DHSS NI"), described how it was "generally the policy of DHSS NI to follow the lead of the Department of Health in London."924

Campaigners within Northern Ireland pressed for a public inquiry. However the response in 2001 from the Minister of Health, Social Services and Public Safety confirmed that Northern Ireland policy was aligned with Westminster:

- 920 Letter from Vaughan Gething to Jeremy Hunt 20 December 2016 WITN3988003. It is unclear whether this letter received a response from ministers in the DH. Jeremy Hunt's statement explains that "we have been unable to locate the reply that was sent." Written Statement of Jeremy Hunt para 44.3 WITN3499001. Vaughan Gething raised the matter again during a phone call with Lord O'Shaughnessy, the Parliamentary Under-Secretary of State for Health, in March 2017, but the latter was "not in a position to take this forward." Letter from Vaughan Gething to Lord James O'Shaughnessy 23 March 2017 WITN3499031
- 921 Letter from Julie Morgan to Jeremy Hunt 29 March 2017 WITN2438006. In January 2017 a debate had been held at the Welsh Assembly with a unanimous vote from attending Assembly Members for a UK-wide public inquiry. Written Statement of Julie Morgan section 5 para 9 WITN2438001
- 922 Letter from Lord O'Shaughnessy to Julie Morgan 21 April 2017 p3 WITN2438007
- 923 Simon Hamilton Transcript 10 June 2021 p88 INQY1000127
- 924 Written Statement of John Breen para 14.1 WITN7515001
- 925 See for example the letter to Members of the Legislative Assembly ("MLAs") asking for support for the Haemophilia Society's Carpet of Lilies Campaign and pressing for a public inquiry. Letter from Anon to Pat Doherty August 2001 DHNI0000038 025. A position paper produced by Haemophilia

"As regards a public enquiry, you will be aware that on this issue, as on many others related to past events, the Health and Personal Social Services (HPSS) here acted as one with the Health Service in England, Scotland and Wales. The matter of a public enquiry into the infection of Haemophilia patients has been raised with the Department of Health, London (DoH(L)) who do not accept that there is a need for one ... The information on research into Hepatitis C and the inactivation of the virus in blood is already in the public domain and the Health Departments generally are satisfied that a public enquiry would not add to what is already well established. I will however continue to monitor any developments on this front." 926

Following publication of the Archer report in February 2009, it is apparent from a submission from civil servants in Northern Ireland to the Health Minister that the Department of Health in Westminster sought supporting statements from each devolved administration.<sup>927</sup>

In the aftermath of the Penrose Inquiry, Simon Hamilton whose belief "the Penrose Inquiry was a whitewash is one that is shared by many victims and their families", 928 wrote to Members of the Legislative Assembly and Northern Irish MPs; he felt that "lobbying for a national inquiry and parity was the only way forward after Penrose." 929 A response from the Northern Ireland Health Minister "indicated that the NI Department of Health would take its lead from the English Department." 930

Simon Hamilton died during the completion of this Report. He told the Inquiry:

"I have received many assurances of support and commitment from ministers, letters of assurance from Prime Ministers and written and verbal assurances of progress from civil servants. In summary, this has not been matched by action ... There are no champions in government who care sufficiently to address the wrongs of the past and present." 931

Northern Ireland explains that prior to the establishment of the Northern Ireland Assembly, people with haemophilia in Northern Ireland had relied on the Haemophilia Society for advocacy, but that this position changed over time. Haemophilia Northern Ireland Position paper to the UK Contaminated Blood Inquiry p11 WITN2339023

Letter from Bairbre de Brún to Pat Doherty p2 DHNI0000038\_023. Virtually identical letters were sent to other MLAs who had raised the question of an inquiry. Letter from Bairbre de Brún to Councillor Eamonn O'Neill October 2001 DHNI0000038\_010, Letter from Bairbre de Brún to Alex Attwood DHNI0000038\_012

<sup>927</sup> Memo from Seamus Camplisson to Andrew Elliott and Michael McGimpsey 21 May 2009 p1 DHNI0000292

<sup>928</sup> Written Statement of Simon Hamilton section 2 para 7 WITN2339012

<sup>929</sup> Written Statement of SImon Hamilton section 3 para 4 WITN2339012

<sup>930</sup> Haemophilia Northern Ireland Position paper to the UK Contaminated Blood Inquiry p12 WITN2339023

<sup>931</sup> Written Statement of Simon Hamilton p28 WITN2339012

# Commentary

In 2000 Carol Grayson wrote this in a letter to the British Medical Journal "Haemophiliacs ... want their day of justice ... part of the psychological healing process is coming to terms with the truth about what has occurred. Haemophiliacs are unable to move on with what is left of their lives until this happens in an official capacity such as a public inquiry. It has been left up to haemophiliacs and their families to dig for that truth largely unsupported." She told the Inquiry in her oral evidence about the importance of people knowing the truth, knowing what had happened to them, knowing why it had happened to them, knowing what their doctors' participation, knowledge, involvement had been. 933

Gareth Lewis stated in an address to the Welsh Assembly "Haemophiliacs in Wales, want their day of justice ... Haemophiliacs are unable to move on with what is left of their lives until this happens in an official capacity such as a public inquiry." <sup>934</sup>

One man infected from a transfusion following a road traffic accident in 1982 but not diagnosed with Hepatitis C until 2007 told the Inquiry: "It is a travesty that an inquiry has not been held before now ... There has to be accountability." <sup>935</sup>

Sue Threakall said to this Inquiry "We will only be able to move on and truly live our lives when we know the truth has come out and everything possible has been done to address this catastrophe ... If anyone had told me in 1985 that I would still be campaigning in 2019 more than 34 years later I would probably have said they were stark raving mad. That I am still campaigning demonstrates to me that there is something fundamentally wrong in this country. Time after time after time we have seen victims having to fight for many years in order to achieve justice. Most recently the Hillsborough families whose campaign like ours went on for decades. There has to be a better way."

Individuals should not have had to try and piece together the truth themselves, whether through undertaking careful and painstaking research,<sup>937</sup> or through targeted Freedom of Information requests;<sup>938</sup> through patiently raising questions of ministers or through MPs time

- 932 Letter from Carol Grayson to the British Medical Journal 19 August 2000 p2 WITN1055064
- 933 Carol Grayson Transcript 8 July 2022 p103 INQY1000223
- 934 Presentation by Gareth Lewis p2 WITN2412012, Written Statement of Beverley Tumelty section 2 para 7 WITN2412008. Gareth Lewis was the founding Chair of Tainted Blood. Written Statement of Sue Threakall paras 4-13 WITN1564022
- 935 Written Statement of ANON paras 43-44 WITN6274001
- 936 Sue Threakall Transcript 8 October 2019 pp92-94 INQY1000037. Sue Threakall became chair and later co-chair with Joseph Peaty of Tainted Blood following Gareth Lewis' death. Written Statement of Sue Threakall paras 13-14 WITN1564022
- 937 See for example Carol Grayson Transcript 8 July 2022 p77 INQY1000223, Written Statement of Alice Mackie paras 8.1-8.9 WITN2189005, Written Statement of Glenn Wilkinson paras 31-33 WITN2050001, Written Statement of Gaynor Lewis pp3-4, p8 WITN2368019, Written Statement of Andrew March paras 3, 85-182 WITN1369014, Written Statement of Bruce Norval paras 8.1-15.5 WITN2235003
- 938 See for example Written Statement of Jason Evans paras 28-41 WITN1210008, Jason Evans Transcript 11 June 2021 pp43-50 INQY1000128, Written Statement of Sean Cavens paras 8.1, 8.14-8.18 WITN1146006

and time again;<sup>939</sup> or through arranging or participating in demonstrations.<sup>940</sup> Those infected and their families, and organisations and groups campaigning on their behalf, had to repeat themselves year after year, letter after letter, coming up against a brick wall and repeated variations of the same lines to take. They were "fobbed off time and time again."<sup>941</sup>

It will be evident from what is set out in this chapter that this failure lies principally at the door of successive UK governments. But the devolved administrations do not escape their share of responsibility. Wales and Northern Ireland brought little independent thinking to bear upon the issue over the years. Scotland too, until the mid 2000s, followed, indeed endorsed, the line from Westminster.

The reasons that were given over the years<sup>942</sup> do not stand up to scrutiny:

- (a) It was said that there was no evidence of wrongdoing. But that was a self-serving assessment. Given the extensive concerns raised by campaigners and others there was an imperative for an independent inquiry to examine and determine the question of fault rather than leave the Department of Health to mark its own homework. It is in any event difficult to understand how the Government could have reached that view without proper investigation; the internal reviews on which the Department latterly relied were limited in both their scope and their reliability.
- (b) It was said that the relevant facts were all in the public domain. They selfevidently were not.
- (c) It was suggested that this was a problem linked to the state of science and technology. That was (plainly) an exceptionally and unduly restrictive way of looking at the issues (and, as detailed elsewhere, the Department of Health repeatedly asserted that "technology" for Hepatitis C screening was not available before 1991, when in fact it was).
- (d) It was even said that these matters had been looked at by Lord Archer and Lord Penrose, in circumstances where the Department of Health had sought to distance itself from each.
- (e) It was said that these events were historic. They were not, and are not, to those who survived and live with the impact of the infections and to the families of those who had died.

<sup>939</sup> See for example the Written Statement of Frederick Bates paras 56-58 WITN0393001 and Letters from MPs to Frederick and Eleanor Bates 2007-16 WITN0393014, Written Statement of Glenn Wilkinson paras 135-146 WITN2050001, Written Statement of Jackie Britton paras 37-54 WITN1838006, Written Statement of Colette Wintle paras 29-280 WITN1056009

<sup>940</sup> See for example the Written Statement of Barry Fitzgerald paras 12-15 WITN2819018

<sup>941</sup> Carol Grayson Transcript 8 July 2022 p138 INQY1000223

<sup>942</sup> Especially after the question of whether there should be an Inquiry came into prominence publicly in the mid-1990s.

(f) Perhaps most astonishing was the assertion that an inquiry would not help those infected and their families: to do so would not be in their interests. <sup>943</sup> Just as clinicians had purported to know what was in patients' interests in terms of the treatment that infected them, now politicians and civil servants purported to know better than those whose lives had been devastated.

There was a failure to consider the matter from the perspective of those infected and affected and their need for answers, as so powerfully articulated by many of them in their attempts to make government listen.

What then were the real reasons?944

The first was an inherent defensiveness – a reluctance for the decisions, actions and omissions of both the NHS and government to be assessed and exposed – combined with a kind of "memory illusion, but at a departmental level, where the people collectively try to remember things as they would like them to have been, rather than as they actually were."945 Jeremy Hunt (rightly) said that the State, including the Civil Service, "didn't have an open mind to this issue. They basically had decided that the State in the 1970s and 80s had done the best it could in the circumstances: a very sad thing had happened; compensation had been put in place; matter closed."946

The second and related reason was what Jeremy Hunt described as the "massive institutional reluctance in the NHS to listen to the stories of ordinary people when things have gone wrong ... there was certainly a very strong view that harm to patients is part of the cost of doing business. It's part of what happens."947 That description is equally applicable to government.

The third was money and the fear of having to pay compensation. That too was the evidence of Jeremy Hunt. As he told this Inquiry, he (as Secretary of State for Health) knew, Number 10 knew, Number 11 knew that a public inquiry might well recommend large sums of compensation and for that reason did not want one. He evidence was consistent with that of another former Health Secretary. Andy Burnham told Parliament, "To the extent that the public know anything much about this scandal, there is a vague sense that it is an argument

- 945 Jeremy Hunt Transcript 27 July 2022 pp38-39 INQY1000235
- 946 Jeremy Hunt Transcript 27 July 2022 p43 INQY1000235
- 947 Jeremy Hunt Transcript 27 July 2022 pp18-19 INQY1000235
- 948 Jeremy Hunt Transcript 27 July 2022 pp115-118 INQY1000235

The Government's view was seemingly shared by UKHCDO's Advisory Committee: Professor Charles Hay wrote to the Haemophilia Society on 27 September 2006 emphasising "their collective view that a public enquiry into this matter is not in the patients' best interests and is likely to harm rather than enhance patient care." Letter from Professor Hay to Margaret Unwin 27 September 2006 p2 HSOC0001265

This is not a finding that each and every minister who maintained the "no public inquiry" line did so for these particular reasons. Some ministers were in office for relatively brief periods of time. Some may have focused on, or prioritised, other matters in connection with infected blood and blood products (such as the establishment of the Skipton Fund). Some may not have had the question of a public inquiry expressly raised with them. Others were not averse to there being public inquiries into other health matters. However, viewed overall and broadly, these are the reasons which underpinned the "established government position" over the years. (For the phrase "established government position" see: Charles Lister Transcript 8 June 2022 pp30-31 INQY1000212)

about money. In my view, it is in the Government's interests to keep it there; they want to keep it there. Why is that? Just as with Hillsborough, if the Great British public knew the real story here, there would be such a wave of public support for the victims that demands for full and fair compensation simply would not be able to be resisted by the Government."949 And as he told this Inquiry, "There weren't any strong defensive lines for the Government's position. They were threadbare lines" and "it is fear of the financial exposure I think that lies at the heart of this."950

It goes without saying that a public inquiry does not lightly recommend compensation – it will only recommend compensation if it believes there is a proper case for it. That government did not want to hold an inquiry because it believed compensation might well be recommended was an implicit acknowledgement that an inquiry might uncover wrongdoing and suffering on a scale to merit such a recommendation. Not holding a public inquiry because of the belief that compensation will be an outcome is not a proper reason for refusing to have an inquiry.

Furthermore, this means that the lines to take that were being articulated were defensive. As set out in the line to take in respect of the Penrose Inquiry, explaining why an inquiry was not to take place in England, it said that the facts were known, though it is clear that this was hotly in dispute. It said that 5,000 relevant official documents had been released, and there was no significant new information to be gleaned, although the Department of Health knew some documents were missing, that by no means all the relevant documents had been released and that much significant new information might well emerge (as indeed it has). As to cost, it spoke of the cost of an inquiry, and that this money should be directed at providing health care, but it said nothing about its real fear on cost, which was that extensive and expensive compensation might follow. These were not valid reasons.951 They were not the real reasons. Government was wrong to say there was no justification for a public inquiry. That was to claim too much: there was ample justification. It is for political judgement whether justification for an inquiry is sufficient, but that judgement has to be reached on a basis which is open, transparent and balanced, and government must be prepared to acknowledge mistakes if, and when, and where they have been made, and to contemplate the possibility that they may have been made.

Jeremy Hunt's evidence was that the view that a public inquiry should not be held was the view of successive governments. There is no reason to doubt that. Alan Milburn described "a very well established view in the Department that transcended successive governments and ministers and so on and so forth that 'the facts were established'." This was a

<sup>949</sup> Hansard parliamentary debate on Contaminated Blood 25 April 2017 RLIT0001578, Andy Burnham Transcript 15 July 2022 pp128-129 INQY1000228

<sup>950</sup> Andy Burnham Transcript 15 July 2022 p129, p138 INQY1000228

<sup>951</sup> Though I accept that if government, the NHS and others had dealt properly with matters as they could have done, much earlier, the money spent on the Inquiry would have been an unnecessary expense. The expense of the Inquiry has been caused by its being necessary in circumstances in which action was not taken when it could and should have been.

Alan Milburn Transcript 14 July 2022 p177 INQY1000227. See also a letter to Mary Grindley dated 6 November 2012. "It has been the view of successive governments that there is no justification for a

collective failure by civil servants and ministers of successive governments, and is all the more serious for being so.

Further, the questions at issue were not simply ones of fact – they involved considering how those facts should be evaluated. It will have become plain to a reader of this Report by now that if they are approached taking the view that the safety of the citizen is the paramount consideration, wrong was done.

This decades-long refusal and failure to examine, interrogate or understand what went wrong and why cannot easily be excused. It involved "the purposeful dismissal of the voices of those who had been infected and affected. Listening to those voices would have entailed a direct confrontation and acknowledgement of mistakes that had been made." Instead of listening to those voices, there was a system:

"which simply trotted out the same mantras without considering whether there had been any change of circumstances or the policy merited looking at afresh, despite the ongoing legitimate need in the infected and affected community for answers and financial support, the fact that not all of those infected with HIV died as anticipated, the fact that the affected community also emerged as needing booth [sic] answers and support, the fact that the transfusion infected community started to become part of the story (who had never properly been considered by government before) and indeed the emergence of the effects of HCV [Hepatitis C]." 954

*public inquiry into these matters in England after all this time.*" Letter from Chris Hall to Mary Grindley 6 November 2012 pp28-29 WITN2336007

<sup>953</sup> Leigh Day Written Submission 22 December 2022 pp373-374 SUBS0000059

<sup>954</sup> Thompsons Written Submission 16 December 2022 p1029 SUBS0000064

# 7.5 Accountability in the Absence of a Public Inquiry

A number of those who had been infected and affected by viral infections caused by NHS treatment fought hard to achieve answers and to hold people and organisations to account. This chapter looks at the avenues which they felt driven to explore in the absence of a public inquiry.

#### **Key Dates**

**1994** Wilson Report published, leads to a new NHS complaints process in **1996**.

**1999** Public Law Project evaluation of the new NHS complaints process.

2002 onwards complaints to various police forces in England, Wales and Scotland.

2003 Department of Health publishes NHS Complaints Reform - Making Things Right.

**November 2004** GMC introduces new fitness to practise procedures.

**December 2004** Shipman Inquiry 5th report *Safeguarding Patients: Lessons from the Past – Proposals for the Future.* 

**February 2013** Report of Mid Staffordshire NHS Foundation Trust Public Inquiry. **December 2015** Parliamentary and Health Service Ombudsman report into NHS complaints finds 40% of investigations are not adequate.

#### **Abbreviations**

**CPS** Crown Prosecution Service

**GMC** General Medical Council

**PPC** Preliminary Proceedings Committee of the GMC

In the absence of a public inquiry or equivalent, some of those who had been infected or affected attempted to achieve answers and/or to hold people and organisations to account by other means.

# NHS complaints procedures

The Inquiry has reviewed a number of different complaints that individuals have made under the complaints processes of a variety of NHS trusts and health boards. No particular patterns are discernible in either the type of complaints that have been made, or the likelihood of outcomes that have resulted. There is considerable variety in the complaints ranging across concerns about the need to wait to receive Hepatitis C treatment, 955 the treatment of liver disease leading up to a brother's death, 956 the management of ascites and whether this accelerated a husband's death, 957 delays in dental treatment because of vCJD status 958 and difficulties in accessing medical records. 959

The adequacy of NHS internal complaints procedures has been analysed and subjected to criticism by external bodies over the years. The 1994 Wilson Report *Being Heard* observed that "Complainants can face an uphill struggle when using NHS complaints procedures: firstly, in making their views known; and secondly, in receiving the sort of response they would wish for." This report led to the introduction of a new complaints process in 1996.

In 1999 the Public Law Project produced Cause for Complaint? An evaluation of the effectiveness of the NHS complaints procedure, which was an independent evaluation of the operation and effectiveness of the new complaints procedure across the UK. The report identified the advantages and disadvantages of "local resolution" (ie where health

- 955 Letter from Brenda Hennessy July 2006 p2 CUFT0000002. The outcome letter from the hospital explained that there was limited funding from the primary care trust and a number of patients on the waiting list: "I am extremely sorry that, having contracted Hepatitis C from contaminated blood products previously supplied by the Health Service, we have been unable to treat you."
- 956 Letter from Mike Deegan 31 December 2008 MUFT0000001
- 957 The complaint concerned the treatment of the husband of Mrs AJ. Written Statement of ANON WITN1303001, ANON Transcript 11 October 2019 pp68-150 INQY1000040. After informal resolution was unsuccessful, this complaint resulted in a report from an independent panel. Some complaints were upheld. The panel found that the decision not to resuscitate had been reached without reference to or discussion with the patient or his wife, and that it had been inappropriate to remove samples from his body after his death without her consent. Report of the Independent Review Panel 19 February 2001 WITN4072006. Some aspects of the complaint were upheld by the Health Services Ombudsman. Report by the Health Service Ombudsman for England of an investigation into a complaint made by ANON 27 June 2002 WITN4072007
- Letter from W McKee to ANON June 2003 p3 BHCT0004113. The response letter acknowledged that there "has been some disruption to this dental service in recent months, because of uncertainty in relation to a putative risk associated with CJD" and explained that further instruments had now been sourced.
- 959 Written Statement of ANON paras 68-77 WITN3797001. The response to the complaint was that records had been destroyed in accordance with retention policies, although as the individual pointed out in correspondence reliance was placed on a retention policy which postdated the date given for destruction of the records.
- 960 Wilson Being heard: The report of a review committee on NHS complaints procedures May 1994 p24 DHSC0047001

bodies themselves attempt to resolve the complaints they receive). The disadvantages included the following:

- "it fails to take account of the imbalance in power in the health professionalpatient relationship and does not recognise how difficult it is for complainants to have to confront and challenge the very organisation or people that treated them;
- it lacks impartiality. Organisations investigate their own complaints giving rise to a potential conflict of interest;
- it fails to demonstrate the accountability of the NHS. As local resolution is internally conducted it can be invisible to complainants, it is not open to external scrutiny and providers of care are not seen to be publicly accountable."961

In 2003 the Department of Health's publication *NHS Complaints Reform – Making Things Right* reported a range of experiences from patients and staff, including that "it is unclear how, and difficult to, pursue complaints and concerns", "there is often delay in responding when concerns arise", "too often there is a negative attitude to concerns expressed", "complaints don't seem to get a fair hearing", "patients don't get the support they need when they want to complain" and "the process doesn't provide the redress patients want."<sup>962</sup>

In December 2004 the fifth report of the Shipman Inquiry considered the handling of complaints against GPs and made recommendations for change.<sup>963</sup>

In 2013 the report of the public inquiry into Mid Staffordshire NHS Foundation Trust undertaken by Sir Robert Francis QC identified reluctance amongst patients and their families to pursue a complaint, in part "the result of the imbalance of perceived power between the patient and the organisation ... There may be a feeling that the organisation will always defend its own. Patients and their families may sense that something wrong has occurred without being sure what that might be through lack of relevant expertise, which they know the organisation will have available to it." Sir Robert observed further that the system for dealing with grievances through the complaints system "is designed understandably to address individual complaints rather than collective ones". 964

A Review of the NHS Hospitals Complaints System – Putting Patients Back in the Picture – commissioned following the Mid Staffordshire report – made a number of recommendations

<sup>961</sup> Wallace and Mulcahy Cause for Complaint? An evaluation of the effectiveness of the NHS complaints procedure September 1999 p8 RLIT0002371

<sup>962</sup> NHS Complaints Reform: Making Things Right 3 April 2003 para 2.8 RLIT0002378

<sup>963</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 RLIT0002370

<sup>964</sup> Report of Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 1: Analysis of evidence and lessons learned (part 1) February 2013 para 3.125, para 3.154 DHSC5113232

for change in the approach to complaints, noting that "Too often hospitals are seen to be 'marking their own homework' and this undermines public confidence." 965

A 2015 report by the Parliamentary and Health Service Ombudsman (*A review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged*) found that 40% of investigations were not adequate to find out what happened ("*Not only are trusts not identifying failings, they are also not finding out why the failings happened in the first place*"), that serious incidents were not being reliably identified by trusts, and that there was a wide variation between and within trusts in terms of how patient safety incidents were investigated. It also found that "*Worryingly, medical records, statements and interviews were missing from almost a fifth of investigations making it even harder for trusts to arrive at what went wrong and why.*"966

Having regard to these various assessments of the NHS complaints procedures, this Inquiry does not need to make any additional findings regarding their adequacy. What is clear is that whilst a complaint about a specific clinician or hospital might address particular concerns regarding the treatment of an individual, such complaints would be considered in isolation and could provide no substitute for a wider inquiry into how and why so many people had been infected.

# **Complaints to the Ombudsman**

Individuals dissatisfied with the outcome of their complaint under NHS complaints procedures could complain further to the Ombudsman: the Parliamentary and Health Service Ombudsman in England, the Scottish Public Services Ombudsman, the Public Services Ombudsman for Wales or the Northern Ireland Public Services Ombudsman.

As with the NHS complaints processes, there is in the material available to the Inquiry considerable variety in the complaints that have been made to an ombudsman. The complaints by the daughters of Peter Gordon-Smith regarding Lothian NHS Board's treatment of their father were upheld by the Scottish Public Services Ombudsman, who found that the Board failed to provide reasonable nursing care to Peter during an admission to the Western General Hospital, failed to provide reasonable medical treatment to him during the admission, failed to make appropriate arrangements for his dental appointment, and failed to

<sup>965</sup> Clwyd and Hart A Review of the NHS Hospitals Complaints System: Putting Patients Back in the Picture Final Report October 2013 pp34-35 RLIT0000669

Parliamentary and Health Service Ombudsman *A review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged* December 2015 p6 RLIT0002372

<sup>967</sup> Professor Charles Vincent, giving evidence as part of the Public Health and Administration Expert Group, observed that "for instance, there are multiple ways of raising concerns in the NHS but it's quite hard to know where you want to go ... It works very variably. You know, you can make a complaint. I think you can report directly into the national incident reporting system, but it's quite a muddle about what you should do, I think, and where you should go ... the asymmetries, it's not some sort of sinister plot by the NHS but I think it's more that the usual thing: that if you're articulate and middle class you'll find a way and you'll push but many of the problems happen to people who are the most vulnerable and it's just hard. You know, it's hard work and you don't quite know how to go about it." (Professor Charles Vincent) Public Health and Administration Expert Panel Transcript 4 October 2022 pp83-84 INQY1000252

handle the complaint in a reasonable manner.<sup>968</sup> A complaint by Khalid Mahmood regarding the care and treatment provided to his late wife for liver disease, contracted through a blood transfusion in 1979, was partially upheld by the Parliamentary and Health Service Ombudsman, on the basis that there was evidence that investigations into her suitability for a liver transplant should have been started sooner and because of the hospital trust's failure to record a rationale for its decision that she was not suitable.<sup>969</sup>

Jason Evans' complaint about the University Hospitals Coventry and Warwickshire NHS Trust and its dealings with his father Jonathan's medical records resulted in a finding in February 2021 from the Parliamentary and Health Service Ombudsman that there had been maladministration: "We find there was maladministration by the Trust. When Mr Evans requested his late father's records, he was wrongly told several times that the Trust did not have them. It was over a year later and with the involvement of a television producer that Mr Evans discovered the Trust did have them."

By contrast, Ann Hume, who was infected with Hepatitis C following treatment with factor concentrates in 1982, complained to the Scottish Public Services Ombudsman that she had been given concentrates unnecessarily and was never made aware of the dangers of the concentrates. She also complained that her blood disorder was never properly diagnosed.<sup>971</sup> The Ombudsman decided not to take any further action on her complaint. The reasoning was as follows:

"At that time factor VIII concentrate was being used in severe cases of von Willebrand's disease associated with a reduced level of factor VIII in the blood. However, as you say, your level was recorded as normal then. Moreover the diagnosis of von Willebrand's disease was subsequently altered to a hereditary form of platelet disorder. These conditions were not so clearly understood 20 years ago when specific tests for von Willebrand's disease were not available.

The dangers of factor VIII concentrate as a source of non-A non-B hepatitis, later identified as hepatitis-C, were known at the time. However the long term dangers of hepatitis-C were not realised and the dangers of haemorrhage in both mother and baby were such that the balance of risk/benefit seemed clear. Dr [Audrey]

Written Statement of Justine Gordon-Smith para 112 WITN2632016, Scottish Public Services Ombudsman decision notice: Complaint about Lothian NHS Board 18 December 2019 WITN2632072

The complaint was made jointly by Khalid Mahmood and his daughter. Parliamentary and Health Service Ombudsman Final report by the Health Service Ombudsman for England into a complaint made about Nottingham University Hospitals NHS Trust 18 November 2016 p2 PHSO0000031. The background to Shamin Mahmood's infection with, and diagnosis of, Hepatitis C is set out in his statement. Written Statement of Khalid Mahmood paras 12-21 WITN3773001

<sup>970</sup> Parliamentary and Health Service Ombudsman Complaint about University Hospitals Coventry and Warwickshire NHS Trust made by Jason Evans 26 February 2021 p1 JEVA0000024. See also: Jason Evans Transcript pp160-163 INQY1000128, Email from Andrew Nield to Jason Evans 31 January 2022 JEVA0000117

<sup>971</sup> Her statement explains that she never received a conclusive diagnosis: she was first diagnosed as having hereditary haemorrhagic disorder, then told she had Haemophilia B and later that she had von Willebrand disorder, although both these diagnoses were later discredited: "Despite the fact that I did not suffer from Von Willebrand's disease I was diagnosed and treated for it in the past." Written Statement of Ann Hume para 3 WITN1299001

Dawson was in the forefront of medical research in this field in the 1970s/80s. In a research-oriented unit, such as Dr Dawson's, this treatment would have been within standard practice.

It is quite possible that a more conservative doctor would have withheld the treatment and only given it if there had been significant haemorrhage but there could have been a disastrous episode of blood loss.

The Haemophilia Society, in a letter on your behalf, ask why synthetic DDAVP [desmopressin] was not considered. There is no mention in the notes of it, but in fact it was never a satisfactory form of treatment, and although it had an effect on the blood levels it was not very useful clinically." 972

Much of what is recorded in this decision is at odds with the evidence which this Inquiry has available to it, such as the statement that desmopressin was "never a satisfactory form of treatment", the apparent suggestion that the long-term dangers of Hepatitis C were not known in 1982, and the assertion that "the balance of risk/benefit seemed clear". 973

The Parliamentary and Health Service Ombudsman can also consider complaints about government departments. However, the limitations of that role are apparent from the terms of a letter sent in response to a complaint from Haydn Lewis about the Department of Health. The terms of the complaint and the Ombudsman's response speak for themselves:

"Mr Lewis, a haemophiliac who contracted HIV and Hepatitis C through infected blood products, complains that the Department of Health prematurely destroyed important papers relating to this issue. Mr Lewis says that the Department have not conducted an enquiry into the destruction of the documents, or a public inquiry into how infected blood products were used on UK patients. Mr Lewis says that he would like a full explanation of what papers were destroyed, by whom and when, to enable a public inquiry to take place into how haemophiliacs were originally infected.

Before I go on to consider Mr Lewis's complaint, perhaps it would be helpful if I explain something about my remit for the benefit of Mr Lewis. The first point to make is that I have no power to question discretionary decisions taken in the absence of maladministration, or to reach different conclusions on the same evidence ...

The papers provided by Mr Lewis indicate that the government made their decision in the light of the Department's assessment that patients were contaminated with HIV and/or Hepatitis C as a result of infected blood products before the development and introduction of viable screening tests, and not because of any wrongful practices. I see no evidence here of maladministration

<sup>972</sup> Letter from Jill Stewart to Ann Hume 12 September 2005 pp2-3 WITN1299012

<sup>973</sup> This is not intended as a criticism of the Scottish Public Services Ombudsman, whose decision was apparently based on advice from an unnamed consultant physician acting as a clinical adviser to the Ombudsman. However, had the Ombudsman's investigators had available to them the evidence which this Inquiry has, the conclusions in this letter could not reasonably have been reached in these terms.

in the government's decision-making process and so there is no basis on which I could reasonably question the merits of the decisions reached, or ask for them to be reviewed.

I can, in principle, investigate Mr Lewis's complaint about the Department's premature destruction of papers relating to the infection of haemophiliacs through infected blood products. Before doing so, I would need to see some evidence of administrative fault on the part of the Department having caused Mr Lewis an unremedied injustice. I would also want to see a reasonable prospect of my intervention achieving a worthwhile outcome. I do not see that these criteria are met in Mr Lewis's case.

It is not in dispute that the Department destroyed relevant papers prematurely. The Department accepted that they had done so in their letters of 9 February 2006 to Mr Charles Clarke MP and 14 March 2006 to The Lord Morris of Manchester ... They apologised for the error and explained that they had investigated the matter and had determined that the papers had been destroyed in error, most probably by an inexperienced member of staff. The Department also explained that, following the discovery that papers had been destroyed, they had reviewed their procedures on the retention and destruction of records, as a result of which they had implemented a number of records management improvements to help prevent such errors in future. While I do not, of course, condone the Department's premature destruction of key papers, they have investigated how and why this occurred; and they have taken appropriate action to help prevent a recurrence. They have also apologised ...

I can find no evidence in the papers that would lead me to question the Department's explanation, and so there is no basis to justify my intervention." 974

In contrast to the Ombudsman, this Inquiry has available to it a far wider range of evidence both as to the destruction of documents and as to the decision not to establish a public inquiry.

### The General Medical Council

The General Medical Council ("GMC") is the professional regulator responsible for the regulation of doctors. It is empowered to undertake fitness to practise investigations and to erase or suspend a doctor's right to practise in the UK.

There were, unsurprisingly, a number of complaints to the GMC made by individuals who had been infected with HIV or Hepatitis C about the clinicians who had treated them with blood or blood products. In no case was a doctor's fitness to practise found to be impaired; indeed, cases did not even reach the stage of a full fitness to practise hearing. Given the findings which this Inquiry has made, that seems surprising. In order to understand how and why this may have happened, it is useful to consider the findings of the fifth report of the Shipman Inquiry.

"Under the 'old' FTP [fitness to practise] procedures, which operated until 1st November 2004, the GMC was empowered to take action on a doctor's registration only if s/he had been found guilty of SPM [serious professional misconduct], if his/her professional performance had been found to be seriously deficient or if his/her fitness to practise was found to be serious impaired by reason of a physical or mental condition ... Under the old FTP procedures, cases of SPM were dealt with under the conduct procedures. Cases of seriously deficient performance (SDP) were dealt with under the performance procedures, which were introduced in July 1997, and cases of serious impairment of fitness to practise by reason of ill health were dealt with under the health procedures ... introduced in 1980.

The GMC has accepted that some aspects of the old procedures were unsatisfactory. On the day on which the Inquiry's oral hearings turned to examine the work of the GMC, Leading Counsel for the GMC, Mr Roger Henderson QC, made frank admissions in relation to many of the shortcomings that had become evident during the Inquiry's investigations. He accepted that the GMC's FTP procedures had failed in many respects to meet the reasonable expectations of patients and the public. His message to the Inquiry was that the deficiencies had been recognised and were being addressed. He spoke of the paramount duty of the GMC to safeguard patient protection, while having due regard for the interests of doctors. At the time he spoke, the GMC was in the process of developing the new FTP procedures that have now been introduced." 975

#### Amongst other findings of the Shipman Inquiry were that:

- (a) no agreed standards, criteria or thresholds for serious professional misconduct had been established at the time when the old conduct procedures became defunct in November 2004, as a consequence of which the operation of the conduct procedures was beset by inconsistent decisions;<sup>976</sup>
- (b) there were defects in the filtering processes through which a case had to pass if it were to reach a Professional Conduct Committee;<sup>977</sup>
- (c) many cases were closed at the initial sifting stage without the GMC having considered whether the allegation might raise a question of serious professional misconduct;<sup>978</sup>

<sup>975</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 paras 100-101 RLIT0002370

<sup>976</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 110 RLIT0002370

<sup>977</sup> There were three filtering processes: an initial sift carried out by GMC staff, then a screening process carried out by medically qualified and lay members of the GMC, and then consideration of the case by the Preliminary Proceedings Committee ("PPC"). Each process was carried out in private and the Shipman Report noted that only a very small proportion (no more than about 5%) of cases survived the three filtering processes and reached the Professional Conduct Committee. The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 108 RLIT0002370

<sup>978</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 111 RLIT0002370

- (d) "The GMC itself did little to investigate those complaints which survived the initial sift";979
- (e) the GMC's attitude towards the collection of information was that it was not its task to make out a complaint against the doctor ("that would be unfair to doctors") its role was to give the complainant the opportunity to advance their complaint "and no more":980
- (f) the way in which the second filtering process (screening) operated for many years was not satisfactory and did not operate for the protection of patients;<sup>981</sup>
- (g) and for those cases which actually reached a Professional Conduct Committee, the procedure followed at the hearing was akin to that of a criminal trial and the standard of proof applied to findings of fact was the criminal standard of proof (ie beyond reasonable doubt).<sup>982</sup>

Furthermore, examining the culture within the GMC, the Shipman Inquiry was:

"driven to the conclusion that the GMC has not, in the past, succeeded in its primary purpose of protecting patients. Instead it has, to a very significant degree, acted in the interests of doctors. Of course, I accept that the GMC also has a duty towards doctors; it must be fair in all its dealings with them. But, in the past, the balance has been wrong and, in my view, the imbalance was due to a culture within the GMC, a set of attitudes and an approach that put what was seen as being 'fair to doctors' ahead of protecting patients." 983

Although new fitness to practise procedures were introduced in November 2004, the criminal standard of proof continued to be applied to the assessment of evidence until 31 May 2008, at which point the civil standard (balance of probabilities) was applied.<sup>984</sup>

The GMC has told this Inquiry that the question of consent was raised in the majority of the complaints it received against clinicians in relation to infections caused by blood transfusion or blood products, and that there were "no cases where a finding was made that a doctor's fitness to practise was impaired or where a doctor was found guilty of serious

<sup>979</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 112 RLIT0002370

<sup>980</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 113 RLIT0002370. Dame Janet Smith observed that this attitude "did not adequately protect patients or the public interest".

<sup>981</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 115 RLIT0002370. The report added that attempts had in recent years been made to introduce some consistency, with standard forms, training and more guidance, but these efforts "were not entirely successful". The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 116 RLIT0002370

<sup>982</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 124 RLIT0002370

<sup>983</sup> The Shipman Inquiry Safeguarding Patients: Lessons from the Past – Proposals for the Future December 2004 para 148 RLIT0002370

Note regarding the General Medical Council's historical fitness to practise procedures p7 WITN3365007. It is also right to note that there have been significant further reforms since that time.

professional misconduct. No action was taken on the registration of any of the doctors complained about."985

Charles Massey, the GMC's Chief Executive and Registrar, told the Inquiry that:

"For some of the cases, there appears to be a decision by a Screener to close a case (before 1 November 2004) and then a further decision made by the Case Examiners to close the case (after 1 November 2004). This was not necessary under the transitional provisions. A case that had already been closed by the Screeners did not need to be considered further. On some cases, we do not appear to have told the complainant or doctor that the Screeners had closed the case. This should have happened and today, we would inform the complainant and doctor of the case closure.

In some cases there was a delay of up to 18 months between a decision by the Screeners to refer the case to the PPC [Preliminary Proceedings Committee] (taken before 1 November 2004) and then a decision by the Case Examiners to close the case (taken after 1 November 2004). On some of the cases, a decision was made by the Screeners to refer the case to the PPC in May or June 2004. However, the case was then never considered by the PPC. Instead a decision was made by the Case Examiners some time after 1 November 2004. 986

... At the time of the case decisions, the Case Examiners would often make their decision on a clinical case without obtaining a report from an independent expert. This was not unusual. The Medical Case Examiner would apply their clinical knowledge to the case and it was not always thought necessary to obtain expert evidence at that stage in the process. An expert report would often be obtained if a case was referred to a hearing. Nowadays, we would nearly always obtain a report from an independent expert on clinical cases in order to assist the Case Examiners in making their decision.

Similarly, at the time these cases were decided, it was not often that we would obtain statements from witnesses of fact before the Case Examiners' decision. Statements would often be taken only if a case was referred to a hearing. Instead, the Case Examiners would rely on any written complaint and documentary evidence. Nowadays, on more serious cases, it is more common for us to take

<sup>985</sup> Written Statement of Charles Massey paras 73-78 WITN3365001

One example of this is the complaint by Ann Hume regarding Dr Audrey Dawson. The screeners' decision, on 25 May 2004, was that the case should be referred to the PPC. Yet in April 2005 the case examiners decided that the matter should be closed with no further action. Table of complaints against Doctors by the General Medical Council WITN3365009\_001. The reasons for the case examiners' decision included that there was "no suggestion that the Dr acted in anything other than the patient's best interests." General Medical Council patient complaint file against Dr Audrey Dawson 01 April 2005 p6 WITN3365026\_002. The caseworker's memorandum to the screeners, on the other hand, had recorded that Dr Dawson "treated Mrs Hume as a haemophiliac with the concomitant use of clotting factor concentrates when she did not necessarily need to do so, subsequently changed Mrs Hume's treatment without her knowledge and consent, and did not warn her of the potential risks of treatment with blood products." General Medical Council patient complaint file against Dr Audrey Dawson 01 April 2005 p21 WITN3365026\_002

statements from witnesses of fact, such as the complainant, patient and other relevant witnesses." 987

Carol Grayson, who complained to the GMC in February 2003 regarding Dr Peter Jones' testing and treatment of her husband Pete Longstaff, described her experience as a complainant in her written and oral evidence to the Inquiry:

"As the complaint progressed it became apparent that Dr Jones was privy to all our allegations but his responses to them were not disclosed to us throughout the course of the complaint. I feel that this was procedurally unfair as it gave Pete and I no opportunity to challenge any information which Dr Jones gave in his response. We were totally in the dark. I had not seen the full response until far more recently. If we had been afforded the opportunity to respond I think we would have been much more likely to succeed in our complaint. The process as it stood allowed inaccurate information to be peddled by clinicians without knowledge of their patient complainants." 988

In relation to her complaint the screeners' decision, in May 2004, had been to refer to the PPC: "the allegations, if proven would represent SPM and therefore I think that the case should go forward to PPC for both doctors." 989

The matter was not referred to the PPC. Instead it was referred to the case examiners. However, the referral form provided to the case examiners noted that there were differing versions of events from the complainant and the doctor, and stated that "as the complainant's version of events differs from that of the doctor's, and given the weight of evidence supplied, coupled with the fact that there are four other related cases, I would argue that there is a realistic prospect of establishing impaired fitness to practise."990

Despite the screeners' decision, and the recommendation in the referral form, in October 2005 the case examiners reversed that decision and decided to close the case with no further action.<sup>991</sup> The case examiners' decision appears to take at face value as correct that which had been put forward on the doctors' behalf. On the complaint of failing to advise regarding the risks of treatment, for example, it said that:

<sup>987</sup> Written Statement of Charles Massey paras 80-84 WITN3365001

<sup>988</sup> Written Statement of Carol Grayson paras 891-892 WITN1055004. In her oral evidence she added "the way we looked at it, they could have been saying absolutely anything, but because we couldn't respond or challenge them we felt like we were arguing in the dark." Carol Grayson Transcript 8 July 2022 p176 INQY1000223. The complaint also covered Dr Peter Hamilton, co-director of the haemophilia centre in Newcastle.

<sup>989</sup> General Medical Council patient complaint file against Dr Peter Jones and Dr Peter Hamilton 18 May 2004 p32 WITN3365014\_001. See also the memo to the screeners which advised that the allegations "clearly reach the threshold of SPM" and "are properly arguable." General Medical Council patient complaint file against Dr Peter Jones and Dr Peter Hamilton 11 May 2004 pp33-37 WITN3365014\_001

<sup>990</sup> General Medical Council patient complaint file against Dr Peter Jones and Dr Peter Hamilton 3 October 2005 p31 WITN3365014\_001

<sup>991</sup> Table of complaints against Doctors by the General Medical Council WITN3365009 001

"the evidence is that the Newcastle centre had drawn up appropriate protocols, developed useful and comprehensive guidance, delivered multi-professional and patient-orientated care within the available NHS resources and appeared to act in patients' best interests. There is no corroborative evidence to show that Dr Hamilton deliberately withheld any information, manipulated knowledge available to him or acted inappropriately in respect of his duties as Medical Director of the Newcastle Haemophilia Centre." 992

It is unclear why "corroborative" evidence was thought necessary.

Mark made a complaint to the GMC regarding Professor Christopher Ludlam in June 2005. 993 On 1 November 2005 the complaint was referred to case examiners, and the referral form set out the investigating officer's view that the realistic prospect test (of establishing impaired fitness to practise) was satisfied with regard to the allegations about failure to inform Mark or his parents of the results of his tests; that it was satisfied with regard to the allegation of failure to inform about the risks of treatment ("Professor Ludlam did not take adequate steps to inform [Mark] or his parents of the risks of Factor VIII so as to provide a foundation for informed consent. Rather they were told that Scottish Factor VIII was the safest in the world. The realistic prospect test is therefore satisfied"); and that it was satisfied with regard to the allegation of Professor Ludlam making a misleading statement to the GMC regarding the AIDS study. 994

On 3 November 2005 the case examiners decided that the allegation regarding the failure to tell Mark and his family of his diagnosis warranted referral to a fitness to practise panel ("the evidence suggests that Professor Ludlam did not in fact take into account what might be in the best interests of his patients, or the public health, for some time"), as should the allegation of misleading the GMC regarding ethical approval and funding for the AIDS study. However, they decided that the allegation regarding the failure to provide information about risks should not be referred to the fitness to practise panel, on the basis that "At the time, it was felt that the risk to British haemophiliacs was minimal, as only a few cases had been reported in the USA ... It was not clear in 1983 that the risk was substantial. However, after this time, it is clear that attempts were made to alert patients to the risks." 995

Somewhat unusually, on 17 January 2006 the case examiners were asked by the GMC to reconsider their decision. Their 3 November decision was characterised as being "draft" (although there is no evidence that it was intended to be anything other than a final decision) and they were asked to "now formally consider the allegations and amend (and re-date) your

<sup>992</sup> General Medical Council patient complaint file against Dr Peter Jones and Dr Peter Hamilton 4 October 2005 pp12-13 WITN3365014 001

<sup>993</sup> Mark is an anonymous witness and this is his pseudonym of choice. Written Statement of "Mark" (ANON) para 6 WITN2232035

<sup>994</sup> General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 pp17-24 WITN3365029\_001

General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 pp13-14 WITN3365029\_001. It is difficult to understand how the case examiners felt able to reach this conclusion, unless it was simply on the basis of accepting what was being said to them on behalf of the doctor.

original [Case Examiners' Decision Forum] accordingly."996 The case examiners duly took a different decision and concluded that there should be no referral to a fitness to practise panel. It is clear from the wording of their decision that it was based on their acceptance of what was said to the GMC by Professor Ludlam in his response to the allegations.997

An internal GMC memo from November 2006 appears to have recognised this:

"whilst the Case Examiners in the re-taken decision particularise the allegations in full, their detailed reasoning does not address the allegations of lack of consent and/or counselling in relation to the performance of the original tests ... Further they do not address the allegation that the patient was not informed that the tests were part of a clinical study. The Case Examiners simply repeat Professor Ludlam's admission that the testing was not for a research project but simply a monitoring process, and that the blood samples were labelled 'AIDS Study' as a short hand to ensure that they were handled correctly." <sup>998</sup>

The GMC's president accordingly decided to review the decision to conclude the complaint with no further action. 999 Charles Massey's statement suggests that this review was carried out prior to the publication of the Archer Inquiry report in February 2009 and that the decision was not to re-open the investigation. 1000

In light of what is set out above, it is not surprising that in closing submissions on behalf of a number of core participants, the GMC's process was characterised as being "such an opaque complaints procedure that the complaints were never properly investigated, and patients were never given sight of the response evidence provided by doctors" and as a "woeful response". 1001 The case examiners' reversal of screeners' decisions (or, in Mark's case, of their own decision), the tendency to accept at face value the account advanced by or on behalf of the doctors, and the failure to ensure that the complainant was afforded the opportunity, where appropriate, to offer any evidence in response to what was being said by the doctors, lead me to agree with Dame Janet Smith that, in relation to its treatment of complaints regarding infected blood and blood products, "the balance has been

<sup>996</sup> Memo from Neil Jinks to Jim Watts and Peggy Arnell 17 January 2006 GMCO0001691\_006

<sup>997</sup> General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 pp2-8 WITN3365029\_001. A later internal GMC memo suggests that the case examiners' second decision was made because the GMC had failed to notify Professor Ludlam of the allegation and documents in support as soon as reasonably practicable after referral to the case examiners. The memo adds that "From a strict legal perspective, the GMC had no power, the Case Examiners having exercised their discretion, to re-take the decision." General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 p104 WITN3365029\_001

<sup>998</sup> General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 p104 WITN3365029 001

<sup>999</sup> General Medical Council patient complaint file against Professor Christopher Ludlam 19 January 2006 pp106-107 WITN3365029 001

<sup>1000</sup> Written Statement of Charles Massey para 87 WITN3365001

<sup>1001</sup> Closing submissions on behalf of those represented by Milners Solicitors 16 December 2022 para 541 SUBS0000055

wrong", evincing "an approach that put what was seen as being 'fair to doctors' ahead of protecting patients". 1002

# The police

Some people have been driven to go to the police in an attempt to find answers.

#### **Dyfed Powys Police**

Carol Grayson explained in her oral evidence to the Inquiry that she and other campaigners approached various UK police forces requesting a criminal investigation into the infection of people with haemophilia with HIV and/or hepatitis as a result of receiving NHS treatment. Initially she made a complaint to Northumbria Police but "didn't get anywhere there." Carol Grayson, Colette Wintle and others then approached the Metropolitan Police to make a complaint but they were informed they would need to go to their local police. Individual complaints were therefore made to various police forces. Carol wrote on 19 July 2002 on her own behalf and on behalf of a number of other named individuals to the Deputy Chief Constable at Northumbria Police to make a complaint. On 26 July 2002, Colette Wintle wrote to Kent Police, and Peter Mossman wrote to Greater Manchester Police, both requesting a criminal investigation. These complaints were in due course referred to Dyfed Powys Police as the force in the UK responsible for investigating corporate manslaughter.

Dyfed Powys responded to Colette Wintle on 9 August 2002 informing her that they were consulting with the Crown Prosecution Service ("CPS") on what was required in order to conduct a criminal investigation. 1008

In a memo dated 4 December 2002 Detective Chief Superintendent Lewis of Dyfed Powys Police wrote that Carol Grayson, her husband Pete Longstaff and Colin Potts, 1009 as representatives of the Haemophiliacs for Action Group, were shown an advice document written by Raymond Wildsmith from the CPS. 1010 It is clear from the memo that the police considered that "there is no likelihood of a viable criminal prosecution in this matter". 1011

- 1002 The Shipman Inquiry Safeguarding Patients: Lessons from the Past Proposals for the Future December 2004 para 148 RLIT0002370. I should make it clear that these findings are based on the complaints made and investigated in earlier years; I am making no findings regarding the current procedures or culture of the GMC.
- 1003 Carol Grayson Transcript 8 July 2022 pp169-170 INQY1000223
- 1004 Letter from Carol Grayson to Deputy Chief Constable of the Northumbria Police 19 July 2002 WITN1055166
- 1005 Letter from Colette Wintle to Robert Ayling 26 July 2002 CWIN0000012
- 1006 Letter from Peter Mossman to Chief Constable of the Greater Manchester Police 26 July 2002 WITN1056161
- 1007 Written Statement of Carol Grayson para 405 WITN1055004, Carol Grayson Transcript 8 July 2022 p170 INQY1000223
- 1008 Letter from Dyfed-Powys Police to Colette Wintle 9 August 2002 CWIN0000034
- 1009 Colin Potts died in October 2008. Written Statement of Anne Potts para 2 WITN2976001
- 1010 Advice statement by Raymond Wildsmith 5 November 2002 POSC0000021
- 1011 Memo from J Lewis to T Grange 4 December 2002 DYPP0000001. See also: Letter from T Grange to Jim Cousins 15 July 2003 WITN1055170

It should be noted that the CPS advice in question, whilst acknowledging that an investigation would be an "*immense task*" and that there were "*difficulties which would have to be overcome for there to be a viable prosecution*", identified possible criminal offences and did not seek to comment upon "*the practicality or viability*" of a criminal investigation. It added that:

"All I can say is that, if evidence is forthcoming that officials were involved in a deliberate decision to licence blood products, or to allow the continued use of those products, at a time when they knew there was a substantial risk that the administration of those products would result in haemophiliacs being infected with serious illnesses, or even in their death, then a prosecution of those officials for at least offences of misconduct in public office or of public nuisance would be a serious consideration." 1012

On 10 December 2002 Detective Chief Superintendent Lewis wrote to Carol Grayson with details of the criminal offences that were considered by the CPS.<sup>1013</sup> On 22 January 2003 she wrote setting out her understanding that the police would not be going forward with the complaints but asked that they keep on their records any documents she might send.<sup>1014</sup>

On 1 March 2003, Carol Grayson contacted Northumbria Police again regarding testing for Hepatitis C without consent.<sup>1015</sup>

In her oral evidence, Carol Grayson said that she had since spoken to a senior person in the police who informed her that their complaint and the evidence they provided were never properly investigated.<sup>1016</sup>

#### Police enquiries in Scotland

In December 2002 a complaint was made to the police in Scotland regarding the supply of blood products to people with haemophilia in Scotland. The enquiry was allocated to Detective Superintendent Stephen Heath.<sup>1017</sup> He was provided by Dyfed Powys Police with documents which it had considered, and with advice from the Crown Prosecution Service's Casework Directorate in London.<sup>1018</sup>

Detective Superintendent Heath produced a report on 17 April 2003. It set out four individual cases<sup>1019</sup> ("understood to represent a 'snapshot' of numerous cases which have not been examined"). <sup>1020</sup> The report was "not intended as an evidential police report, but an overview

- 1012 Advice statement by Raymond Wildsmith 5 November 2002 p13 POSC0000021
- 1013 Letter from Detective Chief Superintendent to Carol Grayson 10 December 2002 WITN1055091
- 1014 Email from Mike Hughes to Simon Powell and others 23 January 2003 WITN1055167
- 1015 Letter from Carol Grayson to Mark Bleasdale 1 March 2003 WITN1055168
- 1016 Carol Grayson Transcript 8 July 2022 pp172-3 INQY1000223
- 1017 Report on Haemophilia, Consideration of criminal proceedings in respect of the use of contaminated blood products 17 April 2003 p3 POSC0000035
- 1018 Advice statement by Raymond Wildsmith 5 November 2002 POSC0000021
- 1019 Including a child infected with HIV following treatment at Yorkhill, Robert Mackie, and Bill Wright.
- 1020 Report on Haemophilia, Consideration of Criminal Proceedings in respect of the use of contaminated blood products 17 April 2003 pp10-13 POSC0000035

of circumstances to aid decision making in establishing whether a criminal enquiry is merited." 1021 In his statement to the Inquiry he described the report as a "scoping exercise"; 1022 it was not his role to decide whether an investigation should be undertaken, although it was his personal view that the issues merited a criminal investigation. He fully expected that the matter would come back to him to investigate, and was surprised that it did not. 1023

Detective Superintendent Heath's report was submitted to William Gilchrist, Deputy Crown Agent within the Crown Office and Procurator Fiscal Service, who approached the Scottish Department of Health to "get a better understanding" of the background to the complaint. He could not, when giving his statement to the Inquiry, recall who he spoke to, but in a memo to the Lord Advocate and Solicitor General on 23 April 2003 he reported that "I have discussed the background to this matter with the Health Department." His view was that "the call for a police inquiry at this late stage is simply a reflection of the frustration on the part of victims that their call for a public inquiry has been rebuffed." He was doubtful of there being sufficient evidence to indicate a criminal failure but wished to clarify what was happening with the police investigation in England and Wales and proposed then to seek Crown Counsel's advice on whether there was sufficient justification for a criminal investigation. 1025

William Gilchrist asked Stephen McGowan, Principal Procurator Fiscal Deputy, to produce a report to Crown Counsel to consider whether or not there should be a criminal investigation. The resultant report, produced in December 2003, concluded that "the benefits of the treatment, and indeed the necessity to treat haemophiliacs outweighed the risks such as they were known" and there was "no evidence whatsoever of any criminal activity in this whole affair"; it was recommended that Crown Counsel instruct that there should not be a police investigation into the allegations. 1027

On 20 February 2004, the Lord Advocate Colin Boyd wrote to the Minister for Health and Community Care stating that Crown Counsel had decided that there would be no further

<sup>1021</sup> Report on Haemophilia, Consideration of criminal proceedings in respect of the use of contaminated blood products 17 April 2003 p14 POSC0000035

<sup>1022</sup> Written Statement of Stephen Heath para 15 WITN0633001

<sup>1023</sup> Written Statement of Stephen Heath paras 16-17 WITN0633001

<sup>1024</sup> Written Statement of William Gilchrist para 30 WITN3837001

<sup>1025</sup> Memo from Deputy Crown Agent to Lord Advocate and Solicitor General 23 April 2003 paras 8-11 COPF000006

<sup>1026</sup> Written Statement of William Gilchrist para 38 WITN3837001, Written Statement of Stephen McGowan para 19 WITN3947001

<sup>1027</sup> Consideration of Criminal Proceedings in Respect of Contaminated Blood Products Report 16 December 2003 pp25-26 COPF0000010. This report included observations such as "one wonders what doctors were supposed to do in the treatment of haemophiliacs. Whilst cryoprecipitate could be used to treat 'mild' haemophilia, the Haemophilia Centre Directors in Scotland told the Health Department that these alternative treatments also had side effects such as thrombosis and anaphylactic shock. The treatment was a matter of clinical judgement. In addition, whilst 'mild' haemophiliacs do not bleed spontaneously, they do not heal if they are injured. In these circumstances they needed life saving Factor VIII treatment to stop the bleeds." It was also asserted that "doctors and officials had little choice but to treat the patients with commercial product." Consideration of Criminal Proceedings in Respect of Contaminated Blood Products Report 16 December 2003 p12, p13 COPF0000010

investigation because there was "insufficient evidence that any criminal offence has been committed." 1028

A request was made in December 2007 that Lothian and Borders Police Force investigate the complaint of two individuals that Professor Ludlam knowingly infected them with AIDS through blood products. Following interviews with the complainants and Professor Ludlam, 1029 Detective Chief Inspector Linda Little wrote to Detective Chief Superintendent Malcolm Graham in September 2009 that there was no evidence that "a specific group was identified amongst all the haemophiliacs who were attending the Royal Infirmary of Edinburgh and deliberately given a particular batch number of Factor VIII in the knowledge they would contract AIDS." 1030 The focus of this enquiry was solely on the specific allegations against Professor Ludlam, and did not examine in depth "the practices, procedures and guidance in place in relation to the use of Factor VIII or issues regarding what information should have been provided to patients and relatives." 1031

# Commentary

As observed in submissions to the Inquiry, "it is incontrovertible that campaigners looked down every alley in their search for justice". They should not have had to do so.

The functions and purposes of a public inquiry were described in a report of the Public Administration Select Committee in 2005 in the following terms:

"Sir Ian Kennedy<sup>1033</sup> identified six functions for an inquiry: the recognition and identification of different, genuine perceptions of the truth; learning; healing; catharsis; prescribing; and accountability. Lord Howe,<sup>1034</sup> who gave evidence to us from his experience of different roles in several public inquiries, identified six similar functions which have been summarised as follows:

- Establishing the facts providing a full and fair account of what happened, especially in circumstances where the facts are disputed, or the course and causation of events is not clear;
- Learning from events and so helping to prevent their recurrence by synthesising or distilling lessons which can be used to change practice;
- Catharsis or therapeutic exposure providing an opportunity for reconciliation and resolution, by bringing protagonists face to face with each other's perspectives and problems;

<sup>1028</sup> Letter from Colin Boyd to Minister for Health and Community Care 20 February 2004 WITN3947002

<sup>1029</sup> See the written statement of John Kavanagh who as a detective sergeant undertook the interviews. Written Statement of John Kavanagh paras 10-13 WITN3832001

<sup>1030</sup> Memo from Linda Little to Detective Chief Superintendent 28 September 2009 p6 POSC0000041

<sup>1031</sup> Memo from Linda Little to Detective Chief Superintendent 28 September 2009 p7 POSC0000041

<sup>1032</sup> Milners Written Submission 16 December 2022 para 541 SUBS0000055

<sup>1033</sup> Sir Ian Kennedy chaired the public inquiry into children's heart surgery at the Bristol Royal Infirmary.

<sup>1034</sup> Lord Howe of Aberavon chaired the committee of inquiry to investigate alleged abuse at Ely Hospital, Cardiff.

- Reassurance rebuilding public confidence after a major failure by showing that the government is making sure it is fully investigated and dealt with;
- Accountability, blame and retribution holding people and organisations to account, and sometimes indirectly contributing to the assignation of blame and to mechanisms for retribution;
- Political considerations serving a wider political agenda for government either in demonstrating that 'something is being done' or in providing leverage for change." 1035

Plainly none of the other avenues – NHS complaints, the Ombudsman, the GMC, the police – that people who were infected or their families felt driven to pursue could have met these objectives. In particular none could have provided a full and fair account of what had happened, or provide any real form of accountability. The lack of a public inquiry for so long, so that people had to try and seek answers elsewhere, merely served to add to their burdens.

<sup>1035</sup> House of Commons Public Administration Select Committee *Government by Inquiry: First Report of Session 2004-05* 3 February 2005 pp11-12 RLIT0002373

# 7.6 Scotland

This chapter considers the government response to people infected and affected in Scotland. It explores the Scottish Office's reliance on "lines to take" largely originating from the Department of Health in Westminster and its response to calls for compensation for people infected with Hepatitis C, and examines measures taken by the Scottish Executive, in particular an internal investigation commissioned in 1999.

#### **Key Dates**

**March 1987** Scottish Office follows the DHSS line that there should be no compensation for people with haemophilia infected with HIV.

**December 1990** Prime Minister announces settlement, in principle, of HIV litigation claims without consultation with Scotland.

**December 1991** Secretary of State for Scotland supports recommendation to provide payments to people infected with HIV through blood transfusion.

**1995-1999** Scottish Office mirrors Department of Health line of no compensation for Hepatitis C infections and "best treatment available".

**September 1999** Scottish Executive starts internal investigation into heat treatment and Hepatitis C, published in **October 2000**.

**December 2000** Health and Community Care Committee decides to hear evidence following petitions to establish an independent inquiry and to establish compensation for people infected with Hepatitis C, with a report published in **September 2001**.

**December 2001** Expert Group announced, which is chaired by Lord Ross and produces a preliminary report in **September 2002**.

**January 2003** Scottish Executive agrees payments (in principle) substantially less than the recommendations of Ross group; Ross Report published in **March 2003**.

August 2003 UK-wide announcement that there will be a scheme for Hepatitis C.

April 2008 announcement of the Penrose Inquiry.

#### **People**

Malcolm Chisholm Minister for Health and Community Care (2001-2004)

James Douglas-Hamilton Parliamentary Under-Secretary of State for Scotland (1987 - 1995), Minister of State (1995 - 1997)

**Susan Deacon** Minister for Health and Community Care (1999 - 2001)

Christine Dora civil servant, Health Department, Scottish Executive (1991 - 2001)

Philip Dolan chair, Scottish Haemophilia Groups Forum

Michael Forsyth Minister of State (1990 - 1992), Secretary of State (1995 - 1997)

Dr Aileen Keel senior/principal medical officer (1992 - 1999), Deputy CMO (1999 - 2014)

**Andy Kerr** Minister for Health and Community Care (2004 - 2007)

Lord Donald Ross chair, Expert Group on Financial and Other Support

**Bob Stock** head of Ancillary Services branch, Health Planning & Quality Division, Scottish Executive (2001 - 2004)

**George Tucker** Assistant Secretary, Scottish Home and Health Department (1989 - 1995)

## Introduction

The primary focus of this part of the Report thus far has been on the decision-making of the Department of Health in Westminster – although the positions in Scotland, Wales and Northern Ireland have also been considered. The purpose of these next chapters is to consider the response of government in, and in respect of, the latter three nations in a little more detail, and to draw together the threads of what has been set out in other chapters regarding that response.

The backdrop to what follows is that prior to 1999, there was administrative devolution in Scotland: other than matters such as foreign policy, defence and social security, everything – including policy in relation to health – fell within the powers of the Scottish Office. At the same time, as Lord Michael Forsyth explained in his evidence to the Inquiry, "we were one Government". On matters of health, the Scottish Office largely followed the lead of the Department of Health. That position fundamentally changed in 1999 with the establishment of the Scottish Parliament and of a Scottish Executive.

This chapter considers the following issues: the calls for compensation for people with haemophilia infected with HIV; the HIV litigation; the response to the position of people infected with HIV through transfusion; the use of "lines to take"; the calls for compensation for people infected with Hepatitis C; the Scottish Executive's investigation and report; the investigation by the Health and Care Committee of the Scottish Parliament; and the approach to holding a public inquiry.

# Calls for compensation for people with haemophilia infected with HIV

In early 1987 the Scottish Home and Health Department ("SHHD") became aware of calls to compensate people with haemophilia infected with HIV by blood products. Writing in February 1987, officials did not think that they could advise the Minister of State in Scotland to take a different view from DHSS ministers, who had already rejected such calls. A minute to the Private Office of Lord Simon Glenarthur said: "we consider that the Minister's replies should not hold out any hope of a change of the Government's policy on this matter, and the

<sup>1036</sup> Lord Michael Forsyth Transcript 20 July 2022 p8 INQY1000231. Michael Forsyth (now Lord Forsyth) was the Parliamentary Under-Secretary of State in the Scottish Office between 1987 and 1990. He became the Minister of State for Scotland in September 1990, a position he occupied until April 1992. He was appointed the Secretary of State for Scotland in June 1995 and remained in that post until May 1997. Between January 1986 and November 1990 Malcolm Rifkind was the Secretary of State for Scotland, but he delegated day-to-day ministerial responsibility for health matters to Michael Forsyth. Written Statement of Sir Malcolm Rifkind paras 8.1-8.3 WITN7009001

<sup>1037</sup> The Scottish Executive was renamed the Scottish Government in 2007.

<sup>1038</sup> Some of these calls came from haemophilia directors. See for example: Letter from David Steel to Dr Christopher Ludlam 23 February 1987 PJON0000072\_076, Memo from C Lugton to Alexander Murray and Dr McIntyre 9 February 1987 p3 SCGV0000013\_082, Memo from C Lugton to Duncan Macniven and David Stevenson 16 February 1987 SCGV0000229 229

<sup>1039</sup> Memo from C Lugton to Alexander Murray and Dr McIntyre 9 February 1987 p1 SCGV0000013 082

drafts attached have been prepared accordingly."<sup>1040</sup> On 17 March 1987, John MacKay, the Parliamentary Under-Secretary of State for Scotland, in response to a question regarding the prospect of compensation for those infected with HIV from Protein Fractionation Centre ("PFC") products, replied that: "There is no scheme to compensate those who allegedly suffer adverse effects as a result of medical treatment. Negligence established by the courts is the basis of liability for most medical injuries; and compensation may be awarded by the courts in cases where negligence has been proved."<sup>1041</sup>

This "no negligence, no compensation" approach dominated the thinking in Scotland over the following years.

In September 1987 Dr (later Professor) Gordon Lowe, of the Glasgow Haemophilia Centre, wrote to the Parliamentary Under-Secretary of State, Michael Forsyth, in support of the Haemophilia Society's campaign for "some recompense from the State to help them cope with the problems of HIV infection." He argued that previous statements by the Government that patients would have to prove negligence in the courts "are to my mind unacceptable in a caring society." The response drafted by officials for the Minister to send drew on a model reply which had been prepared for use by the DHSS in response to "the stream of letters which can be expected once the Haemophilia Society's campaign for compensation is fully under way". The letter sent by Michael Forsyth to Dr Lowe on 9 October 1987 suggested that the Government had reached the conclusion that provision could not be made "only after the most careful consideration." 1044

The decision, one month later, to make an ex gratia payment of £10 million to be administered by the Haemophilia Society (which led to the establishment of the Macfarlane Trust) was taken by the Sub-Committee on AIDS of the Cabinet's Home and Social Affairs Committee – a meeting attended by the Secretary of State for Scotland, Malcolm Rifkind, as well as

<sup>1040</sup> Lord Glenarthur held the post of Minister of State for Scotland between September 1986 and June 1987. Memo from C Lugton to PS/Minister of State 9 February 1987 SCGV0000229\_232, Letter from Lord Glenarthur to Sir Alex Fletcher February 1987 SCGV0000229\_233. The minute of 9 February 1987 referred to contaminated Factor 8 having been "unwittingly" provided, a term similar to the claims of people being infected "inadvertently" which are discussed below and elsewhere. The use of such terms glosses over the fact that, whilst clinicians would not be in a position to know that particular batches of concentrate were infected, they ought to have known of the risk that such concentrates might be infected.

<sup>1041</sup> Parliamentary written answers on AIDS 17 March 1987 LOTH0000009 038

<sup>1042</sup> Dr Lowe also drew attention to the fact that the reference centres in Scotland had not received the funding for counselling that had been provided by the Department of Health and Social Security to reference centres in England and Wales. Letter from Dr Lowe to Michael Forsyth 16 September 1987 p1 SCGV0000007\_054

<sup>1043</sup> Letter from C Lugton to PS/Michael Forsyth 6 October 1987 SCGV0000007\_051, Letter from Michael Forsyth to Dr Lowe October 1987 SCGV0000007\_052, Memo from C Lugton to Duncan Macniven 7 October 1987 SCGV0000229\_195

<sup>1044</sup> Letter from Michael Forsyth to Dr Lowe 9 October 1987 p2 SCGV0000007\_047. A similar letter was sent by the Secretary of State for Scotland, Malcolm Rifkind, to George Younger on 23 October 1987: Letter from Malcolm Rifkind to George Younger 23 October 1987 SCGV0000007\_009. Lord Forsyth told the Inquiry that his own view from the beginning was that this was such an "exceptional and catastrophic thing" which had happened to individuals that the Government should find some way of making an ex gratia settlement to all those infected with HIV through blood and blood products. There was, he thought, a degree of inevitability about the Government having to change its position because it was "so blatantly unfair". Lord Michael Forsyth Transcript 20 July 2022 pp53-54, p59 INQY1000231

Peter Walker (the Secretary of State for Wales) and Dr Brian Mawhinney (Parliamentary Under-Secretary of State for Northern Ireland). 1045 Thereafter SHHD officials had minimal involvement in the setting up of the Macfarlane Trust. 1046

The announcement two years later, in November 1989, by the Secretary of State for Health, Kenneth Clarke, of a further payment to the Macfarlane Trust was taken without prior consultation with or the agreement of the SHHD (or the other health departments). The initial assumption of the SHHD was that the monies would be provided by the Treasury, but in fact contributions were sought from the other health departments. A minute from George Tucker to Michael Forsyth on 1 February 1990 noted that: "There can be no question of Scottish haemophiliacs with HIV not benefiting from the Trust and thus arguably we have a moral obligation to make a contribution." 1048

# **HIV** litigation

Claims against Scottish health boards, the Scottish National Blood Transfusion Service ("SNBTS") and the Secretary of State for Scotland began to be issued in 1988. They came to the attention of Michael Forsyth in January 1989 after a report in the *Daily Record*. Minute from Duncan Macniven on 15 February 1989 informed the Minister that the Secretary of State had to date been served with 13 summonses and that work was being undertaken to prepare defences. Minute from Duncan Macniver of State had to date been served with 13 summonses and that work was being undertaken to prepare defences.

The announcement on 11 December 1990 by Prime Minister John Major, that the Government had agreed in principle to proposals to settle the HIV litigation has been considered earlier in this part of the Report. The Scottish Office had not been expecting the announcement and there had been no prior consultation with it.<sup>1052</sup> Nor had there been any parallel negotiations with Scottish litigants and their lawyers. The chairman of the Scottish Haemophilia/HIV

- 1045 Minutes of Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 CABO0100016\_011
- 1046 The SHHD wrote to Malcolm Harris at the Department of Health and Social Security on 27 November 1987 stating that there was no possibility of it making any significant contribution to the setting up or running of the structure but asking to be kept informed. Letter from C Lugton to Malcolm Harris 27 November 1987 DHSC0003093 001
- 1047 Memo from George Tucker to PS/Michael Forsyth 1 February 1990 p1 SCGV0000230\_145
- 1048 George Tucker was the assistant secretary in the SHHD, having succeeded Duncan Macniven. The minute recorded that the Welsh Office and the Northern Ireland Office had agreed "albeit reluctantly" to contribute. Memo from George Tucker to PS/Michael Forsyth 1 February 1990 p2 SCGV0000230 145
- 1049 See for example Robert Mackie's claim. Defence of Lothian Health Board and SNBTS in Scottish HIV Litigation 1988 DHSC0043352\_156. Two cases were discussed at a meeting between the SHHD and SNBTS in April 1988, at which Professor John Cash claimed that it would have been a "logistic impossibility" to have substituted cryoprecipitate for Factor 8, and that the "professional view" was that the risk did not justify such substitution. Minutes of SHHD and SNBTS meeting 18 April 1988 p2 SBTS0000687\_089. For reasons discussed elsewhere in this Report, Professor Cash was wrong. A note prepared in September 1988 recorded the view of "all defenders" that the actions should be resisted. Memo from S Lindsay to Robert Panton p1 SCGV0000506\_097
- 1050 Memo from Jane Rougvie to C Lugton 18 January 1989 SCGV0000229\_053, Daily Record *You Gave Us AIDS!* 6 January 1989 SCGV0000229\_054
- 1051 Memo from Duncan Macniven to PS/Michael Forsyth 15 February 1989 p1 SCGV0000229 052
- 1052 Letter from Andrew Rushworth to Graeme Dickson 12 December 1990 HMTR0000002 029

Litigation Group, Alfred Tyler, wrote to Ian Lang, the Secretary of State for Scotland, on 12 December to convey the Group's dismay and to point out that there were "clear and identifiable differences between the litigation in Scotland and the litigation in England". 1053 A note produced following a meeting on 19 December 1990 between Richard Henderson (solicitor for the Scottish Office) and Alfred Tyler recorded that the stage of development of the Scottish actions was significantly behind that in England and Wales, partly due to the fact that legal aid had not been available "and therefore no worthwhile preparation could possibly have taken place." The solicitors were thus disadvantaged in terms of being able to advise their clients as to the acceptability of the settlement. Richard Henderson warned of a "politic problem" if the same timescales were imposed as expected for England "in that you will then be seen to be attempting to steamroller a settlement through deliberately without giving an opportunity for proper investigation of the efficacy of the offer. It would be suggested that you were imposing that deadline and time limit simply to sabotage any proper assessment of the offer and to place undue pressure onto an already vulnerable group". 1054 This concern was duly conveyed to ministers, 1055 and led to a request from lan Lang to William Waldegrave for some flexibility "for the particular Scottish position." 1056

The claims in Scotland were eventually settled, on terms similar, although not identical, to those in England and Wales.<sup>1057</sup> However, as indicated earlier in this Report, there should have been earlier consultation with those bringing claims in Scotland (as Lord Forsyth, in his evidence to the Inquiry, agreed).<sup>1058</sup> The absence of such consultation meant that the rights and positions of the Scottish pursuers had received no separate consideration in the decision of the UK Government to settle.<sup>1059</sup> It also meant that they were, in reality, left with

<sup>1053</sup> The Scottish Haemophilia/HIV Litigation Group was an association of Scottish firms of solicitors representing people with haemophilia who had been infected with HIV. Letter from Alfred Tyler to Ian Lang 12 December 1990 p1 PRSE0003064

<sup>1054</sup> Letter from Richard Henderson to George Tucker 19 December 1990 pp2-3 DHSC0003655\_004. By this time Balfour + Manson, the lead solicitors, were acting for 41 pursuers, although not all had commenced legal action.

<sup>1055</sup> Memo from George Tucker to PS/Minister of State 21 December 1990 p2 SCGV0000501\_138. George Tucker recalled that despite the lack of consultation: "our approach at SHHD was to cooperate with the DoH [Department of Health] where possible in that we did not want to cause any embarrassment to their Ministers or to our Ministers in the Scottish Office. Co-operation meant working in tandem with the DoH to secure settlement of the HIV litigation on terms that were acceptable to all parties. It did not mean agreeing to everything that the DoH suggested." Written Statement of George Tucker para 8.1 WITN7609001

<sup>1056</sup> Letter from Ian Lang to William Waldegrave 17 January 1991 p2 DHSC0003660\_009. Richard Henderson would later become the Solicitor to the Scottish Executive.

<sup>1057</sup> Counsel Presentation on Scottish Office and SHHD Decision-Making September 2022 paras 647-671 INQY0000373

<sup>1058</sup> Lord Michael Forsyth Transcript 20 July 2022 p81 INQY1000231. Lord Forsyth said that the Scottish Office should "Of course" have been consulted: "I would have been furious at the discourtesy and the non-involvement of the Scottish Office in what was a very sudden change of position on the part of the Department of Health, whilst at the same time being pleased that they had made that change of position. But pretty angry that they'd not taken account of Scottish circumstances and, in particular, the position of the Scottish plaintiffs." See the chapter on HIV Haemophilia Litigation.

<sup>1059</sup> See further the submissions made on behalf of those core participants represented by Thompsons solicitors and in particular the observation that the Scottish pursuers were an afterthought. Written submissions on behalf of the core participant clients represented by Thompsons Scotland 16 December 2022 pp1113-1116 SUBS0000064

little choice but to accept the terms that were then offered, though as the chapter on the *HIV Litigation* explains, the waiver for Scottish pursuers omitted any reference to limiting future claims for hepatitis.

# The position of people infected with HIV through transfusion

It was on 17 February 1992 that the Secretary of State for Health, William Waldegrave, announced that the "*special provision*" already made for people with haemophilia infected with HIV would be extended to those infected with HIV as a result of blood transfusion or tissue transfer in the UK.<sup>1060</sup>

This issue had been considered within the Scottish Home and Health Department during the preceding two years, 1061 with Michael Forsyth expressing the view that the scheme should be extended to those infected through transfusion. Thus in January 1990, having seen a draft reply prepared for him to send to an MP who had raised the issue, his assistant private secretary wrote to George Tucker that "Mr Forsyth would be grateful if you could give consideration to the extension of the scheme to include people infected in this way."1062 Responding on 6 February 1990, George Tucker explained that an earlier campaign by Robin Cook MP and Clare Short MP had been resisted on the grounds that people with haemophilia differed from recipients of blood transfusions because they were already suffering from a serious disability (haemophilia) and the hereditary nature of that condition meant that more than one family member could be affected. He continued that: "We have been in touch with officials in the Department of Health and there are no plans to extend the remit of the Macfarlane Trust to cover non-haemophiliacs who have become HIV infected. There has never been a system of 'no fault' compensation for medical accidents under successive Governments. The Scottish Office could not adopt a policy which would undermine the stance taken by other UK Health Departments." He noted that the number of people infected with HIV in Scotland from transfusion was reported to be 12. A handwritten note on this minute records Michael Forsyth's view that "These arguments do not stand up". 1063

This view was repeated by Michael Forsyth a year later, around the time of the settlement of the HIV litigation: he was "concerned that compensation does not apply to others who have been infected by HIV through deficient blood products but who are not haemophiliacs, eg people suffering from leukaemia who have received transfusions." 1064

<sup>1060</sup> Department of Health Press Release Government Announces Help for HIV Infected Blood Transfusion Recipients 17 February 1992 p2 DHSC0002578\_001. See also the chapter on Government Response to HIV Infections through Blood or Tissue Transfer.

<sup>1061</sup> Dr Archibald McIntyre, Principal Medical Officer within the SHHD, recorded the Government's position, as at the end of 1989, namely that there was no intention to extend the scheme to other groups. Letter from Dr McIntyre to Dr Porter-Boveri 21 December 1989 SCGV0000230 062

<sup>1062</sup> ie through blood transfusion. Memo from Derek Bearhop to George Tucker 29 January 1990 p2 DHSC0002840 002

<sup>1063</sup> Memo from George Tucker to PS/Michael Forsyth 6 February 1990 p1 DHSC0002840\_018. See also: Memo from Derek Bearhop to George Tucker 9 February 1990 DHSC0002839\_015

<sup>1064</sup> Memo from David Binnie to PS/Secretary of State 17 January 1991 SCGV0000231 017

In late 1990 and March 1991 the Department of Health was involved in correspondence with Scottish solicitors with regard to payments for patients infected through transfusion. On 18 April 1991 Richard Henderson advised that it was wrong for the Department of Health to be corresponding in relation to matters falling within the responsibility of the Secretary of State for Scotland, noting that: "Ministerial responsibility in relation to matters concerning blood transfusion in Scotland rests with the Secretary of State for Scotland. Equally departmental responsibility in relation to those matters and the activities of the Scottish National Blood Transfusion Service lie with the Scottish Office Home and Health Department." He did not appear impressed with the Department of Health's reasoning with regard to the differences between those with haemophilia and those infected through transfusion.

Richard Henderson provided further advice on 25 April 1991, drawing ministers' attention to the leader comment in *The Observer* on 21 April describing the Department of Health's claimed distinction between people with haemophilia and people without haemophilia as "such patent nonsense that it is extraordinary that it should have been seriously put forward." However, he reported that "for the time being" the position of "HM Government" was that compensation in respect of whole blood transfusion HIV victims was resisted. Referring to the Department of Health line, he did not pull his punches with regard to the argument that there were special circumstances applicable to people with haemophilia that did not apply to those infected through transfusion:

"In effect the argument is that because haemophiliacs are as a class in an economically vulnerable group then they should receive special treatment. If you say that then it will be answered. The answer will be; look at the victims of whole blood transfusion now. It will be asserted that now those victims are equally economically disadvantaged as are haemophiliacs. It is a strange proposition to assert that because somebody starts off in a weaker position then they are to be given protection when they are injured, even though when another person who starts in a stronger position who suffers an injury becomes equally weak." 1068

On 29 April 1991 George Tucker advised ministers about this correspondence, suggesting that "as the issue of compensation is a UK one" the Scottish Office should not seek to take over responsibility in responding to the firm of solicitors representing infected individuals. <sup>1069</sup> Whilst the position of the Secretary of State Ian Lang was inclined towards letting the

<sup>1065</sup> See: Letter from J & A Hastie Solicitors to William Waldegrave 18 December 1990 DHSC0003657\_119; the letter in response from the Department of Health: Letter from David Burrage to J & A Hastie Solicitors 26 February 1991 DHSC0002851\_012; and another letter: Letter from J & A Hastie Solicitors to Virginia Bottomley 20 March 1991 DHSC0014965\_087

<sup>1066</sup> Letter from Richard Henderson to Robert Panton 18 April 1991 p1 SCGV0000233 047

<sup>1067</sup> The Observer Blood Money 21 April 1991 HSOC0019432 032

<sup>1068</sup> Richard Henderson advised that the SHHD should move away from the contrasting of whole blood victims with victims with haemophilia, adding: "It goes without saying that you may expect to receive escalating criticism." Memo from Richard Henderson to George Tucker 25 April 1991 p1, p3 SCGV0000509 027

<sup>1069</sup> The minute advised ministers that officials were not consulted on the terms of the Department of Health's replies and did not consider that the reasons advanced by the Department of Health had substance. Memo from George Tucker to PS/Secretary of State 29 April 1991 p1 SCGV0000233 124

Department of Health make the running "on this awkward issue",<sup>1070</sup> Michael Forsyth thought the Government's position was "indefensible ... we are in danger of losing a lot of goodwill carping over a small financial obligation". He hoped that "we might try to change the Government's line on this matter."<sup>1071</sup> In response the Secretary of State agreed that it was a serious matter but thought the Department of Health "should make the running for the Government as a whole."<sup>1072</sup>

On 17 July 1991 George Tucker briefed ministers again on the question of compensation for blood transfusion recipients with AIDS, advising that there was no doubt that a decision to extend the scheme would be "popular" and that it would "defuse political and media pressure at present on the Government." The counter argument was that a concession would send a message that the Government "will compensate if faced with an orchestrated campaign" and that it would be difficult to establish "a credible ring-fence" to prevent further movement towards a general no fault scheme for medical accidents. The Scottish numbers were small (around 12) but the Treasury was likely to resist "any further concessions being made". The advice was that it would be difficult to take a separate Scottish initiative if this was considered by ministers to be advantageous. The Secretary of State for Health was maintaining the current stance of resistance; the assumption was that Scottish ministers "will wish to endorse the Department of Health line". 1073

By November 1991 claims arising out of HIV infection through transfusion had been received by the Scottish Office, although George Tucker reported that "the Government line remained the same and that there were no signs of DoH [Department of Health] opening up compensation to non-haemophiliacs." <sup>1074</sup>

William Waldegrave's letter of 2 December 1991 to the Chief Secretary to the Treasury, recommending a change of policy, was copied to the Secretary of State for Scotland. SHHD officials recommended that Ian Lang give his support to the proposal, noting that the media was sympathetic and that the arguments that had been deployed so far in defending the differences between those with haemophilia and this group of patients "have

<sup>1070</sup> Memo from J Gallagher to George Tucker 1 May 1991 p1 SCGV0000509 025

<sup>1071</sup> Memo from Ian Kernohan to PS/Secretary of State 2 May 1991 SCGV0000234\_198. As Lord Forsyth told the Inquiry, it was "a completely illogical distinction ... a completely untenable line" and "an utterly ridiculous argument." Lord Michael Forsyth Transcript 20 July 2022 p89, p91 INQY1000231

<sup>1072</sup> Memo from J Gallagher to PS/Minister of State 8 May 1991 SCGV0000234 181

<sup>1073</sup> Memo from George Tucker to PS/Minister of State 17 July 1991 pp1-2 SCGV0000237\_181. It remained the position that the SHHD followed the Department of Health line: thus in October 1991 George Tucker, drafting a reply for Michael Forsyth to send to an MP, wrote that: "We have confirmed with the Department of Health that there are no plans to extend the special financial help to haemophiliacs to those infected with HIV through blood transfusion." Memo from George Tucker to PS/Minister of State 22 October 1991 SCGV0000041\_120

<sup>1074</sup> Note of meeting to consider management of HIV infected blood transfusion cases 5 November 1991 SCGV0000237\_094

<sup>1075</sup> Letter from William Waldegrave to David Mellor 2 December 1991 DHSC0002921 009

*increasingly been recognised as untenable.*"1076 The Secretary of State for Scotland duly wrote on 17 December 1991 confirming his agreement.1077

Matters relating to the timing and publication of the announced change in policy remained in the hands of the Department of Health and the SHHD's "influence on the detail of the policy" remained "relatively small." The SHHD established its own panel for determining whether an individual was eligible for the scheme (ie for determining on the balance of probability whether infection with HIV was caused by transfusion or tissue). The Scottish scheme did not include the undertaking limiting the individual's rights in connection with hepatitis infection which was a feature of the scheme established by the Department of Health. 1079

#### **Lines to Take**

The chapter on *Lines to Take* explores the development of, and reliance upon, certain lines to take which originated within the Department of Health but which were taken up across the UK, including in Scotland. When the Department of Health's lines underwent change, the Scottish Office would be notified – presumably so that it could follow the same line. An internal Department of Health minute of 7 June 1996 recorded that: "*In order to ensure a consistent line between Health Departments, we have therefore spoken to Scottish Office officials who confirm that they are content to follow our current line, which we are copying to them.*" 1082

Thus, for example, when on 4 October 1996, the Secretary of State for Scotland was informed that John Horam, the Parliamentary Under Secretary of State for Health, had written to the Haemophilia Society to explain that there would be no compensation scheme for people infected with Hepatitis C,<sup>1083</sup> and that *World In Action* was due to screen a programme about Hepatitis C on 7 October, the line to take provided to the Secretary of State described

- 1076 Memo from George Tucker to PS/Secretary of State 11 December 1991 p1 SCGV0000237\_089. The SHHD was willing to find the money if the Treasury insisted on contribution from the health departments, although a later minute noted that: "we have made no provision for this settlement and we would have to raid other budgets next year." Memo from George Tucker to Chief Executive 12 February 1992 SCGV0000237\_026
- 1077 Letter from Ian Lang to David Mellor 17 December 1991 HMTR0000003 046
- 1078 Memo from George Tucker to Chief Executive 12 February 1992 SCGV0000237 026
- 1079 Memo from George Tucker to PS/Chief Executive 9 April 1992 pp2-3 SCGV0000239\_024. On 21 April 1992 the Chief Medical Officer ("CMO") of Scotland wrote to directors of public health/chief administrative medical officers and to general managers with details of the scheme and requesting that consultants be asked to consider if they had any patients who were HIV positive as a result of blood transfusion or organ or tissue transfer. Letter from Dr Robert Kendell to Directors of Public Health and Chief Administrative Medical Officers 21 April 1992 MACK0000044
- 1080 Examples of their use in Scotland are set out in the chapter on *Lines to Take*.
- 1081 See for example: "You will wish to be aware of the revised line on requests for compensation for those infected with Hepatitis C through blood products which Ministers have just agreed. Copies of our revised standard replies to letters to Ministers on this subject follow, for information." Fax from Ann Towner to Gary Wildridge 14 June 1996 p6 SCGV0000167\_066. See also the fax providing: "our standard letter concerning haemophilia patients who have been infected with hepatitis C." Fax from Leonard Levy to Sandra Falconer 23 April 1996 p1 SCGV0000167\_070
- 1082 Memo from Ann Towner to Paul Pudlo 7 June 1996 p2 SCGV0000167 067
- 1083 Letter from John Horam to Reverend Alan Tanner 1 October 1996 HSOC0023572. See also the chapter on the *Government Response to Hepatitis C Infections*.

infection with Hepatitis C as "an unforeseen<sup>1084</sup> side effect of NHS treatment"; denied that there had been any negligence; asserted that "These patients were given the best treatment available in the light of medical knowledge at the time and treatment which was necessary at that time"; and stated that money spent on compensation would be "money diverted from the care of other patients."<sup>1085</sup>

"[B]*est treatment available*" was also part of the explanation given to Scottish solicitors enquiring about the likelihood of an ex gratia payment scheme, 1086 and part of the response provided to MPs by Scottish ministers. 1087

A submission provided to the new Minister for Health and Community Care (Susan Deacon) in July 1999, following the transition to legislative and executive devolution brought about by the Scotland Act 1998, explained that the previous administration rejected claims for financial support on grounds which included that "the patients concerned received the best treatment available at the time which was essential for their survival". 1088 There was no suggestion in this submission that this line to take was wrong or should now be abandoned; indeed a submission in September 1999 repeated that "The Government's position has been that there is no fault on the part of the NHS because patients received the best treatment available given the state of knowledge at the time." 1089

The use of "inadvertent" to describe the circumstances in which people had been infected was used in Scotland as in England. Thus the Scottish Office's Health Care Policy Division wrote to an individual in October 1998 stating that the needs of people "whose condition results from inadvertent harm" were met from benefits available to the population in general. 1090 Sam Galbraith, Minister of State in the Scottish Office, writing to Michael Martin MP in March 1999, referred to those infected with Hepatitis C as "sufferers, whose conditions have resulted from inadvertent harm". 1091 A draft reply to be sent in November 1999 from Susan Deacon to an MP whose constituent had been infected with Hepatitis C following a blood transfusion in 1990 asserted that "the risks of not receiving the transfusion were apparently deemed to outweigh the risk of any infection being transmitted" and the "resultant transmission"

<sup>1084</sup> Since it was foreseeable since 1944, even if not then called Hepatitis C, and recognised as a serious problem as non-A non-B Hepatitis in the 1970s and 1980s, this was a bold mis-statement. It was simply untrue.

<sup>1085</sup> Memo from Gary Wildridge to PS/Secretary of State 4 October 1996 p3 SCGV0000167\_056

<sup>1086</sup> Letter from Gary Wildridge to Brian Donald 24 July 1996 pp3-4 SCGV0000167\_065

<sup>1087</sup> See for example: Letter from James Douglas-Hamilton to Thomas Graham January 1997 SCGV0000167\_088, Letter from James Douglas-Hamilton to Norman Hogg 23 May 1996 SCGV0000167\_089, Letter from James Douglas-Hamilton to Jim Wallace 29 January 1996 SCGV0000167\_090

<sup>1088</sup> Memo from David Bell to PS/Minister for Health and Community Care 15 July 1999 p2 SCGV0000176 118

<sup>1089</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 8 September 1999 p2 SCGV0000043 047

<sup>1090</sup> Letter from David Bell to Anon 20 October 1998 SCGV0000045\_128. A similar letter was written in September 1998 by Sandra Falconer: Letter from Sandra Falconer to Anon 2 September 1998 SCGV0000045 165

<sup>1091</sup> Letter from Sam Galbraith to Michael Martin 23 March 1999 SCGV0000038 109

of Hepatitis C was a tragic but inadvertent consequence of this balance of risks."1092 In July 2000, during discussions about how to present the report of the internal investigation commissioned by Susan Deacon to the Health and Community Care Committee (an issue examined further below), the Minister wished to approach the presentation in terms which included sympathy "with all haemophiliacs and indeed non-haemophiliacs who had suffered inadvertent harm through their NHS treatment".1093 A letter produced by Sandra Falconer on behalf of the Minister to accompany the provision of the report to "Individual Haemophiliacs, CSA, DH(E), Welsh Assembly, Health and Social Services Executive, Northern Ireland" in September 2000, repeated the expressions of sympathy "to haemophiliacs infected through blood products, as indeed to all people who have suffered inadvertent harm through medical treatment."1094 In December 2001 a press release reported Malcolm Chisholm, who was now the Health and Community Care Minister, as sharing with the Health and Community Care Committee "the desire to help and support those who have inadvertently contracted this serious disease through health service treatment."1095

Dr (later Professor) Aileen Keel was a senior medical officer in the SHHD in the 1990s. 1096 She was also a haematologist by training and had worked at the Royal Hospital for Sick Children at Yorkhill with Dr Michael Willoughby between January 1981 and January 1983; at Glasgow Royal Infirmary between February 1983 and August 1986, during the latter part of which she did joint clinics with Professor Lowe; and from 1995, whilst still working at the SHHD, she carried out a weekly general haematology clinic with Dr (later Professor) Christopher Ludlam at Edinburgh Royal Infirmary. 1097 Rather than disavowing the line to take, Professor Keel told the Inquiry that it was her view that the treatment provided had been the best available in light of medical knowledge at the time. Indeed, it was something that she "strongly" believed. Asked what that was based on, this was the first part of her answer:

"I think the internal report that SHHD carried out in, I think, about 2000 into the efforts made by the Blood Transfusion Services in the UK, both the Protein Fractionation Centre and the Bio Products Lab, south of the border, in introducing, or discovering how to treat plasma products so that you inactivated certain viruses, I think that demonstrates the absolute complexity of this field. So the coagulation factors that were being given to, let's say, haemophilia patients prior to the introduction of testing were state-of-the-art at the time. It wasn't until, unfortunately, 1987 that SNBTS began to produce a product called Z8, which was HCV safe and in sufficient quantities to supply all of the needs in Scotland.

<sup>1092</sup> Draft Letter from Susan Deacon to John Swinney November 1999 p2 SCGV0000176 019

<sup>1093</sup> Memo from Christine Dora to PS/Minister for Health and Community Care 31 May 2000 p2 SCGV0000240\_082

<sup>1094</sup> Letter from Sandra Falconer 29 September 2000 p1 SCGV0000172 003

<sup>1095</sup> Scottish Executive Press Release Executive to Look at Future Health Compensation System 11 December 2001 p1 SBTS0000358\_040

<sup>1096</sup> She was a senior medical officer from March 1992 to December 1998, Principal Medical Officer from December 1998 to June 1999, and then Deputy Chief Medical Officer from June 1999 to 2014. Written Statement of Professor Aileen Keel para 2 WITN5736003

<sup>1097</sup> Professor Aileen Keel Transcript 25 July 2022 p3, pp7-12, p44 INQY1000234 001

However, that didn't mean that they were not putting their very best efforts in, as were BPL [the Blood Products Laboratory] south of the border, to developing viral products that were virus safe, be it from HIV or hepatitis C." 1098

One difficulty with that answer is that it views "best treatment available" solely from a fractionator's perspective. Whether PFC and the Blood Products Laboratory ("BPL") were "putting their very best efforts in" (in the sense examined later by the Scottish Executive) goes only to the development of methods of viral inactivation. It says nothing about other measures for reducing risk (such as reduced pool sizes, treatment with cryoprecipitate or with fresh frozen plasma or with desmopressin ("DDAVP"), batch dedication policies, or a conservative treatment approach) or about the need for informed consent. 1099

A further difficulty is that the "best treatment available" line that was taken in the briefing which Professor Keel was being asked about encompassed not only those infected through blood products but also those infected through transfusion, for whom the "very best efforts" of the PFC and BPL were irrelevant, 1100 and in respect of whom various measures (such as better use of blood, more robust donor screening and selection, surrogate testing of blood donations, and earlier introduction of Hepatitis C screening) would have reduced the number infected, as would telling patients of the risk since the number of non-essential transfusions would have fallen.

The foundation for Professor Keel's view – and presumably her advice to the SHHD at the time – was therefore highly shaky. Furthermore it is apparent that she was not necessarily an impartial adviser in this regard. She had worked with a number of the clinicians who had given patients treatment which transmitted infection (indeed she was still, at the relevant time, working with Dr Ludlam).

The second part of Professor Keel's answer was that concentrates were "the best available treatment at the time" because they had revolutionised the treatment of haemophilia. "In the 1960s, for example, the mean age of death of a haemophiliac individual was 37. By the 1980s, haemophiliacs had a nearly normal lifespan because of the introduction of Factor VIII and IX products, which saved them from dying of bleeding, saved them from disabling complications of bleeds, particularly into joints. So yes, I strongly support that sentence." 1101

<sup>1098</sup> Professor Aileen Keel Transcript 25 July 2022 pp115-117 INQY1000234\_001

<sup>1099</sup> It should also be remembered that commercial concentrates were also used in the treatment of people in Scotland, most notably – with dreadful consequences – at the Royal Hospital for Sick Children including at the very time that Professor Keel worked there (albeit in a relatively junior capacity). Those commercial concentrates with which children were treated cannot conceivably be regarded as the best treatment available and any attempt to argue so would be crass and objectionable. Professor Keel, when asked if the commercial concentrates given to the children at Yorkhill were the best available treatment in light of medical knowledge at the time, answered: "I suppose with hindsight the answer is no." Professor Aileen Keel Transcript 26 July 2022 p122 INQY1000234\_002. There should be no need to resort to hindsight to know that the treatment provided to the children at Yorkhill was in fact the worst possible treatment.

<sup>1100</sup> This was acknowledged by Professor Keel in her oral evidence. Professor Aileen Keel Transcript 24 July 2022 pp126-127 INQY1000234 001

<sup>1101</sup> Professor Aileen Keel Transcript 25 July 2022 p117 INQY1000234\_001. The sentence in question being this: "The main argument against compensation is that the treatment offered was the best

The difficulty with **this** answer is that it ignores the fact that the major contribution to the increased life expectancy of people with haemophilia came with the use of cryoprecipitate. 1102

Professor Keel's view was no doubt influenced by her understanding of what was known about the risks of transmission at the time. However, the difficulty there is that her understanding was wrong. She told the Inquiry that: "In 1984, there was only just the beginnings of the emergence of the possibility that that virus [ie AIDS] could be transmitted by blood products."1103 This is simply wrong. That possibility had emerged in 1982, was known to be a strong possibility by the DHSS in London no later than 16 July 1982, 1104 and was or should have been known to haemophilia clinicians by the end of 1982.1105 Her evidence in relation to non-A non-B Hepatitis was equally wrong. She said that "If we had known in 1984 what we now know about the impact of non-A, non-B hepatitis, then maybe the choice would have been to choose cryoprecipitate, but we didn't know that then."1106

# Calls for compensation for Hepatitis C

As detailed earlier in this Report, throughout the 1990s calls were made for some form of compensation, or financial support, or ex gratia payment, to be made to those infected with Hepatitis C through blood or blood products, but the position of the UK Government remained that no such payments would be forthcoming.

In 1995 the Department of Health sought the views of the Scottish Office on this issue. 1107 On 25 May 1995 Ian Snedden, who had taken over from George Tucker, responded that he had discussed the position with medical and legal advisers and that:

"we are of the view that the scheme as it is proposed would give rise to a number of complex legal and medical questions. I can advise you that the consensus which emerged from these initial considerations was that whilst the 'no compensation' position was becoming increasingly untenable, the proposals to link payments to social needs and the degree of harm suffered would be very difficult to establish and the (clinical) judgements required would also make it costly and complex to administer."

available in the light of medical knowledge at the time." Memo from Ian Snedden to PS/Minister of State June 1995 p5 SCGV0000165\_035

<sup>1102</sup> See the chapter on Treatment of Bleeding Disorders.

<sup>1103</sup> Professor Aileen Keel Transcript 25 July 2022 p121 INQY1000234 001

<sup>1104</sup> Memo from Stan Godfrey to Dr John Holgate 16 July 1982 DHSC0002219\_009

<sup>1105</sup> See the chapter on Knowledge of the Risks of AIDS.

<sup>1106</sup> Professor Aileen Keel Transcript 25 July 2022 p121 INQY1000234\_001. See also: "the general perception in the early, certainly to the mid-1980s, was that this was a relatively benign disease that only caused elevation of liver enzymes". Professor Aileen Keel Transcript 25 July 2022 p125 INQY1000234 001

<sup>1107</sup> Letter from Roger Scofield to David Hogg 9 May 1995 DHSC0006946 010

He indicated that he was obliged to seek the views of ministers before responding substantively. 1108

The views of ministers were sought in a minute dated July 1995, sent to the Private Offices of the Minister of State, the Secretary of State and the Parliamentary Under-Secretary of State. 1109 This explained that the Department of Health had put together proposals for a possible scheme but "without any presumption that such a scheme would be desirable or inevitable." Ministers were asked to agree to respond in terms of an attached draft letter which identified the difficulties in the proposed scheme and recommended "that pressure to establish a no-fault compensation scheme should continue to be resisted."1110 The minute recorded that although most of the political interest in the issue had been directed at the Department of Health, the Scottish Office had had "a number of Green Folders" and letters for official reply on the matter over the past 9 months and we have recently dealt with 2 PQs tabled by Dr Norman Godman for written reply." There were three legal cases against the SNBTS and the Secretary of State, all of which were currently sisted (stayed). It was recognised that mounting pressure "in the political arena" and pending legal actions might make it "increasingly difficult" to hold the line for no compensation, and the minute questioned whether the case for not offering compensation was "sufficiently robust to hold up". However, the Department of Health's proposals (which envisaged payment on the basis of need or harm suffered) were seen as unworkable and it was suggested that if a scheme were to be established it would realistically require compensating all those infected through blood products on equal terms. 1112 The draft letter prepared for ministers asserted that the

- 1108 Letter from Ian Snedden to Roger Scofield 25 May 1995 SCGV0000165\_046. Professor Keel suggested in her evidence to the Inquiry that the "untenability" of the no compensation position arose from the fact that there was an increasing degree of lobbying from organisations such as the Haemophilia Society. Professor Aileen Keel Transcript 25 July 2022 p112 INQY1000234\_001. However, the fact of lobbying, whilst adding to the pressure to change the policy, was not what rendered the position untenable: rather it was the underlying illogicality of the position, and the disparity between the treatment of those infected with HIV and those infected with Hepatitis C.
- 1109 Attempts were made prior to briefing ministers to ascertain the number of people with haemophilia in Scotland infected with Hepatitis C, with Gary Wildridge speaking to Dr Ludlam on 22 June 1995. Dr Ludlam was reported to consider the figure of 240 an underestimate and that the true number was between 250 and 300. It is noteworthy that Dr Ludlam reported that the "general policy of haemophilia directors" was to discuss the possible effects and offer testing "when patients attend for treatment. Many patients with mild haemophilia visit treatment centres only infrequently and these patients have not been asked to attend simply to discuss HCV." Note by Gary Wildridge regarding the number of people with haemophilia who have Hepatitis C 22 June 1995 SCGV0000165\_030
- 1110 Memo from Ian Snedden to PS/Minister of State and Scottish Office ministers 13 July 1995 p1 SCGV0001032\_008. The summary of the background in the minute recorded that: "Where technically possible, heat treatment to inactivate viruses in blood products was introduced in 1984 when it became clear that clotting factor concentrates such as Factor VIII, used in the treatment of haemophilia, had transmitted the HIV virus. Before this time clotting factors were also likely to contain HCV". The clear inference is that from 1984 concentrates would no longer transmit Hepatitis C. This is inaccurate in three respects (of which the third is of particular significance to Scotland): BPL's heat-treated Factor 8, which did inactivate Hepatitis C, was available from 1985 rather than 1984; commercial heat-treated concentrates capable of transmitting Hepatitis C continued to be used in the latter half of the 1980s; and in Scotland the concentrates produced by the PFC, in contrast to BPL, were not successfully virally inactivated in relation to Hepatitis C until 1987.
- 1111 Professor Keel's recollection was that this referred to correspondence from MPs. Professor Aileen Keel Transcript 25 July 2022 p114 INQY1000234 001
- 1112 Memo from Ian Snedden to PS/Minister of State and Scottish Office ministers July 1995 p3, pp6-7 SCGV0001032\_008

treatment given "conformed to the best medical and scientific knowledge at the time";1113 noted that it was not clear whether the argument would be sufficiently robust for the courts;1114 expressed the view that it was not realistic to contain the scheme to those infected by blood and blood products; acknowledged the argument that the HIV settlement constituted a significant precedent ("while it may be difficult to maintain the distinction between the way in which the Government has responded to 2 different, but both potentially fatal viruses it may be necessary to do so, at least for the moment");1115 raised concerns about where the funding would come from;1116 and stated that the policy and general principles of a scheme would need to be considered collectively by UK health ministers and possibly the Cabinet. It concluded that: "my Minister of State is of the view that claims for compensation should continue to be resisted, at least until the outcome of the Court cases is known and a more precise estimate can be made of the likely numbers and costs involved."1117

The Minister of State at the Scottish Office, James Douglas-Hamilton, responded with the comment that it "is likely that the view of the layman, and of the electorate as a whole, would probably be that those infected should receive compensation. Those infected had become so through no fault of their own, while being treated by the NHS, and those infected with HIV have already been compensated."<sup>1118</sup> He recognised, however, that it might set a precedent and that there would be "costs to be borne by way of compensation" and requested a more accurate estimate of cost. The minute recording his views continued:

"Lord James has also commented that he feels that there would be a political pay-off to be gained from compensation, and feels that it would serve as hard evidence to back up the Secretary of State's pledge to listen to the people. Thus, the goodwill benefits to be gained must be weighed against the potential detriment to other NHS services, and the cost to public funds. Lord James' own conviction is that, if the Government appears niggardly, this will increase public displeasure, in a situation where there is much to be gained from what is perceived to be a fair and balanced approach.

Fairness to the patient and the patient's family would be seen as the appropriate response. If necessary, it may be desirable to approach the Treasury for

- 1113 Draft Letter from Ian Snedden to Roger Schofield July 1995 p1 SCGV0000165\_109
- 1114 To suggest that an argument that the best was done might not be robust enough for the courts suggests uncertainty about whether indeed an objective reviewer would consider it the best. The concern was expressed for two particular reasons the fact of the HIV settlements, and that an offer had been made by Baxter Healthcare Corporation to patients infected with Hepatitis C by using their product, Gammagard, an immunoglobulin.
- 1115 Draft Letter from Ian Snedden to Roger Schofield July 1995 p2 SCGV0000165 109
- 1116 Officials in the NHS Management Executive in Scotland had expressed the concern that this would pose "a serious threat to the resources that we can devote to allocating to Health Boards to purchase health care for their populations." Memo from John Aldridge to Ian Snedden 21 June 1995 SCGV0000165\_033. A similar concern was expressed by the SHHD's Finance Directorate: Memo from David Palmer to Ian Snedden 15 June 1995 SCGV0000165\_040
- 1117 Draft Letter from Ian Snedden to Roger Schofield July 1995 p3 SCGV0000165 109
- 1118 Memo from Jane Macbeth to Ian Snedden 18 July 1995 p1 SCGV0000165\_022. James Douglas-Hamilton was Parliamentary Under-Secretary of State for Scotland between June 1987 and July 1995 and became Minister of State for Scotland on 6 July 1995, remaining in post until 2 May 1997.

extra funds, if the amounts involved are likely to be substantial. In conclusion therefore, Lord James believes that there is more to be gained from action than inaction, from fairness than from unfairness, and from firm decisiveness than from indecision. Lord James therefore feels that it would be inappropriate for the letter to issue as drafted." 1119

A handwritten note on the minute added: "Please ensure that any policy decision on Hep C is taken within the context of other potential claims where patients [and] families have suffered as a consequence of NHS treatment given in good faith and in the light of knowledge at the time." 1120

The Chief Medical Officer ("CMO") of Scotland, Dr Robert Kendall, advised the Minister at a meeting on 24 August 1995 that the issue of financial compensation would have to be decided on a UK basis. The CMO followed that up with a memo in which he drew attention to a recent statement by the Secretary of State for Health, Stephen Dorrell, which "*very strongly*" suggested that the Department of Health would resist offering compensation and informed the Minister that in those circumstances it would be extremely difficult for Scotland to attempt to adopt a different policy.<sup>1121</sup>

On 28 September 1995 further advice was provided by officials to the Minister of State regarding the costs involved in setting up a payment scheme. The estimate of the likely numbers infected remained 650 (comprising approximately 300 people with haemophilia and a further 350 infected through transfusion, but it was acknowledged that the latter figure would be subject to revision following completion of the lookback exercise). The possible level of compensation suggested by the Minister (£20,000) was seen as too low:

"the scheme established by the Government to compensate those infected with the HIV virus through blood or blood products established £60,000 as the 'going rate' for compensation. Although there are clear differences in the effect of the 2 viruses there is no doubt that HCV can have very serious or fatal long term consequences and the level of compensation offered would have to be seen to reflect the potentially severity of the condition. Even if we were to argue that the HCV virus should attract a considerably lower level of compensation than the HIV scheme this is unlikely to be acceptable to the Haemophilia Society in particular, since many older haemophiliacs have been infected with both HIV and HCV. For these patients, because of the underlying HIV infection, HCV poses a serious threat to health. Consequently an offer of £20,000 to haemophiliacs would be seen as inadequate." 1122

<sup>1119</sup> Memo from Jane Macbeth to Ian Snedden 18 July 1995 pp1-2 SCGV0000165 022

<sup>1120</sup> The handwritten note was probably from Geoff Scaife, chief executive of the NHS in Scotland. Memo from Jane Macbeth to Ian Snedden 18 July 1995 p1 SCGV0000165 022

<sup>1121</sup> Memo from Dr Kendall to PS/Minister of State 24 August 1995 p1 SCGV0000166 065

<sup>1122</sup> Memo from Ian Snedden to PS/Minister of State 28 September 1995 p2 SCGV0000166\_082. A second reason was the level of payment believed to have been made (£50,000) by Baxter in an out-of-court settlement with 40 patients in the UK who had been infected with Hepatitis C through Gammagard.

Officials' understanding that the Secretary of State for Health (Stephen Dorrell) wanted to hold the current line was set out. A revised letter was attached, adjusted to "reflect the Minister of State's sympathy for the establishment of a compensation scheme" but recognising the prohibitive costs involved. If, however, "the Minister of State wishes to open up the debate about a compensation scheme for HCV at Ministerial level in Whitehall we would, of course, be happy to let him have a draft letter." 1123

The following day the Minister noted the advice and asked for the letter to the Department of Health to be amended to acknowledge "the fact that this is a matter for the collective view of the Government."<sup>1124</sup>

On 5 October 1995 a response was sent by Ian Snedden to the Department of Health on behalf of the Scottish Office. This recorded the Minister's sympathy with the campaign for some form of no fault compensation for those infected with Hepatitis C but expressed concern about the costs and the impact on other health spending. Consistent with the Minister's request, the letter also stated that the general principle of any compensation scheme for Hepatitis C "is a matter for collective consideration by the Government." 1125

During 1996 the Scottish Office maintained the same line on compensation: thus, by way of example, James Douglas-Hamilton wrote to Winifred Ewing MEP on 12 January 1996 affirming both the lack of plans to make payments (on the ground of no negligence) and the "best treatment available" line. 1126 In February 1996 Ian Snedden, writing to Kevin Guinness in the Department of Health, emphasised that the observations made in the 5 October 1995 letter remained unchanged. He noted that if it were agreed that compensation should be made, the only practical option was a payment to all individuals (not just people with haemophilia) infected by blood, blood products or tissue, at a level of payment that would need to be both affordable and sufficiently high to deter continued legal action. 1127 In July 1996 Gary Wildridge, responding to a letter from Scottish solicitors enquiring about the likelihood of an ex gratia payment scheme, explained that the Government did not accept that there had been negligence and had no plans to make ex gratia payments. HIV sufferers were "accepted as being a very special case", whereas in contrast "Many people with Hepatitis C live perfectly normal lives for decades without any symptoms appearing." There was "no case" for using funds which would "otherwise go towards the care and treatment of other NHS patients to make special payments to those affected."1128

<sup>1123</sup> Memo from Ian Snedden to PS/Minister of State 28 September 1995 pp4-5 SCGV0000166\_082

<sup>1124</sup> Memo from Jane Macbeth to Ian Snedden 29 September 1995 SCGV0000166 056

<sup>1125</sup> Letter from Ian Snedden to Kevin Guinness 5 October 1995 DHSC0006933\_046. Kevin Guinness responded to Ian Snedden by letter on 13 October 1995, stating that it was important to keep in regular touch over this issue to ensure "a consistent presentation of policy, which as you say is ultimately a matter for collective consideration by the Government." Letter from Kevin Guinness to Ian Snedden 13 October 1995 p1 SCGV0000166 054

<sup>1126</sup> Letter from James Douglas-Hamilton to Dr Ewing 12 January 1996 p1 SCGV0000166\_019. This was in addition to a similar letter to Jim Wallace MP: Letter from James Douglas-Hamilton to Jim Wallace 29 January 1996 SCGV0000167\_090

<sup>1127</sup> Memo from Ian Snedden to Kevin Guinness 5 February 1996 SCGV0000166 025

<sup>1128</sup> Letter from Gary Wildridge to Brian Donald 24 July 1996 p2 BNOR0000130\_036. Gary Wildridge was a higher executive officer in the Scottish Office, and his correspondence reflected the decisions and

In July 1998 Frank Dobson, the Secretary of State for Health, decided not to establish any form of scheme for those infected with Hepatitis C.<sup>1129</sup> Officials in Scotland recommended that a similar position be adopted in Scotland, adding that:

"This issue has always been viewed as a UK-wide matter which requires the four territorial Health Departments to adopt a consistent line. Mr Dobson's announcement therefore effectively binds Scotland, Wales and Northern Ireland to following the same line. Unfortunately Department of Health officials were unable to give us prior warning of this announcement (we were first advised yesterday afternoon). However, we see no reason to deviate from the decision reached by the Secretary of State for Health and would recommend that Mr Galbraith<sup>1130</sup> agree to adopt a similar position in Scotland." <sup>1131</sup>

Sam Galbraith agreed. 1132

There matters rested when the Scotland Act 1998 created the Scottish Parliament and the Scottish Executive, and the Scottish Executive took over responsibility with effect from 1 July 1999. 1133

## The Scottish Executive investigation and report

### **Origins**

On 15 July 1999 briefing was provided by the Health Care Policy Division of the new Scottish Executive to the Minister for Health and Community Care, Susan Deacon. The purpose was to tell the Minister about the Haemophilia Society's continuing campaign for compensation for people with haemophilia infected with Hepatitis C. The issue having hitherto been treated as a "UK-wide matter on which the four territorial Health Departments should adopt a consistent line", it now came "within the remit of the Scottish Parliament and it appears from the attached correspondence, and a recent enquiry from James Douglas-Hamilton, that the Haemophilia Society is now focusing its efforts on the Parliament." The advice from officials was that a further examination of the issue would "only draw the same conclusions previously reached" and it was recommended that the Minister endorse the decision taken by her predecessor.<sup>1134</sup>

policies formulated at a more senior level.

<sup>1129</sup> See the chapter on Government Response to Hepatitis C Infections.

<sup>1130</sup> Sam Galbraith was a minister in the Scottish Office between 1997 and 1999.

<sup>1131</sup> The minute recorded that there were 122 known cases of HCV positive Scottish patients, with 10-12 currently pending court actions. Memo from Andy Nichol to Sam Galbraith 28 July 1998 p3 SCGV0000167 181

<sup>1132</sup> Memo from Rachel Sunderland to Andy Nichol 29 July 1998 SCGV0000167 178

<sup>1133</sup> Later known as the Scottish Government.

<sup>1134</sup> Memo from David Bell to PS/Minister for Health and Community Care 15 July 1999 p3 SCGV0000176\_118

On 5 August 1999, however, the Minister was notified that the BBC was planning to run a story on claims for compensation from people with haemophilia who had contracted Hepatitis C. It was to be claimed that in Scotland the heat treatment required to kill the virus was not introduced until a year after it was applied in England, and that that was negligent. 1135 Notification of this came from Michael Palmer of the Health Care Policy Division. His note asserted that whereas in 1986 the English blood service had introduced 80° celsius heat treatment, hot enough to kill both HIV and Hepatitis C viruses, it was in April 1987 "Following re-engineering of its product" that SNBTS introduced 80° celsius heat treatment. He then added the following words in italics for emphasis: "as soon as practically possible to do so." He went on to say: "This chronology makes clear that although there was a period between 1986 and 1987 when Scottish products were not as safe from Hepatitis C as English products. this was not due to any negligence on the part of SNBTS." He also said that it was not feasible for Scotland to import the safer English product between 1986 and 1987 because not enough of the product could be produced for domestic English consumption, let alone for distribution elsewhere in the UK. Having expressed these conclusions in firm terms, the briefing added that officials would investigate these events with SNBTS more thoroughly in the next few weeks "to confirm for ourselves that the correct action was taken." 1136

A line to take for public response to the programme was suggested. It included the words:

"The actions taken by the NHS in Scotland in the 1980s to ensure the safety of blood products administered to haemophiliacs do not suggest that there was any negligence on the part of the health services, given the state of knowledge at that time about protection against Hepatitis C and the practical difficulties of introducing a Hepatitis C-safe product any sooner in Scotland.

This suggests that compensation for this set of patients, tragic as their case may be, would not be appropriate, as compensation should only be paid where the NHS or individuals working in it have been at fault." 1137

In a press release from the Haemophilia Society the following day, Philip Dolan, speaking on behalf of Scottish members, appealed to the Scottish Parliament "who could decide to act now for Scottish people with haemophilia and HCV." That same day Margaret Smith MSP, convener of the Health and Community Care Committee, called for an immediate

- 1135 Memo from Michael Palmer to PS/Minister for Health and Community Care 5 August 1999 p1 WITN4436004
- 1136 Memo from Michael Palmer to PS/Minister for Health and Community Care 5 August 1999 p2 WITN4436004
- 1137 Memo from Michael Palmer to PS/Minister for Health and Community Care 5 August 1999 p3 WITN4436004. The note went on to inform Susan Deacon about a separate set of issues surrounding those infected via blood transfusions, stating that legal advice in England suggested that the Department of Health would probably be liable for a failure to introduce screening for Hepatitis C as quickly as it should have done and it suggested that compensation should be paid to anyone who contracted the virus between May 1991 and September 1991 when screening became universally available. This was described in the note as representing "a considerable shift in policy which will require careful presentation and will have implications for the other UK territories". Memo from Michael Palmer to PS/Minister for Health and Community Care 5 August 1999 p3 WITN4436004
- 1138 Memo from Michael Palmer to PS/Minister for Health and Community Care 8 September 1999 p5 SCGV0000043\_047

Executive inquiry and signalled that in due course she would be willing to ask the Committee to examine the matter. 1139

Susan Deacon told the Inquiry how at that point she had to examine properly what had happened in the 1980s around heat treatment and wished to set out the facts "as best we could in the public domain." So she first decided to instruct officials to pool together "proper facts" on that and, second, wanted to speak to the Haemophilia Society and people who had experienced infected blood products in Scotland. On 6 September 1999 she responded to Margaret Smith MSP explaining that officials had been instructed to undertake an immediate investigation and that she would meet the Society on 14 September to hear their concerns at first hand. 1141

### The process of investigation

Before the Minister met the Society to hear those concerns, officials had, in the meantime, met Professor Ian Franklin of SNBTS and Drs Robert Perry and Ron McIntosh of PFC on 30 August 1999,<sup>1142</sup> and Professor Ludlam and Professor Lowe on 1 September 1999. The note of the latter meeting recorded that: "Both Professor Lowe and Professor Ludlam confirmed that it was normal practice within their centres to inform patients of the result of a test if they were found to be HCV positive." The use of the word "confirmed" suggests

- 1139 Letter from Margaret Smith to Susan Deacon 6 August 1999 SCGV0000176\_102. Michael Palmer informed the Minister on 16 August 1999 that officials had already written to SNBTS, the Department of Health, and haemophilia clinicians in Scotland, requesting detailed information on these events, and provided a draft reply to be sent to Margaret Smith MSP: Memo from Michael Palmer to PS/Minister for Health and Community Care 16 August 1999 SCGV0000176\_101
- 1140 She said she was presented with preliminary conclusions by her civil servants, and being briefed what to say in support of what had been tentatively predetermined but she wanted to have a discussion which was more open, whereas the starting point of the department was "no change, no engagement". She recalled that "it was just a pre-existing practice of, you know, keeping things very closed, and and thinking that sometimes ministers shouldn't be allowed out alone just to speak to folk and make up their own minds." Susan Deacon Transcript 29 July 2022 pp32-46 INQY1000237
- 1141 Letter from Susan Deacon to Margaret Smith 6 September 1999 SCGV0000176\_100
- 1142 The officials in attendance were Michael Palmer, Dr Keel, Lynda Towers and Sandra Falconer. Note of meeting to discuss the investigation of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 30 August 1999 SBTS0000379\_040. The note records that a paper had been submitted by SNBTS to the Scottish Executive which was described as giving a full history of events during the critical period. SNBTS had provided two reports: Factor VIII Concentrates Manufactured by SNBTS (1974-1999) and Some Background Notes on the Development of Hepatitis-Safe Factor VIII Concentrate by SNBTS. These can be respectively found at: Fax from Jane Pelly of PFC to Michael Palmer 5 August 1999 pp3-5 SCGV0000169\_075, Some Background Notes on the Development of Hepatitis-Safe Factor VIII Concentrate by SNBTS 18 August 1999 SCGV0000169\_041. Letter from Michael Palmer to SNBTS National Director 11 August 1999 p1 SCGV0000169\_056, Letter from Dr Perry to Michael Palmer and Dr Keel 27 August 1999 SCGV0000169\_040
- 1143 Note of meeting to discuss the information required to assist in the investigation of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 1 September 1999 p2 PRSE0000978. This meeting was attended by Dr Keel, Michael Palmer and Sandra Falconer. What was not apparently raised at this meeting is the fact of delays in inviting people to be tested, which in the case of people with mild haemophilia could mean substantial delays before being offered testing, as acknowledged by Dr Ludlam in his meeting with Gary Wildridge in June 1995. Note on the number of people with haemophilia in Scotland who have Hepatitis C by Gary Wildridge 22 June 1995 SCGV0000165 030

(as Professor Keel confirmed in her oral evidence) that their assertion was being taken at face value. 1144

Susan Deacon received a briefing note from officials on 8 September 1999. This set out the Government's position to date – "that there is no fault on the part of the NHS because patients received the best treatment available given the state of knowledge at the time" – and it set out an initial overview of the events in the mid 1980s. 1145 The briefing note ended by giving the initial impressions of the officials: that SNBTS had done all they could at the time to develop a Factor 8 product which was safe from Hepatitis C, given the state of knowledge at the time and the key objective of combating HIV, and that there was no evidence that SNBTS lagged without good reason behind England. On the contrary they were ahead of England on the key target at the time – HIV – and in hindsight they were ahead of most other manufacturers on Hepatitis C. And finally, it was said that the "Haemophilia Society's claim that 'Scotland's 500-600 haemophilia patients may have been exposed to the risk of hepatitis C infection for up to a year longer than people treated in the rest of the UK' can be firmly rebutted in light of the fact that from 1985-1987 most patients in England and Wales continued to be treated with commercial Factor VIII, which was not safe from hepatitis C."1146

It should be noted that this last point was not a dispute of the fact that PFC took 18 months longer than BPL in England to produce a hepatitis-safe Factor 8 concentrate but rather that, because of the failure to achieve self-sufficiency south of the border, patients there went on receiving commercial factor concentrates which were likely to and, probably, did infect them with Hepatitis C. BPL hepatitis-safe product accounted for around one third of the total consumption; the balance of products supplied might have been heat treated so as generally not to transmit HIV, but the heat treatment had not eradicated the transmission of hepatitis by those commercial products.<sup>1147</sup>

A further briefing note from Michael Palmer was provided to the Minister on 10 September 1999. This recommended that she emphasise to the Haemophilia Society that the Health Department was at arm's length from SNBTS and was engaged in an "*impartial and objective*" analysis of events, and that the Health Department aimed to report on its

1147 See the chapter on *Viral Inactivation*.

<sup>1144</sup> Professor Keel also told the Inquiry that she knew from her own clinical practice in Glasgow, doing clinics with Professor Lowe, that that was the practice there. However, her employment in Glasgow was between 1983 and 1986 which was before Hepatitis C had been identified and before any tests were available. Professor Aileen Keel Transcript 26 July 2022 pp11-12 INQY1000234 002

<sup>1145</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 8 September 1999 pp2-4 SCGV0000043\_047

<sup>1146</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 8 September 1999 pp7-10 SCGV0000043\_047. It was also stated that officials' consultations suggest that from the late 1970s, when non-A non-B Hepatitis first surfaced, to the mid 1980s, there was very little evidence that it produced adverse symptoms and that it was generally regarded as mild and non-progressive. This is incorrect, both as to when non-A non-B Hepatitis first surfaced – it was recognised from 1974, not the late 1970s – and as to it being regarded as mild and non-progressive until the mid 1980s. Those who regarded it as such were wrong: see the chapter on *Hepatitis Risks 1970 and After*.

investigations within a month, with the Scottish Executive issuing its conclusions as soon as possible thereafter. 1148

The meeting with the Haemophilia Society took place on 14 September 1999. Issues raised by those attending from the Society included: delays in informing people that they had been infected; the lack of information given to patients at the time in terms of the risks of contracting non-A non-B Hepatitis before 1987; people being given inaccurate assurances about the benign nature of Hepatitis C; that people were dying of Hepatitis C; that those infected were subject to social stigma associated with infection and encountering difficulties in trying to obtain mortgages or insurance. Susan Deacon assured the Haemophilia Society that these issues would be investigated.<sup>1149</sup>

An interesting and revealing exchange then took place immediately after this. Michael Palmer, who had been present at the meeting, sent a memo in respect of it to the Minister (copied to the Private Offices of the First Minister, Finance Minister, Permanent Secretary, CMO and others). His report described how it became clear during the meeting that there were other strands of inquiry which the Haemophilia Society wished the Scottish Executive to pursue in its investigation, including the information provided to patients by clinicians. He reported that the Minister assured the Society that these issues would also be investigated, although this would take longer than the expected month.<sup>1150</sup>

In handwriting, on the face of the submission, the First Minister of Scotland Donald Dewar, wrote: "I am a bit concerned that an open mind = an open cheque book. What is our likely exposure if compensation is awarded?" 1151

When these words were relayed to Susan Deacon's office there was another handwritten note recording a response. This read that: "Ms Deacon's office advises that this is very much a PR exercise and there is unlikely to be any compensation paid."<sup>1152</sup>

Susan Deacon, for her part, refuted having used any such words. 1153 Whoever used the words, they portray a cynical attitude, and suggest that by meeting people who had been infected and the Society which represented them the Minister was going through the motions, rather than conducting a meaningful consultation. I emphasise that is not what she herself said. She suggested, rather, that it was one of the civil servants: "at least I can think of at least one person who was involved who -- or around it anyway -- who at least initially

<sup>1148</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 10 September 1999 p1 SCGV0000170 164

<sup>1149</sup> Minutes of Minister for Health and Community Care and Haemophilia Society meeting 14 September 1999 p2 SCGV0000170\_232

<sup>1150</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care September 1999 SCGV0000170\_153

<sup>1151</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care September 1999 SCGV0000170\_153. An email on behalf of the First Minister on 23 September 1999 set out the same concern: Email from Karen Jackson on behalf of First Minister to Sandra Falconer and others 23 September 1999 SCGV0000170 152

<sup>1152</sup> Email from Karen Jackson on behalf of First Minister to Sandra Falconer and others 23 September 1999 SCGV0000170\_152

<sup>1153</sup> Susan Deacon Transcript 29 July 2022 p61 INQY1000237

had given me that re-articulation, if you like, of -- you know, that we didn't need to look at this and that had been resolved and that we'd want to continue that position."1154

Karin Pappenheim, chief executive of the Haemophilia Society, wrote to Susan Deacon on 23 September 1999, expressing the hope that communication between the Minister and the Society would continue over the coming months in order that information and views could be shared fully and openly. She emphasised the importance of impartiality. It is clear from her letter that the Society was still pressing for a full inquiry into how people with haemophilia in Scotland came to be infected with Hepatitis C – including but not limited to the narrower question of why the domestic product exposed them to the risks of Hepatitis C for longer than the BPL product.<sup>1155</sup>

A consequence of the discussions was the addition of a second element to the remit of the investigation, which would consider the alleged lack of information given to patients about the risks of contracting Hepatitis C/non-A non-B Hepatitis and the alleged delay in informing people with haemophilia that they were Hepatitis C positive after they had been tested.<sup>1156</sup> However, the Minister declined to undertake any wider investigation.<sup>1157</sup>

A meeting took place on 25 November 1999 between SNBTS and the Haemophilia Society, attended also by Dr Keel.<sup>1158</sup>

In December 1999 the Haemophilia Society provided a written submission to the Scottish Executive. This continued to make clear the Society was pressing for a full independent inquiry into how people with haemophilia were infected with HIV and Hepatitis C. The lack of any official report or apology was identified as a source of considerable anger and distress. The Society said that the investigation should not be conducted solely by officials of the Scottish Executive, and expressed deep concern that the investigation being undertaken at the Minister's behest by the Executive "may be seen as a PR exercise which does not deliver the independence required." The Society was, of course, unaware that within the

<sup>1154</sup> Susan Deacon Transcript 29 July 2022 p67 INQY1000237

<sup>1155</sup> Letter from Karin Pappenheim to Susan Deacon 23 September 1999 WITN4436006

<sup>1156</sup> Letter from Susan Deacon to Karin Pappenheim 27 September 1999 HSOC0005179. Bill Wright wrote to the Minister on 29 September 1999 expressing concern at the lack of independence in a Health Department enquiry, which might involve officials being asked to criticise themselves "or other public servants whom they have worked closely with." He advocated an independent inquiry with a wider remit. Letter from Bill Wright to Susan Deacon 29 September 1999 p3 WITN2287024

<sup>1157</sup> Letter from Rachel Sunderland on behalf of Susan Deacon to Karin Pappenheim 9 November 2000 HSOC0011771. In this letter, Susan Deacon stated that specific concerns arising from the treatment of individual patients were matters which should be pursued through the NHS complaints procedure, but that the Health Department would consider what wider policy issues might be raised by these case histories, for example with regard to past guidance.

<sup>1158</sup> Notes on Haemophilia Society and SNBTS meeting 25 November 1999 WITN2287021. Bill Wright, who attended the meeting, recalled "the surprise expressed by SNBTS representatives that someone could be infected as late as 1986 and us responding 'He is sitting here'". Written Statement of William Wright para 2.6 WITN2287019. Professor Keel could not recall that being discussed, but there is no reason to doubt Bill Wright's recollection on an issue that directly affected him. Professor Aileen Keel Transcript 26 July 2022 pp51-52 INQY1000234 002

Minister's own office it had indeed been viewed as a PR exercise. A wide range of questions were posed, including questions about treatment in the 1970s and early 1980s. 1159

The investigation was to be undertaken by a principal-grade civil servant, Christine Dora, who was new to the Health Department (taking up her post in early December), with advice from Dr Keel and other colleagues including Lynda Towers. 1160

Health Department officials met on 14 January 2000 to agree "the remit and the timetable and process for the preparation of the Report to the Minister." The remit of the investigation was agreed (between the officials) as being: "To examine the circumstances surrounding the heat-treatment of blood products between 1985 and 1987, in relation to the allegations that patients in Scotland with haemophilia were exposed to the risks of HCV longer that [sic] they should have been, given the state of knowledge at the time." 1161

A week later Christine Dora sent a minute to the Minister. It noted that the Haemophilia Society had not confined matters to heat treatment between 1985 and 1987. She sought approval for a remit which was already different from that agreed a week earlier by officials. It was now:

- "• to examine evidence about the introduction of heat treatment in Scotland for Factor VIII in the mid-1980s, to assess whether or not patients in Scotland with haemophilia were exposed to the risks of HCV longer than they should have been, given the state of knowledge at the time;
- to examine evidence about the information given to patients with haemophilia in the 1980s about the risks of contracting HCV from blood products." 1162

These became the approved remit. (As it happened, the report did not answer either of these two questions: reasons for saying this come later).

- The Haemophilia Society Response to the Scottish investigation into hepatitis C infection via contaminated blood within the haemophilia community December 1999 p3 PRSE0001404. For example, the submission said: "We need to know far more about the steps taken by the various UK wide and Scottish bodies at the time to ensure that the safest possible blood supplies and treatment products were in use. In this context information is required on the blood donor selection policy used in Scotland in the '70s and '80s (selection, screening, testing)? In particular, since hepatitis transmission via blood products was known to take place, what measures were taken and when (and why) to screen out hepatitis from the blood supply. Were these measures adequate? How did they compare with measures taken internationally?" and "Again looking at this from the perspective of how best patients might have been protected from risks, we need to know when products (home and commercial) were known/expected to have probably caused infection, what steps were taken to ensure these products were no longer used/recalled? Were these steps adequate? Were they timely?" The Haemophilia Society Response to the Scottish investigation into hepatitis C infection via contaminated blood within the haemophilia community December 1999 p5 PRSE0001404
- 1160 Written Statement of Christine Dora para 5.2 WITN7246001. Christine Dora was a principal grade civil servant in the Health Department of the Scottish Executive between December 1999 and May 2001. An example of Christine Dora seeking advice from Dr Keel is at: Memo from Christine Dora to Dr Keel 21 January 2000 SCGV0000170\_070. Lynda Towers was a senior solicitor advising the Scottish Executive. Written Statement of Lynda Towers para 2 WITN7469001
- 1161 Note of meeting to discuss the way forward with the enquiries into the events surrounding the heat treatment of blood products between 1985 and 1987 14 January 2000 p1 SCGV0000170 078
- 1162 Memo from Christine Dora to PS/Minister for Health and Community Care 21 January 2000 p2 SCGV0000170\_071

The second bullet point of the remit came because (as Dr Keel told Scottish haemophilia directors) the Society was interested in pursuing "the issue of what patients were told at the time of Hepatitis C testing, including the clinical implications of a positive diagnosis. In addition, the Society allege that Scottish patients were often completely unaware of possible adverse effects resulting from plasma derived blood products, and of other potential treatment options."<sup>1163</sup>

Haemophilia directors were invited to attend a meeting with officials. This took place on 10 February 2000, attended by various officials (including the head of division, Thea Teale, Dr Keel and Christine Dora) and by haemophilia centre directors from across Scotland, including Professors Lowe and Ludlam. Dr Keel reported the concern of Haemophilia Society members about the information provided to them, and Lynda Towers said that it was necessary to try to establish "whether there was a general policy on what patients were told and whether there [was] an assessment of risk and if patients were given a choice." 1164 Various assertions were recorded as being made, including that:

- (a) Until the late 1980s the perception was that non-A non-B Hepatitis was a mild non-progressive condition. This was recorded as being said by Professor Ludlam.<sup>1165</sup> For reasons discussed elsewhere in this Report, it was wrong (or if that was the perception of clinicians, they were mistaken).<sup>1166</sup>
- (b) The first serious study on liver biopsy was undertaken in 1985. This was recorded as being said by Professor Ludlam. It was wrong. It ignored the 1978 Sheffield study.<sup>1167</sup>
- (c) The clinician "would have had to make the decision of whether to hand the patient a host of information or outline the benefits/risks of particular products." This was recorded as a comment from Dr Henry Watson (Aberdeen Haemophilia Centre).
- (d) The policy was that patients would be informed that they were being tested for Hepatitis A, Hepatitis B, Hepatitis C and HIV and that the results would be discussed at their next appointment. This was said by Professor Lowe. It is unclear whether this was intended to convey the position in Glasgow or a wider policy. It is in any event inconsistent with much of the evidence of actual practice which the Inquiry

<sup>1163</sup> Letter from Dr Keel to Scottish Haemophilia Directors 17 January 2000 ARCH0003312 031

<sup>1164</sup> Note of meeting to discuss the information required to assist in the examination of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 14 February 2000 p2 ARCH0003312 020

<sup>1165</sup> When asked about this in his oral evidence, Professor Ludlam said that this was an "*inaccurate* summary of my perceptions" and that mid rather than late 1980s would be a more accurate reflection of his views. Professor Christopher Ludlam Transcript 1 December 2020 pp115-116 INQY1000077

<sup>1166</sup> Although there was room for thinking that generally it was mild during the acute phase, there was no sufficient evidence to suggest it was non-progressive. See the chapter on *Hepatitis Risks* 1970 and After.

<sup>1167</sup> Professor Ludlam has told the Inquiry that this should probably have read "the first liver biopsy study to demonstrate that the hepatitis was potentially serious was reported in 1985".

<sup>1168</sup> Note of meeting to discuss the information required to assist in the examination of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 14 February 2000 p3 ARCH0003312\_020

- has received. Professor Keel told the Inquiry that what Professor Lowe said was accepted at face value by the investigation. 1169
- (e) In relation to the position of those with mild haemophilia, it was said that DDAVP could have been used from 1979 but that this was a matter of clinical judgement and "patients were desperate at that time to be prescribed concentrate as this allowed them to treat themselves at home." This too was recorded as having been said by Professor Ludlam. That the use of DDAVP involved the exercise of clinical judgement was of course correct. But people with bleeding disorders were entitled to be informed that it existed as a form of treatment and advised about its benefits (or disadvantages). The suggestion that patients were desperate to be prescribed concentrate reads as an attempt to throw the responsibility for treatment decisions onto the very people who were (as the Inquiry has found) not being given the information to which they were entitled in order to enable them to give informed consent to treatment.

Professor Ludlam is noted as having sought advice on whether haemophilia directors should be looking back to try and identify what had happened to people whose whereabouts and status were unknown. Lynda Towers referred to the Central Legal Office and said that haemophilia directors should follow their advice on whether any further investigation or tracking down of patients was necessary. 1171 This is a concerning exchange, because the question of trying to find people who might be unaware that they had been infected with Hepatitis C from their NHS treatment should be a matter for clinical and ethical judgement and not legal advice; and there is evidence that some doctors were reluctant to carry out lookback for fear that if a patient were identified as infected litigation might follow. 1172 She explained in her evidence to the Inquiry that haemophilia directors were being advised by the Central Legal Office (not by her), so any legal advice should come from them and thought that the minuted exchange has been "written short" and that what was in discussion was whether Professor Lowe should tell a medical predecessor of their former patient's current status. Her view was that that would probably require legal advice especially over patient confidentiality, and it should be the Central Legal Office, not her, who should be giving that advice since the haemophilia directors were not her clients. Be that as it may, as minuted it reads that the question (whether attempts should be made to identify what had happened to people now known to have been at risk) should be determined by legal advice, which would not be correct. Lynda Towers confirms that the upshot was that the matter would not

<sup>1169</sup> Professor Aileen Keel Transcript 26 July 2022 p39 INQY1000234 002

<sup>1170</sup> Note of meeting to discuss the information required to assist in the examination of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 14 February 2000 p3 ARCH0003312\_020. This was recorded in the note as being said by Professor Ludlam. In response to the criticisms being put to Professor Ludlam under the Inquiry Rules 2006, Professor Ludlam said that this would have referred to patients with severe haemophilia requesting home treatment and that the note is therefore a confused record.

<sup>1171</sup> Note of meeting to discuss the information required to assist in the examination of circumstances surrounding the safety of SNBTS blood products from Hepatitis C 14 February 2000 p4 ARCH0003312 020

<sup>1172</sup> See the chapter on Hepatitis C Lookback.

be determined by clinical judgement, but by legal judgement: "The clinicians would have made the decision to further investigate based on the legal advice of CLO [the Central Legal Office]."1173

It is right to record that in her written statement Lynda Towers goes on to say "With the benefit of hindsight and many years practice since then, I believe today that a lookback exercise, with appropriate safeguards in place to assist and support the patients unaware of the potential risk of infection, would have been appropriate at that time."<sup>1174</sup>

At that stage it was anticipated that a report would be put to the Minister in March.

The same month SNBTS sent to the Scottish Executive a paper in response to requests for information from Christine Dora and Professor John Cash also provided papers.<sup>1175</sup>

On 28 March 2000 Christine Dora emailed Dr Keel and Lynda Towers. She had, she said, waded through the papers obtained from Professor Cash and "I don't understand half of them!". She wrote:

"as far as I can make out, 'we' (in Scotland) were only getting round to seriously thinking about ALT testing of donations in March 1988 – after the period in question. I suppose we could try to emphasise how unreliable it was – but that in itself is a big dollop of hindsight. The Haemophilia Society are not going to let it rest if we put nothing in about testing. Can you give me any advice in relation to the sequence of events as they might relate to our investigation? Even something demonstrating that by the time adequate testing of donations was available, heat treatment was already protecting people? Or something demonstrating that the testing available at the time was inadequate?". 1176

This is a revealing passage. It indicates that the investigation was less than impartial: having encountered something that might not have been done as it should, the instinctive response was to try to find a way round any criticism.<sup>1177</sup>

Thea Teale wrote to Christine Dora on 30 March, in response to her query about testing, that it was "a balance between sticking to what we were asked to do & anticipating further demands. I am still inclined not to cover testing in the body of the report." Asked whether

- 1173 Written Statement of Lynda Towers paras 11-12 WITN7469001
- 1174 Written Statement of Lynda Towers para 15 WITN7469001
- 1175 SNBTS Investigation concerning events surrounding the introduction of heat treatment for blood products in the mid 1980s February 2000 PRSE0001249, Email from Thea Teale to Christine Dora 23 March 2000 p1 SCGV0000171\_054. Thea Teale commented "I am a bit concerned ... about what might come out of John Cash's papers. Can we make sure that we look carefully for any suggestions that the state of knowledge was other than that which SNBTS have offered."
- 1176 Email from Christine Dora to Dr Keel and Lynda Towers 28 March 2000 SCGV0000171 052
- 1177 Christine Dora also sought advice about what to do with a letter she had found amongst Professor Cash's papers from David McIntosh which was critical of civil servants and Government. Christine Dora did not want to be accused of having suppressed the letter, but the very fact that she asked for advice as to what to do about it suggests a less than fully open approach within the Scottish Executive.
- 1178 Handwritten note dated 30 March on the email from Christine Dora to Dr Keel and Lynda Towers 28 March 2000 SCGV0000171\_052

the concern about alanine transaminase ("ALT") testing was, irrespective of the remit of the report, identified as an issue for the Minister to consider, Professor Keel could not recall but thought they probably regarded it as an irrelevance in the context of trying to understand the efforts made by SNBTS in the mid 1980s.<sup>1179</sup>

No attempt was made during the investigation to meet individuals who had been infected. In her statement to this Inquiry Christine Dora stated that she took patients' written statements at face value and that no attempt was made to consider medical records. 1180

Christine Dora circulated a draft of the report to officials in March 2000. 1181 Dr Keel provided comments on 23 March, recommending that the conclusion should be made "more definite". She reminded Christine Dora that the Department of Health was very nervous about financial help; Dr Keel herself had "reassured" Mike McGovern of the Department of Health that "we recognised that compensation in this area would set a very difficult precedent for the Government, given the many claims for compensation that it receives." 1182 Asked during her oral evidence why it was relevant for her to raise this issue with Christine Dora, Professor Keel said:

"it was a material issue that was discussed – being discussed at that time. I mean, it's not directly relevant to the investigation but clearly from previous documents we have seen that the Scottish Office, Scottish Executive subsequently, had over the years already done some pre-planning around the impact that setting up a compensation scheme would have. Not expecting that that would be the case, but in preparation for that, should it be an eventuality." 1183

This is not a credible explanation as to why Dr Keel had felt it necessary to remind Christine Dora about the Government's nervousness regarding financial assistance. The reminder was clearly there to reinforce that the investigation report should not provide support for the Society's calls for compensation.

This conclusion is strengthened by a subsequent email exchange between officials in April, when Christine Dora circulated a draft ministerial submission. 1184 John Aldridge, director

- 1180 Written Statement of Christine Dora paras 9.1 and 10.2 WITN7246001
- 1181 Letter from Dr Keel to Christine Dora 23 March 2000 pp3-12 SCGV0000171\_053
- 1182 Letter from Dr Keel to Christine Dora 23 March 2000 pp1-2 SCGV0000171 053
- 1183 Professor Aileen Keel Transcript 26 July 2022 pp53-54 INQY1000234 002
- 1184 Email chain between Christine Dora, John Aldridge and others 19 April 2000 p2 SCGV0000171 031

<sup>1179</sup> Professor Aileen Keel Transcript 26 July 2022 pp45-46 INQY1000234\_002. A discussion about ALT testing had taken place at the meeting between SNBTS and the Haemophilia Society, attended by Dr Keel, in November 1999. In response to questions about why ALT testing was not introduced in the UK, Dr Brian McClelland (correctly) stated that the link between high ALT and hepatitis was known in the 1970s. Dr Keel stated that the Advisory Committee on the Virological Safety of Blood ("ACVSB") had considered this issue over a number of years, on each occasion agreeing that ALT testing should not be introduced because of the poor specificity of the test. This was not wholly accurate. The ACVSB was not established until 1989. Discussions about surrogate testing (including ALT) had taken place in various forums in the 1980s (see the chapter on *Hepatitis C Surrogate Screening*) with few conclusions being reached. Asked about this during her oral evidence, Professor Keel admitted that she did not know what other bodies or organisations or individuals had considered the question of surrogate testing. Professor Aileen Keel Transcript 26 July 2022 pp48-49 INQY1000234 002

of finance, replied that the Minister "should be pointed very firmly in the direction of not agreeing to compensation or special priority treatment for Hep C sufferers who may have been infected by NHS treatment". 1185 Christine Dora, responding, commented that the Macfarlane Trust was "an uncomfortable precedent in this respect, so we'll need to marshal the arguments carefully. I also understand that Lord Hunt at the Dept of Health has been reflecting on the idea of a possible hardship fund for Hepatitis C victims; I really think it would be wise to have both Ministers discuss and at least decide whether to operate in step with each other (although I am hoping they will decide the same thing and it won't be compensation)."1186

The expression of hope by a civil servant that people infected with a serious, debilitating and potentially fatal virus will not receive compensation is both surprising and concerning to read. In her statement to this Inquiry Christine Dora has sought to explain that she hoped that compensation would not be the outcome of ministerial deliberations because that would have "furthered the notion that people should be compensated for events that were not the fault of the NHS", which would lead to damaging financial implications for the provision of services. Such a hope was, she said, "in line with departmental thinking at the time." Nonetheless, Christine Dora did invite the Minister to further consider the issue of "the possible provision of financial help to haemophiliacs who have been infected through blood products". 1188

On 25 April 2000 the draft report was sent to the Minister. A covering submission set out officials' view that, in relation to the first part of the remit, there was no undue delay in introducing appropriately heat-treated blood products in Scotland. The second part of the remit was described as much more difficult to research: "There appears to be no evidence that clinicians had a policy to deliberately mislead their patients about the risks of using Factor VIII." 1189

The Minister was asked to agree to the draft report being shared with SNBTS, the Haemophilia Society and haemophilia directors, and to consider what if any further action was required. The Minister responded, broadly content with the report but requesting some

- 1187 Written Statement of Christine Dora para 17.2 WITN7246001
- 1188 Submission from Christine Dora to Susan Deacon 25 April 2000 p4 SCGV0000171 029
- Submission from Christine Dora to Susan Deacon 25 April 2000 pp2-3 SCGV0000171\_029 attaching the draft report, Hepatitis C and heat treatment of blood products for haemophiliacs in the mid 1980s 25 April 2000 SCGV0000171 030

<sup>1185</sup> He added that this would be resisted strongly by colleagues in other parts of the UK and by the Treasury, "as well as by me!". Email chain between Christine Dora, John Aldridge and others 19 April 2000 pp1-2 SCGV0000171 031

<sup>1186</sup> Email chain between Christine Dora, John Aldridge and others 25 April 2000 p1 SCGV0000171\_031. Susan Deacon did communicate with Lord Philip Hunt in the course of April 2000 regarding her understanding that the Department of Health was considering proposals by the National Blood Authority to settle claims brought under the Consumer Protection Act litigation by 113 people infected through transfusion; she expressed concern that any decision in England was bound to result in pressure to settle in similar terms in Scotland and asked if a common approach could be developed. Letter from Susan Deacon to Lord Hunt 13 April 2000 SCGV0000240 096

fine-tuning. A meeting between the Minister and officials on 30 May recorded that the former was keen to "move on" with publication. 1190

The draft report was provided to SNBTS and to haemophilia clinicians to enable them to comment and comments were received from them. 1191 Contrary to what had been anticipated by Christine Dora, it was not provided to the Haemophilia Society in draft form. 1192 This reflected a decision of Susan Deacon, taken at the meeting on 30 May. 1193

### Delay in publication of the report

In late September 1999 officials' expectation, as communicated to the Haemophilia Society, was that they would have examined the necessary evidence within a month. This subsequently shifted to allow receipt of submissions from the Haemophilia Society, SNBTS and others in December 1999. On 21 January 2000 Christine Dora updated the Minister about progress. Further information was going to be sought from the Scottish haemophilia directors. The Minister was reminded that there were some individual legal cases and officials' view was that "In order to safeguard the position of both the Executive and of the UK Government, and to consider whether there may be any liability arising, we believe we need to consult fully with Solicitors and with DH colleagues before our assessment of the information available can be released". All this meant that the Executive was unlikely to have the "full picture" ready for presentation within a month of the Society's submission. 1195

On 25 April, as set out above, the draft report was sent to Susan Deacon. Christine Dora has told the Inquiry that the report was essentially ready by then. 1196 It is unclear why it was not released until October.

On 7 June 2000 Margaret Smith MSP wrote to Susan Deacon, noting that the report had not yet been provided and asking on behalf of the Health and Community Care Committee that the inquiry be extended to include people who did not have haemophilia but who had also been infected with Hepatitis C. The Committee requested that results of the inquiry be published by the first week in July. 1197 The request to widen the scope of the inquiry was

<sup>1190</sup> Memo from Christine Dora to PS/Minister for Health and Community Care 31 May 2000 p1 SCGV0000240 082

<sup>1191</sup> Email from Christine Dora to Lynda Towers 26 June 2000 p1 SCGV0000172 114

The plan instead was for the Haemophilia Society to have advance sight of the final report by a few days. Email from Christine Dora to Kate Cunningham 25 August 2000 SCGV0000172\_069. Christine Dora was unable to explain to the Inquiry why this was the case. Written Statement of Christine Dora para 14.1 WITN7246001

<sup>1193</sup> Memo from Christine Dora to PS/Minister for Health and Community Care 31 May 2000 p1 SCGV0000240 082

<sup>1194</sup> Letter from Susan Deacon to Karin Pappenheim 27 September 1999 HSOC0005179

<sup>1195</sup> Minute from Christine Dora to PS/Minister for Health and Community Care 21 January 2000 SCGV0000170 071

<sup>1196</sup> Written Statement of Christine Dora para 15.2 WITN7246001

<sup>1197</sup> Letter from Margaret Smith to Susan Deacon 7 June 2000 SCGV0000171 005

rejected by the Minister, on the somewhat curious basis that there was limited value in directing resources towards examining an issue "of which we already know the outcome". 1198

The Haemophilia Society too was concerned by the delay. It wrote to Susan Deacon on 7 June pointing out that more than eight months had elapsed since their meeting and more than five months since the Society had provided its submissions to the investigation. 1199

On 26 June 2000 Christine Dora wrote to Susan Deacon providing a further draft of the report. She suggested that now was the time for the Minister to state clearly her policy on compensation. It was recognised that the Haemophilia Society would not be satisfied with the report and that there would be criticism of the exercise "as not having gone far enough." A "defensive briefing" was attached with the line to take on this issue being "Little point in a wider exercise – we already **know** it's a tragedy, and we know why it happened." The Minister's agreement was sought for the release of the report on 5 July. 1201

A further submission and proposed final report were sent to Susan Deacon on 4 September 2000.<sup>1202</sup> The suggested themes for lines to take included that the risk of liver disease was "mentioned in instruction leaflet which came with the product" and "Stopping treatment would itself have posed great risk to the patient's life and health."<sup>1203</sup> A defensive briefing accompanying the submission, under the heading "Compensation?" asserted that "The risks of not treating haemophiliacs would have been serious indeed."<sup>1204</sup>

The report was not in fact published until 24 October 2000.<sup>1205</sup> On that date the Scottish Executive wrote on the Minister's behalf to the Health and Community Care Committee seeking to justify the decision not to extend the remit of the investigation, on the basis that "the general background to infection through HCV through transfusions of whole blood is well known within the scientific and policy-making community". This letter also asserted that some people were given blood in the 1970s and 1980s "which no-one could know was

<sup>1198</sup> Letter from Susan Deacon to Margaret Smith 13 June 2000 SCGV0000171\_010. The Committee wrote again to the Minister on 10 July 2000 seeking clarification of the Minister's position: the Committee was unsure of the reasons for the narrow remit of the investigation or for the exclusion of those infected through transfusion. Letter from Margaret Smith to Susan Deacon 10 July 2000 pp4-5 SCGV0000173 130

<sup>1199</sup> Letter from Karin Pappenheim to Susan Deacon 7 June 2000 SCGV0000179\_070

<sup>1200</sup> Submission from Christine Dora to PS/Minister for Health and Community Care 26 June 2000 p30 SCGV0000172\_110. Emphasis in original.

<sup>1201</sup> Submission from Christine Dora to PS/Minister for Health and Community Care 26 June 2000 SCGV0000172\_110

<sup>1202</sup> Submission from Christine Dora to PS/Minister for Health and Community Care 4 September 2000 SCGV0000172 049

<sup>1203</sup> Submission from Christine Dora to PS/Minister for Health and Community Care 4 September 2000 p4 SCGV0000172 049

<sup>1204</sup> Submission from Christine Dora to PS/Minister for Health and Community Care p34 SCGV0000172 049

<sup>1205</sup> Scottish Executive Health Department Hepatitis C and Heat Treatment of Blood Products for Haemophiliacs in the mid 1980s October 2000 GGCL0000010

infected; the blood was as safe as the medical knowledge of the day allowed". 1206 This was patently untrue.

The Minister wrote also to Andrew Welsh MSP (who had written on behalf of constituents in June 2000) enclosing a copy of the report and noting that the report "did not find evidence of any intention by Haemophilia Centre Directors deliberately to mislead patients about the risks of hepatitis." She added that she could not deal with individual cases where a patient believed they were nevertheless misled "although I sympathise with any patient who was unable for whatever reason to appreciate the risks of their treatment." The reference to patients unable "for whatever reason" to "appreciate" the risks wrongly shifts the responsibility for a lack of understanding of risks from the clinician to the patient.

### The reaction to the report

The Haemophilia Society was gravely disappointed by the report. Its scope was too narrow and fell very far short of a full inquiry. It failed to consider surrogate screening or the actions of ministers and officials and offered "only a very partial view". On the question of information provided to patients, the Haemophilia Society said this:

"Very disturbingly, the report appears to have reached its conclusions about the information given to patients without even talking to patients themselves. Surely it is patients and their families who are best able to provide evidence on what, if any information, was provided about the risks of blood borne viruses in haemophilia treatment products? Whilst the authors of the report evidently had discussions with both SNBTS and haemophilia centre doctors in preparing the report, no discussions were held with patients and the experiences of patients are only referred to in one paragraph. This is particularly serious given that one of the two central areas the report set out to address was the information given to patients at the time – the report's conclusions on this are based solely on what doctors have said – no attempt has been made by the report's authors to find out from patients themselves what they were told."

The Haemophilia Society suggested that an "internal inquiry has been carried out behind closed doors in a manner which has not been open and transparent". 1208

The Minister, Susan Deacon, declined the Society's request for a meeting. 1209

Bruce Norval described the outcome of the review as "insulting" because "it seemed to just accept the opinion of doctors without taking account of the evidence of haemophiliacs and

<sup>1206</sup> Letter from Ian Turner to Jennifer Smart 24 October 2000 WITN4436007. The letter continued: "and the risks of unknown viruses then as now would have to be weighed against the risks of not receiving the transfusion", which is premised on the idea that hepatitis as a result of transfusion was not known of at the time. It had in fact been known for some 40 years before the events complained of.

<sup>1207</sup> Letter from Susan Deacon to Andrew Welsh October 2000 p2 SCGV0000179 011

<sup>1208</sup> Haemophilia Society *Hepatitis C and heat treatment of blood products for haemophiliacs in the mid* 1980s October 2000 p2 HSOC0009390

<sup>1209</sup> Letter from Susan Deacon to Karin Pappenheim 5 December 2000 HSOC0011976

their families."<sup>1210</sup> He felt "completely impotent on the back of Susan Deacon's report. I felt we had gone backwards rather than forwards with the campaign."<sup>1211</sup>

### The conclusions of the report

The problem with the report's approach to the first issue lay not so much with what it did consider as that which it did not.

The remit is set out above.

The conclusion does not in fact answer either of the two questions which the report set out to answer. The final words of the first part of the remit called for an assessment of whether patients in Scotland were exposed to risks of Hepatitis C "longer than they should have been, given the state of knowledge at the time". The answer given was:

"The facts strongly suggest that SNBTS made very reasonable progress in developing products with reduced viral risk, relative to activity elsewhere. We accept that they were not the first. Scientific knowledge and technical expertise in this area were developing rapidly during the period in question, spurred on by the drive to eliminate HIV. It is worth remembering that commercial products available during the time in question were not proven to be HCV-safe (and many were subsequently withdrawn). We accept SNBTS' assertion that they were able to provide sufficient hepatitis C inactivated Factor VIII to cover the needs of all haemophiliac patients in Scotland by 1988 – we know of no other country which could make the same claim." 1212

The conclusion therefore does not address the first part of the remit at all, because it does not assess the delays (if they were truly delays) in providing a virally inactivated product in Scotland when one had been provided 18 months before in England. More importantly, the remit agreed by officials (which was specific to the period 1985-1987) was not the remit from the Minister, which left the time-frame open. It gave room for a far wider investigation than took place. It simply does not deal with how patients were exposed to risks of Hepatitis C (or non-A non-B Hepatitis) nor how those risks might have been reduced or avoided. These might (by way of example only) have included the question of whether surrogate testing should have been introduced (an issue which the Scottish Executive declined to investigate) or whether people with haemophilia should have been given information and choice over methods of treatment, including the possibility of using alternative forms of treatment (such as cryoprecipitate or DDAVP).

Even with the focus on the period in the mid 1980s, the report failed to explore whether steps should have been taken to obtain a modest supply of 8Y so that those who would most

<sup>1210</sup> Written Statement of Bruce Norval para 13.7 WITN2235003

<sup>1211</sup> Written Statement of Bruce Norval para 13.12 WITN2235003

<sup>1212</sup> Scottish Executive Health Department *Hepatitis C and heat treatment of blood products for haemophiliacs in the mid 1980s* October 2000 pp12-13 GGCL0000010

benefit from it – people who were previously untreated or minimally treated – could be given a product that might not transmit Hepatitis C, as opposed to a product that undoubtedly would transmit the virus.<sup>1213</sup>

Dr Keel was insistent that the remit of the investigation had been agreed with the Haemophilia Society: see, for example, her oral evidence to this Inquiry, where she said the remit had been "agreed by the Haemophilia Society";1214 her statement that "the report's remit was governed by the Haemophilia Society's wishes";1215 and her criticism of the Health and Care Committee's observations on remit which she said "fails to acknowledge that this was agreed with the Haemophilia Society, who were fully signed up to its terms before we embarked on it."1216 However, this was plainly not the case. Whilst the question relating to the different position in England and Scotland in 1985-1987 was a principal issue raised by the Haemophilia Society, the Society made clear in its meeting with, and letters to, the Minister that it considered the remit should be significantly wider.

In the second part of the remit the report had been asked to examine evidence about the information given to patients about the risks of contracting Hepatitis C from blood products. The conclusion was: "In relation to information given to patients about the risks involved with their treatment, we accept that knowledge of the effects of HCV would have been limited. We accept that clinicians would have had available to them information about the general risks of blood-borne disease, including hepatitis, and that they would have been able to pass this information on to patients." 1217

By way of comment these conclusions – perhaps tellingly – do not make any assessment of the information actually given **to patients**. It says there was information that could have been given, but does not begin to say whether it was.

It was further concluded that there was "no evidence of any policy by Haemophilia Centre Directors deliberately to mislead patients about the risks of hepatitis." This too is not an answer to the guestion of what information was provided to patients.

#### The conclusion continued:

"We accept that it would be good practice to offer people a test for HCV when it became available and to discuss the result with them. We have seen no evidence that clinicians had a policy to test without informing patients. Whether these policies may have failed in the case of any individual patient is outwith the scope

<sup>1213</sup> See the chapter on Haemophilia Centres: Policies and Practice.

<sup>1214</sup> Professor Aileen Keel Transcript 26 July 2022 p49 INQY1000234\_002

<sup>1215</sup> Scottish Parliament Health and Community Care Committee *Haemophilia and Hepatitis C* 23 May 2001 p4 MACK0001929\_029

<sup>1216</sup> Memo from Dr Keel to Sandra Falconer 3 October 2001 p2 SCGV0000247 094

<sup>1217</sup> Scottish Executive Health Department Hepatitis C and heat treatment of blood products for haemophiliacs in the mid 1980s October 2000 p13 GGCL0000010

of this exercise; we have outlined a complaints procedure in this report and we also note that some patients have started legal proceedings." 1218

Five comments. The remit was to examine evidence about information given in the 1980s. Testing specifically for Hepatitis C did not begin until 1991, so speaking of direct tests would, strictly, fall outside the remit. Second, no part of the remit asks about the practice in respect of **testing**. Third, the remit was concerned not with being told of the results of the administration of blood products (which is what testing would be concerned with: hence this would be an after-the-event conversation) but about the risks of being infected by them (ie a before-the-event conversation): testing looks at whether someone has been infected, whereas advice as to the risks looks to whether someone will or may be. Fourth, whether policies failed in individual cases addresses a different question from that set out in the remit, albeit one that had been raised by the Haemophilia Society and one which Susan Deacon had said in her letter of 27 September 1999 would be considered. Fifth, and most importantly, if the report was going to consider testing, it should have done so adequately so as to answer the questions which had led to it reviewing testing. What was in issue were the concerns the Haemophilia Society had expressed: that some patients had been tested and not told the results; that in many cases there was delay ("well over a decade") in being told; and that in some centres PCR1219 testing had not been done properly.1220 The report did not address these concerns.

The conclusions in the text as to testing thus do not actually answer the questions posed by the remit. Moreover, if in addressing testing it had been intended to address the concerns expressed by the Haemophilia Society, it did so in a way which was both inappropriate and inadequate.

The conclusion of the report about information given to patients was very carefully worded. It did not say what patients knew. It did not say that they had been told of risks by their clinicians. It said merely that the clinicians were in a position to tell them, not that they did. It does not say whether individual clinicians had the practice of not informing their patients – what the report dealt with was whether "clinicians" (using that word generally) had a "policy to test without informing patients" – a policy is generally agreed in advance to apply across the board, as a statement of what should be done; it is different from a "practice", which is what usually happens and may be individual. To ask if the clinicians had such a "policy" does not answer the question whether that is what they did in individual cases, nor whether some had a practice of doing so, but also, and significantly, said absolutely nothing about what patients had been told about the risks of contracting the virus.

<sup>1218</sup> Scottish Executive Health Department Hepatitis C and heat treatment of blood products for haemophiliacs in the mid 1980s October 2000 p13 GGCL0000010

<sup>1219</sup> Polymerase chain reaction: a test to detect the presence of a virus.

<sup>1220</sup> See: Memo from Michael Palmer to PS/Minister for Health and Community Care 17 September 1999 SCGV0000170\_153, The Haemophilia Society Response to the Scottish investigation into hepatitis C infection via contaminated blood within the haemophilia community December 1999 PRSE0001404

<sup>1221</sup> Scottish Executive Health Department Hepatitis C and heat treatment of blood products for haemophiliacs in the mid 1980s October 2000 p13 GGCL0000010

In evidence, the following exchange took place between Counsel and Susan Deacon:

"Q. I'm not asking you whether or not you think that the conclusions are right but whether they actually adequately addressed what the report set out to address?

A. I thought we had gone some way -- I say 'we' in the collective sense of the Executive -- I thought that we had gone some way towards opening up discussion and providing evidence around some of what had gone on. It was very clear to me that there were many, many other more questions and, you know, it surprised me a little, to be honest ... how much store was put on this piece of work. It was what it was." 1222

This fell short of being an endorsement of the report such as asserting it had fully and properly addressed its remit.

She was pressed in evidence on the way the report had dealt with the second part of the remit, where officials said "We have seen no evidence that clinicians had a policy to test without informing patients" and asked:

"Q. What is difficult about no evidence of nothing happening is that there is nothing to see if it hasn't happened. The only way of finding out is by asking the patients. Did you challenge or ask the people who compiled this report how many patients they had spoken to?

A. Well, there was some articulation of that in the report and, again, you know, this is over 20 years ago, so I genuinely can't recall discussions that took place along the way, there would have been discussions. But I think I was sufficiently satisfied at the time that there had been". 1223

A similar phrase was used in the press statement which accompanied the report. In that press statement Susan Deacon was quoted as saying:

"Having studied all the facts, I have concluded that there is no evidence that the relevant authorities did anything other than their best for patients. As a result I do not believe that the NHS should pay compensation for non-negligent harm to those haemophiliacs who contracted Hepatitis C during the period covered by the report. When I announced this exercise I stressed that we would – as a new Executive – take a fresh look at the evidence. And we have done this. But we have seen no new evidence and nothing to demonstrate that compensation is owed." 1224

Counsel asked her about the phrase "no evidence that the relevant authorities did anything other than their best for patients", reminding her of evidence which Jeremy Hunt had given about the way in which institutions closed ranks after something had gone wrong. He called it "groupthink": which Counsel summarised as beginning by thinking that "these were

<sup>1222</sup> Susan Deacon Transcript 29 July 2022 p78 INQY1000237

<sup>1223</sup> Susan Deacon Transcript 29 July 2022 p81 INQY1000237

<sup>1224</sup> Haemophilia Society Trustees News and Information 5 27 October 2000 p3 HSOC0016541

good people trying to do their best, and we just needed to recognise that it wasn't an easy decision." Then the "groupthink" moves on to: "we need to protect these people who are only trying to do their best." 1225

Having described this evidence, Counsel then asked: "Now, looking at the language that you have used or has been attributed to you in this news release, do you think, looking back, that the approach that the Department had to the investigation and to the process that they went through may have involved some element of that groupthink of 'Well, look, these were good people trying to do the best they can, so therefore we must protect them'?"<sup>1226</sup>

#### Susan Deacon's answer was:

"Undoubtedly ... in addition, to the groupthink that you've described, I think there was also a degree of concern and defensiveness across the entire system, and I – you know, I think this has included us as ministers, you know, about just where – I use this phrase again – where we would go next and what the costs and consequences might be. But that was not devoid of concern for individuals ... So if you had a parallel bit of groupthink, if you like, which was also about there's all this litigation, there's all these things we could be asked to pay for, there's all these, you know, things that might come down the track, then yeah, ... I think that combines to take you to a particular place, which isn't necessarily the right one." 1227

Counsel's next question was "the premise of my question was: looking back, what – do you think this is what has happened? You said yes. The follow-on question from that then is: was that groupthink apparent to you at the time?" 1228

The answer was a long one. It included "I would expect ... there to be an element of groupthink in any organisation ... then yes, I was conscious of that across a range of different areas. But I think you are right: I think you see more of that, obviously when you look through -- when you look back". 1229

On a separate point the press release talked about the outcome of treatment with blood products in the 1980s as having been "unforeseen". 1230 Susan Deacon was challenged on the use of that word and agreed that it certainly was not unforeseen. 1231

The expectations (or at least the hopes) of the Haemophilia Society for the report on the one hand, and of Susan Deacon on the other, were very different. The Haemophilia Society was looking for a comprehensive account of how it was that so many people with haemophilia

- 1225 Susan Deacon Transcript 29 July 2022 pp85-86 INQY1000237
- 1226 Susan Deacon Transcript 29 July 2022 p86 INQY1000237
- 1227 Susan Deacon Transcript 29 July 2022 pp86-88 INQY1000237
- 1228 Susan Deacon Transcript 29 July 2022 p88 INQY1000237
- 1229 Susan Deacon Transcript 29 July 2022 pp88-90 INQY1000237
- 1230 Haemophilia Society Trustees News and Information 5 27 October 2000 p3 HSOC0016541
- 1231 Susan Deacon Transcript 29 July 2022 pp90-94 INQY1000237

came to be infected with Hepatitis C, yet had been given inadequate or no information about the risks. Susan Deacon's inquiry was simply prompted by the allegation that Scotland had lagged behind England in producing a heat treatment which was also effective against both HIV and Hepatitis C and after meeting the Society she widened it to include information provided to patients. The report as she commissioned it thus had a more limited focus.

On a strict reading of the remit the question asking if patients were exposed for longer than they should have been is asking when they should not have been exposed to the risks at all, or at least whether those risks should have been reduced. That was not really the question which the Scottish Executive set out to answer. But nor was it a general examination of the whole scope of what had caused or contributed to infection.

The evidence is revealing of the reaction more generally of the Civil Service in Scotland. Although it is sometimes not easy to follow the thread of answers which Susan Deacon gave, she, like Jeremy Hunt, also thought that there was an element of closing ranks around doctors against whom allegations were made, where these allegations were made generally, on the basis that they were certainly trying to do their best, and needed to be protected. She thought groupthink arose, and thought this at the time.<sup>1234</sup>

It is, ultimately, a lost opportunity that – rather than this investigation by civil servants who had the mindset Susan Deacon described, which looked only at a small part of a very large picture – there had not, instead, been a wider, clearly independent, inquiry with a much broader scope.

The fact that Scottish patients did not have access to 8Y is highlighted by considering the report in context. It should be noted that this is not simply a question of 8Y being made available, 1235 but is a reflection of the fact that there was not enough 8Y to supply the needs of English and Welsh patients. This in turn is a consequence of a failure to achieve self-sufficiency, and part of that, as the chapter on *Self-Sufficiency* highlights, is that full use was not made of the Scottish production facilities, though it both could and should have been. If the availability of hepatitis-safe products 1236 had been seen as a UK priority for previously untreated people with bleeding disorders, such as children and some adults with mild conditions – adopting a UK-wide perspective 1237 rather than taking an approach that treated

<sup>1232</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 8 September 1999 p11 SCGV000043 047

<sup>1233</sup> Memo from Michael Palmer to PS/Minister for Health and Community Care 17 September 1999 pp1-2 SCGV0000170 153

<sup>1234</sup> Susan Deacon Transcript 29 July 2022 pp85-90 INQY1000237

<sup>1235</sup> See the chapter on Haemophilia Centres: Policies and Practice.

<sup>1236</sup> Once it had become probable that 8Y was effective against hepatitis, which would be increasingly apparent after March 1986. Smith et al *Interim Results of Surveillance for NANBH in Patients Receiving Heated Concentrates Produced in England* Developments in Biologicals 1987 p3 WITN6914063

<sup>1237</sup> The problem of achieving this was that the supply of 8Y was not enough to supply even half of the requirements for England and Wales. The balance was supplied by purchasing commercial concentrates, of which none that was available was hepatitis free. Thus to supply even some of the needs of Scotland and Northern Ireland for hepatitis-free product would mean being unable to supply such product to as many people in England and Wales as possible. If, however, a UK-wide perspective

nations as separate – this would have reduced the number of infections in these particularly vulnerable groups. This was the sort of issue that a more curious investigation could have brought to light. Instead, the Scottish Executive report was a missed opportunity for the new Executive to investigate the issues on behalf of Scottish citizens who had become infected in the course of NHS treatment.

## The investigation by the Health and Care Committee

Following the publication of the Scottish Executive report, Karin Pappenheim issued a statement which described the work as very thin and incomplete, failing to address the central concerns of those infected. "Reading this today", she said, people "must feel a strong sense of injustice because so many issues of vital concern to them have not been touched upon." The Society would continue to push for a full public inquiry to ensure all the issues were dealt with. 1238

The events that followed – the investigation by the Health and Care Committee, the establishment of the expert group under Lord Donald Ross, the interactions between Malcolm Chisholm and first Alan Milburn and then John Reid, and the announcement in August 2003 of what would become known as the Skipton Fund – are referred to in other parts of the Report, 1239 but are set out below so as to provide a more comprehensive picture of the response of government within Scotland.

The position in the Scottish Executive, both before and in the aftermath of the publication of the Scottish Executive report, remained one of fundamental opposition to financial support or compensation for those infected with Hepatitis C, as Professor Keel confirmed in her evidence.<sup>1240</sup> Professor Keel herself regarded it as a "dangerous precedent."<sup>1241</sup>

On 19 February 2001 Christine Dora sent an email to the Minister, Dr Keel and other officials to report a conversation which she had had with Charles Lister at the Department of Health, which indicated that Lord (Philip) Hunt inclined towards sympathy for "the plight of the affected haemophiliacs" and had agreed to meet Lord Alf Morris to revisit the idea of compensation: "Charles and I acknowledged that if one of the 4 administrations should crack, it becomes presentationally much more difficult for the others not to." Handwritten onto the email were these words from the Minister: "This gives me enormous concern. Please

had been adopted, there would most probably have been enough to supply such vulnerable groups. A failure to coordinate English and Welsh with Scottish and Northern Irish supply arrangements as if the two were one unit thus exposed vulnerable people in Scotland and Northern Ireland to a risk which they need not have faced, and should not have done. Sadly, there is no evidence that any representations were made at government level to rectify this. Nor did Susan Deacon's report examine it as it might have done.

<sup>1238</sup> Haemophilia Society *Trustees News and Information 5* 27 October 2000 p6 HSOC0016541. See also: Letter from the Haemophilia Society to Susan Deacon 27 October 2000 HSOC0011980

<sup>1239</sup> See the chapters on *Delay in Holding a Public Inquiry* and *Government Response to Hepatitis C Infections*.

<sup>1240</sup> Professor Aileen Keel Transcript 26 July 2022 pp61-62 INQY1000234 002

Written Statement of Professor Aileen Keel p44 WITN5736003, Professor Aileen Keel Transcript 26 July 2022 p62 INQY1000234\_002

arrange for urgent contact to be made with Philip Hunt's office ... emphasising that we have withstood enormous pressure on this issue ... any movement from the previous position, without discussion with other administrations, would, in my view, be quite unacceptable."1242 The existing policy was, however, adhered to by Lord Hunt, in response to which it was recorded that Susan Deacon "will be vvv relieved!"1243

The Health and Care Committee of the Scottish Parliament, which had received two petitions on Hepatitis C – PE185 (calling for the establishment of a system of compensation)<sup>1244</sup> and PE45 (calling for an independent inquiry)<sup>1245</sup> – and had decided in December 2000 to take further evidence, convened on 14 March 2001 to hear evidence from representatives of SNBTS and of the Haemophilia Society, including Philip Dolan and Bill Wright.<sup>1246</sup>

On 6 April 2001, judgment in *A and Others v National Blood Authority* having been handed down on 26 March, Susan Deacon wrote to Lord Hunt to urge the Department of Health/ National Blood Authority to seek permission to appeal.<sup>1247</sup>

On 26 April 2001 a debate took place in the Scottish Parliament on a motion in support of compensation for people infected with Hepatitis C, during which the Deputy Minister for Health and Community Care, Malcolm Chisholm, reiterated the "no compensation" in "cases of non-negligent harm" position.<sup>1248</sup>

Both Susan Deacon and (to a limited extent) Dr Keel appeared before the Health and Care Committee on 23 May 2001. 1249

Having concluded its evidence gathering sessions, the Health and Community Care Committee issued its report on 26 September 2001 – 11 months after the Scottish Executive's report. The report considered three principal issues. The first was whether ALT testing should have been introduced. The Committee had limited evidence on this issue, such that it was difficult to reach a definitive conclusion. However it accepted the case put by SNBTS and observed that there appeared to have been a number of important reasons for not using the test, including the risk of running out of blood supplies. (This Inquiry

- 1242 Email from Christine Dora to Sandra Falconer 19 February 2001 SCGV0000174\_068. Emphasis in original.
- 1243 Email chain between Minister for Health and Community Care and the Scottish Health Department 21 February 2001 p1 SCGV0000174 066
- 1244 Petition for the establishment of a scheme to compensate and assist people who have been infected with Hepatitis C through blood transfusions 26 April 2000 WITN2235013
- 1245 Petition to the Scottish Parliament calling for an independent inquiry into contaminated blood products 7 December 1999 WITN2235012
- 1246 Health and Community Care Committee Report 14 March 2001 SBTS0000356 022
- 1247 Letter from Susan Deacon to Lord Hunt 6 April 2001 SCGV0000241\_036. Lord Hunt informed her on 10 April that the Department of Health had decided "reluctantly" not to appeal. Letter from Lord Hunt to Susan Deacon 10 April 2001 SCGV0000241\_034
- 1248 Scottish Parliament Official Report on Hepatitis C 26 April 2001 p5 SBTS0000357 013
- 1249 Scottish Parliament Health and Community Care Committee *Haemophilia and Hepatitis C* 23 May 2001 MACK0001929 029
- 1250 Health and Community Care Committee Report on Hepatitis C 2001 MACK0001929 001
- 1251 Health and Community Care Committee Report on Hepatitis C 2001 p17 MACK0001929 001

has had the benefit of rather more evidence regarding this issue and is satisfied that ALT testing, coupled with Hepatitis B core antibody ("anti-HBc") screening, should have been introduced). 1252 The second issue was the delay in Scotland in introducing heat treatment for its domestically produced concentrates, compared to the position in England; again the Committee acknowledged its evidence was limited but its provisional view was that there was no evidence of negligent delay on the part of SNBTS. 1253 The third issue related to the failure to inform patients fully of the risks involved. Here the Committee suggested that it was regrettable that some clinicians were not more open with their patients. 1254 The Committee, whilst regretting that the Executive's report did not address a number of important matters, did not recommend a public inquiry, both because of the lapse of time since the events in guestion and because such an investigation would perpetuate the link between faultfinding and examining the case for providing practical assistance. 1255 However, having made these findings (some of them provisional), the Committee turned to what it described as a fundamental question of fairness and consistency and the moral case for providing support. It pointed to the recent A and Others v National Blood Authority decision, and the existence of the Macfarlane Trust, and was persuaded by the moral case for providing financial assistance to those infected through blood and blood products. 1256 concluding that:

"financial and other practical assistance, awarded on a no-fault basis, is the clearest solution to the issues raised in these petitions. We believe as a matter of fairness that individuals who have suffered serious, long-term harm as a result of NHS treatment should receive some practical assistance. We also believe that this solution is required for reasons of consistency, in recognition of the fact that HIV sufferers already receive assistance, under clearly analogous circumstances, via the MacFarlane Trust." 1257

It recommended that a mechanism for achieving this should be set up and come into operation within a period of twelve months.

Professor Keel expressed the view to the Inquiry that the report was slightly naive and rather illogical. Her recollection was that her views were shared by colleagues within the Health Department of the Scottish Executive. 1258 Her strength of feeling that there should not be any compensation is demonstrated by her statement to the Inquiry that she "regretted" that the judgment of Mr Justice Burton had "forced" a move away from the principle of no negligence, no compensation. 1259 Indeed, towards the conclusion of her evidence she explained that "I

<sup>1252</sup> See the chapter on Surrogate Screening for Hepatitis C.

<sup>1253</sup> Health and Community Care Committee Report on Hepatitis C 2001 p19 MACK0001929\_001

<sup>1254</sup> Health and Community Care Committee Report on Hepatitis C 2001 p20 MACK0001929\_001

<sup>1255</sup> Health and Community Care Committee Report on Hepatitis C 2001 p22 MACK0001929\_001

<sup>1256</sup> Health and Community Care Committee Report on Hepatitis C 2001 p24 MACK0001929 001

<sup>1257</sup> Health and Community Care Committee Report on Hepatitis C 2001 p26 MACK0001929 001

<sup>1258</sup> Professor Aileen Keel Transcript 26 July 2022 pp73-74 INQY1000234 002

<sup>1259</sup> Written Statement of Professor Aileen Keel p60 WITN5736003. She defended this in her oral evidence, explaining that it seemed "logical" to her that the previous principle was a sound one. Professor Aileen Keel Transcript 26 July 2022 pp75-76 INQY1000234\_002

still believe that the logic here would have been not to set up a financial assistance scheme specifically with this group of patients, because it elevated their problems to a higher level than many other groups". 1260

Notwithstanding the recommendation of the Committee, Susan Deacon told John Hutton (Minister of State at the Department of Health) in mid November 2001 that "We will hold the current view" – ie no compensation – "and try and sustain it as best we can". 1261

On 28 November 2001 Malcolm Chisholm replaced Susan Deacon as Minister for Health and Community Care (having been Deputy Health and Community Care Minister since October 2000). On 30 November 2001 a submission was provided to the First Minister, recommending that the Committee's recommendations be rejected and that instead the Executive should offer to set up an expert group to examine whether the general principle of offering financial and practical support was right and practicable, and if so what universal criteria could be applied. 1262

The submission argued that it would be wrong to "create an expectation that these people would automatically receive compensation for exposure to an unknown risk for which no preventative measures could be taken." Adopting the Committee's recommendation would, according to the submission, have that effect. The difficulty with that argument is twofold. The first is the assumption that **no** preventative measures could be taken. That was plainly not the position here, to take but one example – that of surrogate testing. The second is that non-A non-B Hepatitis was not an **unknown** risk – it was a known one – and thus would not set a precedent in respect of genuinely unknown risks. 1264

In response to a query from a Cabinet colleague, Malcolm Chisholm confirmed on 5 December that the Executive response "appears to rule out financial compensation in the terms suggested by the Committee." He acknowledged this might seem a harsh stance, but said it was justified "in terms of the need to avoid establishing a new, wide-ranging precedent on compensation." 1265

- 1260 Professor Aileen Keel Transcript 26 July 2022 p115 INQY1000234 002
- 1261 Note of telephone conversation between Susan Deacon and John Hutton 14 November 2001 p3 SCGV0000247\_036. It is to be noted that when Susan Deacon said that she wanted to look at it from a UK perspective, John Hutton said "But it is an entirely devolved matter" the reverse of the position taken by Alan Milburn a year later when he was attempting to stop the Scottish Executive from proceeding with a financial support scheme. See the chapter on Government Response to Hepatitis C Infections.
- 1262 Response to the Health and Community Care Committee's Report on Hepatitis C in Blood November 2001 p10 SCGV0000247\_002. The submission recorded that officials in England and Wales had expressed the support of their administrations for the rejection of the compensation recommendation and the establishment instead of an expert group. No specific response had been received from Northern Ireland but officials had previously indicated that the absence of a response should be taken to indicate support.
- 1263 Response to the Health and Community Care Committee's Report on Hepatitis C in Blood November 2001 p4 SCGV0000247\_002
- 1264 Malcolm Chisholm Transcript 28 July 2022 pp44-46 INQY1000236
- 1265 Email from Scott McIntyre to the First Minister and others 5 December 2001 SCGV0000248 077

On 11 December the Executive announced the intention to establish an expert group to look at "the pros and cons of a system to offer financial and other support for people who have been harmed by health service treatment and where the NHS is not at fault." Its press release asserted that extending the current regime to those infected with Hepatitis C would be unfair to those affected by "other conditions in a similar way" and would create a risk-averse culture within the NHS.<sup>1266</sup>

In his oral evidence to the Inquiry Malcolm Chisholm suggested that the Executive's thinking was "if we're going to give assistance in situations like this, we're not happy just about this being on an ad hoc basis, and therefore it will be a precedent. We want to know what the principles are for making such awards. What criteria will be used? How will we have general standards and principles in accordance with which we can make awards?" That was, he said, the reason for setting up the expert group, although ultimately they were unable to come up with such principles and ended up with the ad hoc position. 1267

The expert group was established under the chairmanship of Lord Ross. <sup>1268</sup> Its preliminary report was released to Malcolm Chisholm in early September 2002. <sup>1269</sup> It noted that those infected with HIV had received some financial support and concluded that it was inequitable that those infected with Hepatitis C had received nothing, and that this inequity should be addressed by introducing new arrangements. <sup>1270</sup> Its first recommendation was that a discretionary trust should be established and funded to provide: an initial lump sum of £10,000 to those infected with Hepatitis C from blood, blood products or tissue; an additional lump sum of £40,000 to those who developed chronic Hepatitis C; and additional financial support (to be calculated on a common law damages basis) to those who subsequently suffered serious deterioration in their health. <sup>1271</sup>

<sup>1266</sup> Scottish Executive Press Release *Executive to Look at Future Health Compensation system*11 December 2001 p1 SBTS0000358\_040. Its formal response to the Health and Community Care
Committee is at Report on Hepatitis C – Response from Scottish Executive SCGV0000044\_012

<sup>1267</sup> Malcolm Chisholm Transcript 28 July 2022 pp36-38 INQY1000236

<sup>1268</sup> Its membership was wide-ranging and impressive: it included, for example, the head of policy at the Royal College of Nursing in Scotland, the chair of the British Medical Association in Scotland, the director of nursing at a Glasgow NHS trust, two individuals who had been infected with Hepatitis C (one of whom was Philip Dolan of the Scottish Haemophilia Group Forum), the medical director of a Scottish NHS trust, a professor in medical ethics and the chair of the Scottish Academy of Royal Colleges and Faculties. Preliminary Report of the Expert Group on Financial and Other Support September 2002 p29 HSOC0003349. Its chair, Lord Ross, had not long before retired from his position as Lord Justice Clerk, the second most senior judge of the Court of Session.

<sup>1269</sup> Preliminary Report of the Expert Group on Financial and Other Support September 2002 HSOC0003349

<sup>1270</sup> Preliminary Report of the Expert Group on Financial and Other Support September 2002 para 2.4 HSOC0003349. Robert Stock, who was head of the Scottish Executive's ancillary services branch (Health Planning & Quality Division) between May 2001 and November 2004, was critical of the expert group because he felt they had omitted to take into account aspects of their terms of reference "regarding the possibility of inhibition of innovation and creativity, being consistent with efficient health service provision and representing a fair deal for ALL patients". Written Statement of Robert Stock para 9 WITN7078001

<sup>1271</sup> Preliminary Report of the Expert Group on Financial and Other Support September 2002 pp10-11 HSOC0003349

Malcolm Chisholm told the Inquiry that the fundamental problem confronting him on receiving the report was the cost (which was "going to cause enormous problems for me in the Health budget") but that it was fair to say that there was also resistance in terms of who would receive a payment because the thinking in the Executive was that "it was more looking like compensation if everybody received the payment." 1272

A Cabinet paper on 30 October 2002 recorded that the Minister did not feel it would be right to accept the recommendation as it stood. He identified three options: decline to respond until the final report was produced; accept the recommendation in principle but with a reduced scope (with the suggestion that payments might only be made to people who had developed cirrhosis, liver cancer or liver failure); or reject the recommendation outright on the basis of principle. His view, as communicated to Cabinet colleagues, was that the choice was between the second and third options; the third option (rejecting the recommendation) was "correct but would create an enormous outcry"; Malcolm Chisholm was "driven to conclude that [the second option] is the least bad option, although there are financial and Westminster difficulties attached to it." 1274

On 4 November 2002 the discussion took place between Malcolm Chisholm and Alan Milburn that has been described earlier in this Report. A note of the discussion (prepared by Alan Milburn's Private Office) noted that Malcolm Chisholm was due back before the Health and Community Care Committee imminently and "feels he has to offer something, probably around payments to people once they become seriously ill." This was described to him by the Secretary of State as a grave mistake. He was advised to tough it out, and a query was raised as to whether or not this was a devolved matter. This resulted in a letter from Malcolm Chisholm to Andrew Smith, the Secretary of State for Work and Pensions, the following day, regarding both the question of whether this was within devolved competence and the question of amending social security legislation to disregard any payments that the Scottish Executive might decide to make.

On 6 November 2002 the Scottish Executive's response to the Ross group's preliminary report was announced by way of a press release, which recorded that there were complex medical, legal and financial considerations to take into account, and that the Executive needed to "think carefully about who needs help, what is the best way to design a scheme and structure payments so that the individuals involved benefit fully, while taking account of the costs of any payment scheme in the light of other health priorities." The "interface" with the social security system was being looked at and discussions were taking place with the

<sup>1272</sup> Malcolm Chisholm Transcript 28 July 2022 pp63-64 INQY1000236

<sup>1273</sup> Financial and Other Support for Patients Who Have Contracted HCV from Blood Transfusions etc: Recommendations of Expert Group 30 October 2002 p3 SCGV0001037\_050

<sup>1274</sup> Financial and Other Support for Patients Who Have Contracted HCV from Blood Transfusions etc: Recommendations of Expert Group 30 October 2002 p4 SCGV0001037 050

<sup>1275</sup> Email from Sammy Sinclair to Charles Lister 4 November 2002 DHSC0042275\_129. Malcolm Chisholm told the Inquiry that this was an accurate report. Alan Milburn "certainly wasn't happy" and "obviously tried" to change his mind, but "I wouldn't say he was too heavy about it." Malcolm Chisholm Transcript 28 July 2022 p73 INQY1000236

<sup>1276</sup> Letter from Malcolm Chisholm to Andrew Smith 5 November 2002 WITN6942015

Department of Work and Pensions. 1277 Malcolm Chisholm appeared before the Health and Care Committee that same day.

On 9 December a meeting took place between the Minister, representatives from the financial services sector and representatives from the Scottish Haemophilia Groups Forum and Scottish Hepatitis C Group. 1278

On 11 December 2002 Lord Ross and Philip Dolan gave evidence to the Health and Community Care Committee in support of the preliminary report. Lord Ross was asked about the stance in Westminster, which remained set against payments, and observed that the group "all felt strongly that it would not be a good answer to our recommendations ... to say that because it has been decided south of the border not to give compensation, we should do the same. We must think about what is appropriate for Scotland and we have the power to do so."1279 Asked about the fear of precedent setting, he confirmed that the group "did not feel that a dangerous precedent would be set in this case any more than was the case with the Macfarlane Trust. This is a very special situation and experience shows that cases such as Macfarlane or the compensation of people with CJD have not led to a flood of further claims. We do not believe that an acceptance of what we are proposing would establish a precedent leading to a flood of other claims."1280 Philip Dolan explained to the Committee how the expert group had taken time to examine seriously how Hepatitis C affected people "physically, socially and psychologically". He expressed, "like most people who are affected", astonishment, disappointment and anger at the group's recommendation seeming to be dismissed by the Minister: "What was the point of having an expert group then ignoring its main recommendations?"1281 Malcolm Chisholm then addressed and was questioned by the Committee. 1282

A paper on 22 January 2003 from Malcolm Chisholm to the Cabinet sought Cabinet agreement to an approach for making lump sum payments to those experiencing long-term symptoms or signs of liver inflammation, with increased awards to those developing more serious conditions such as cirrhosis. Three options were identified, with the Minister supporting the third option (£25,000 + £25,000) because of the financial implications. He sought agreement to be able to say to the Health and Care Committee, before whom he was

<sup>1277</sup> Scottish Executive Press Release Chisholm welcomes expert group preliminary recommendations 6 November 2002 p1 SCGV0000192 005

<sup>1278</sup> Minutes of Provision of financial services for people infected with Hepatitis C meeting 9 December 2002 DHSC5541441

<sup>1279</sup> Scottish Parliament Health and Community Care Committee Official Report on Hepatitis C 11 December 2002 p7 SCGV0000250\_019

<sup>1280</sup> Scottish Parliament Health and Community Care Committee Official Report on Hepatitis C 11 December 2002 p10 SCGV0000250\_019

<sup>1281</sup> Scottish Parliament Health and Community Care Committee Official Report on Hepatitis C 11 December 2002 p13 SCGV0000250 019

<sup>1282</sup> Scottish Parliament Health and Community Care Committee Official Report on Hepatitis C
11 December 2002 pp20-44 SCGV0000250\_019. The briefing provided to the Minister in advance
of his appearance, including lines to take on the final pages, is at Briefing for Health and Community
Care Committee meeting 3 December 2002 pp2-30 SCGV0000250\_022

due to appear again on 29 January, that the Executive favoured such a scheme, although it was still awaiting advice from the UK government on the devolved powers issue. 1283

The Cabinet agreed, following a brief discussion, to the option of £25,000 + £25,000 but a submission from Bob Stock on 29 January reported that "We have now further reviewed the costings and numbers currently known to have Hepatitis C, and have concluded that this goes beyond what would be affordable ... We have therefore costed a scheme on the basis of making lump sum payments of £20,000 to all those who now have Hepatitis C – with a further £25,000 to those who have cirrhosis, liver cancer or liver failure." This was, with the First Minister's agreement, put forward by Malcolm Chisholm to the Health and Community Care Committee when he appeared before them on 29 January 2003. The proposal was limited to those who were still alive and differed from the amounts recommended by the expert group, but was intended to cover anyone who had contracted the virus. The position in Ireland was distinguished on the ground that there was fault in Ireland but "no fault here." 1285

Malcolm Chisholm told this Inquiry that it was a matter of regret for him that he did not have the money to implement the Ross report in full.<sup>1286</sup> The perspective of a transfusion recipient involved in the work undertaken by the Ross group, however, was that the recommendations:

"were then almost completely ignored by the then Health Minister Malcolm Chisholm and Scottish Government. They simply re-devolved this responsibility of financial payments back to Westminster which then went on to set up the Skipton Fund. We objected to this as it was well within the devolved powers of the Scottish Government to deal with such payment schemes from a local Scottish perspective as a specific area of concern for Scottish patients who were infected via NHS procedures and to this day I am still not sure why this happened." 1287

The final report of the expert group under Lord Ross was issued in March 2003. 1288 This affirmed the group's recommendation that the Scottish Executive should agree to make compensation payments as a matter of urgency to anyone who could demonstrate on the balance of probabilities that they received blood, blood products or tissue from the NHS in Scotland (before the dates when they were made Hepatitis C safe) and who were subsequently found to be infected with Hepatitis C. The group expressed disappointment that the Minister had not accepted the preliminary recommendations on Hepatitis C in full. In particular it considered it "manifestly unjust" that no payments were proposed in respect of

<sup>1283</sup> Financial and Other Support for Patients Who Have Contracted HCV from Blood Transfusions etc: Scheme Options 22 January 2003 pp2-3 SCGV0000251\_034. The other options were similarly structured into two staged payments, but option 1 was £50,000 for each stage and option 2 was £35,000 for each stage.

<sup>1284</sup> Submission on Scottish Executive Proposal for Ex Gratia Payment Scheme (Hepatitis C from Blood) 29 January 2003 p2 SCGV0000251 018

<sup>1285</sup> Health and Community Care Committee meeting Transcript 29 January 2003 p27 RLIT0001091

<sup>1286</sup> Malcolm Chisholm Transcript 28 July 2022 p84 INQY1000236

<sup>1287</sup> Written Statement of ANON para 34 WITN2137001. An analysis called "The Ross Report: 10 years on" shows how many of Lord Ross's recommendations were not implemented. The Ross Report: Ten Years On 2014 WITN2287031

<sup>1288</sup> Report of the Expert Group on Financial and Other Support March 2003 HSOC0020367

those who had died: "it can only add a feeling of unfairness to the grief of the relatives". The group continued to believe there was a moral obligation to provide compensation and that justice would not be done unless its recommendations were implemented in full, or at least to a greater extent than was proposed.<sup>1289</sup>

As described in the chapter on *Government Response to Hepatitis C Infections*, the decision was then taken in June 2003 by the new Secretary of State for Health, John Reid, that some form of payments should be made in England. Following a meeting between John Reid and Malcolm Chisholm on 10 July, at which they agreed to try to develop *approach that showed solidarity*, the former wrote on 28 July confirming that Scotland's proposed scheme was accepted as being within devolved competence, and that officials in England and Scotland would work together over the summer on the scope of the scheme.

On 6 August Bob Stock sent a submission to Scottish ministers which recorded that Department of Health officials favoured the establishment of a single charitable trust that would administer payments on a UK basis and sought ministers' agreement to that. The Department of Health was regarded as being very concerned that developments did not leak out prior to the joint ministerial announcement, and believed that the proposal not to make payments to the dependants, relatives or estates of deceased patients "may well be contentious." 1292

The outcome was the announcement, in Scotland as in England, on 29 August 2003 of what would become the Skipton Fund. 1293

On 9 September 2003 Malcolm Chisholm appeared before the Health and Community Care Committee and confirmed the "good news" that the UK Government had agreed that the Scottish Executive had the powers to establish its proposed scheme and that the Department of Health had stated that it would also establish a scheme. There was no explicit reference to this being a UK-wide single scheme but he indicated that there "might be other advantages to the new situation and we will explore them". Asked about the difference between the payments being made in Ireland and those proposed for Scotland, the Minister said that in Ireland the Government had agreed that "wrongful practices were used" and that the payments in Ireland were compensation. "We", he said, "are making an ex gratia payment." 1294

<sup>1289</sup> Report of the Expert Group on Financial and Other Support March 2003 pp27-29 HSOC0020367

<sup>1290</sup> Email chain between Graham Bickler, Richard Gutowski, Sammy Sinclair and Richard Douglas 20-24 June 2003 p2 DHSC5320726

<sup>1291</sup> Letter from John Reid to Malcolm Chisholm 28 July 2003 DHSC0028241

<sup>1292</sup> Submission on Ex Gratia Payment Scheme for 'HCV from Blood' Patients 6 August 2003 p4 SCGV0000255 051

<sup>1293</sup> Following a telephone discussion between John Reid and Malcolm Chisholm on 26 August 2003. Email chain between Sammy Sinclair, Lee McGill, David Reay and others 27 August 2003 DHSC0014997\_120

<sup>1294</sup> Malcolm Chisholm Health Committee of the Scottish Parliament Transcript 9 September 2003 pp1-2 DHSC5325070

The response of the convener was that "it is so far from what Lord Ross recommended that I cannot believe that it is good news for those who have hepatitis C or their surviving relatives and partners." 1295

## **Public inquiry**

The intransigent failure to hold a public inquiry is examined in detail in another chapter. 1296 In summary, however:

- (a) The Haemophilia Society's calls for a public inquiry in the UK were echoed by campaigners in Scotland.
- (b) What resulted from those calls was the narrow and internal investigation established by Susan Deacon.
- (c) In December 1999 petition PE45 was lodged with the Scottish Parliament, calling for an independent inquiry. 1297
- (d) Following the publication of the Scottish Executive report in October 2000, there were renewed calls from campaigners and politicians in Scotland for an independent and open public inquiry.
- (e) The Scottish Executive continued to hold the line that no public inquiry was warranted, with that position being consistently articulated by successive ministers Susan Deacon, Malcolm Chisholm and Andy Kerr, between 2000 and 2006.<sup>1298</sup>
- (f) The principal (or at least significant) reason for refusing to hold a public inquiry in Scotland was the concern that it could result in large sums having to be paid in compensation.

- 1296 See the chapter on Delay in Holding a Public Inquiry.
- 1297 Petition to the Scottish Parliament calling for an independent inquiry into contaminated blood products 7 December 1999 WITN2235012
- 1298 Bill Wright described to the Inquiry the increasing disillusionment experienced in 2004-05 with the response of both the UK and Scottish Governments, with the rejection by Andy Kerr of a public inquiry after the Health and Care Committee's April 2006 support for one as "a particular low point." Written Statement of William Wright para 2.24 WITN2287019. Andy Kerr asked the Committee to reconsider their decision to call for a public enquiry: "I cannot see that there is any possible justification for the efforts and costs that would be involved, or that this would bring any benefit to the patients involved." Letter from Andy Kerr to Roseanna Cunningham 16 June 2006 p6 WITN2287040

<sup>1295</sup> Malcolm Chisholm Health Committee of the Scottish Parliament Transcript 9 September 2003 p1 DHSC5325070. A briefing on 26 September 2003 for a meeting between Malcolm Chisholm and Philip Dolan sought to answer the question of why the scheme was at variance from that recommended by the Executive's own expert group in this way: "The underlying principle behind the ex gratia payments announced is that they should go to people who are still alive and suffering. Have to weigh the issue of making a fair and reasonable payment to these people against all the other demands on the health budget. Lord Ross and the Expert Group were asked to ensure that any recommendations be consistent with efficient health service operation and represent a fair deal for all patients – but clearly they did not have access to information on other demands on the health budget to enable them to make that sort of judgement." Briefing on Hepatitis C – Public Enquiry Issues 26 September 2003 p5 SCGV0000256 077

- (g) As at May 2006 advice from officials in Scotland to Scottish ministers continued to be "very strongly against holding a public inquiry." 1299
- (h) Continued campaigning activities, a call from the Health and Care Committee in 2006 for an independent public inquiry, the judicial review claims which succeeded before the Court of Session in early 2008, and the new Scottish Government's position, consistent with its manifesto, that a public inquiry was warranted, led eventually to the announcement in April 2008 of what became known as the Penrose Inquiry.
- (i) For many of those infected and affected in Scotland (and indeed elsewhere), the Penrose Inquiry did not bring the answers or closure which they had fervently campaigned and hoped for.

# Commentary

It is clear that in the period prior to July 1999 the response of government to the plight of those infected and affected was determined in Westminster, and that the Scottish Office essentially followed the path mapped out by the Department of Health. There is little or no evidence of time being spent by health ministers in Westminster liaising with ministers in the Scottish Office in respect of the response to the infection of patients, or of Scottish Office ministers being able to influence the thinking in Westminster. Such interaction as there was took place at civil servant level, and civil servants in the Scottish Office did not challenge the thinking of those within the Department of Health.

Accordingly the same damaging approach as has been detailed earlier in this Report – an unwillingness to provide financial support, a misplaced fear of setting precedents, the repetition of inaccurate and harmful lines to take, the absence of any meaningful or robust or independent investigation – was mirrored in Scotland. Those infected in Scotland with HIV from blood products were, as in England, forced to resort to litigation, but having done so were not even consulted on the principle of, or terms of, settlement at a time when they should have been. Those infected with HIV from transfusion experienced the same delays in receiving financial support as those elsewhere in the UK – notwithstanding the clear views of the minister with responsibility for health policy in the Scottish Office, Michael Forsyth, that the attempts to distinguish their position were indefensible and unfair. Unjustified and unjustifiable claims that those infected had received the best treatment available and/or that they had been infected inadvertently served to bolster the continuing refusal to do anything more for them.

The move to devolved government in 1999 did not bring about the sea change that campaigners may have hoped for. In part this was a consequence of the institutional groupthink described above and the continued involvement of civil servants who had, pre devolution, followed the Department of Health line: Dr Keel, for example, plainly held firm

1299 Memo from Gerard Hetherington to Becky Spavin 26 May 2006 p2 DHSC0041159\_205 1300 See the chapter on *Delay in Holding a Public Inquiry.* 

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(but, on proper analysis, unfounded) views in relation to the treatment people had received, knowledge of risk, and the actions of clinicians. In part this was a consequence of the desire to avoid having to pay compensation – in Scotland, as in England, this was a driving force. Christine Dora's inappropriate expression of "hope" that people would not receive compensation<sup>1301</sup> was indeed the thinking in the Health Department.

The establishment of a Scottish Executive did, however, provide the impetus for a series of key events.<sup>1302</sup> It was a catalyst that led to UK-wide action.

It led first to the internal investigation and report produced by the Scottish Executive. Unhappily, however, that flawed process served only to compound the frustration and anger of those infected:<sup>1303</sup>

- (a) It excluded in their entirety those infected through transfusion (notwithstanding a request from the Health and Care Committee for their inclusion), on the curious and spurious basis that this was an issue where the outcome was already known.
- (b) The remit in relation to people with bleeding disorders was unduly narrow. Key issues that could have been included and explored were not.
- (c) The process was not open, transparent nor even-handed.
- (d) The evidence shows that to some at least it was no more than a "PR exercise", which would deflect criticism and provide a further basis for refusing compensation.
- (e) The information provided by clinicians was accepted uncritically and at face value, 1304 such that there was no real interrogation of the question of whether in reality sufficient information was provided to people to enable them to give informed consent to treatment.
- (f) Even the narrow remit of the report was not properly or adequately answered.

Karin Pappenheim was right to say that those reading the report "must feel a strong sense of injustice because so many issues of vital concern to them have not been touched upon." <sup>1305</sup>

Further, the fact that this investigation had been undertaken was then used as a reason to reject ongoing calls for a public inquiry.

<sup>1301</sup> It is the word "hope" which is misplaced. It was a reasonable view to think that no compensation should be awarded unless wrong had been done, and Christine Dora plainly felt that was the case. Written Statement of Christine Dora para 17.2(b) WITN7246001

<sup>1302</sup> Without which it is unlikely that the Skipton Fund would have been established.

<sup>1303</sup> As submitted on behalf of those represented by Thompsons solicitors, this led to "an inevitable sense of greater frustration and alienation at the hands of the State amongst the infected and affected community in Scotland ... Though the system had allowed the door to be opened, it had ... immediately been slammed in their face." Written submissions on behalf of the core participant clients represented by Thompsons Scotland 16 December 2022 p1044 SUBS0000064

<sup>1304</sup> This deference to the medical profession has echoes of the clinical freedom arguments deployed to justify government inaction in the 1970s and 1980s.

<sup>1305</sup> Haemophilia Society Trustees News and Information 5 27 October 2000 p6 HSOC0016541

Dissatisfaction with the Scottish Executive's report led to the second key event: the investigation by the Health and Care Committee, following receipt of petitions PE45 and PE185. This culminated in the Committee's recommendation, in its September 2001 report, that as a matter of fairness and moral responsibility a mechanism for the provision of financial and other practical assistance should be set up.

Hopes were swiftly dashed when instead of implementing those recommendations Malcolm Chisholm announced the establishment of an expert group. A strong inference is that this was an attempt on the part of the Scottish Executive to buy time in the face of increasing public and political support for compensation. It led, however, to a third key event: recommendations in a report issued by the expert group under the chairmanship of Lord Ross in September 2002 that financial support should now be provided.

Yet again, however, these recommendations were not implemented. Instead, a combination of reluctance on the part of the Scottish Executive to commit to the expenditure that this would have entailed, combined with the alarm this engendered in Westminster and the intervention of Alan Milburn in late 2002, led eventually to the introduction of a much more limited scheme that became the Skipton Fund.

These events comprised a series of missed opportunities to remedy (in some small measure at least) the injustices that had been, and continued to be, experienced. A fairer and more comprehensive Scottish Executive investigation, prompt acceptance of the Health and Care Committee's recommendations, implementation of the recommendations of the eminent expert group established by the Scottish Executive for that purpose – any one of these, if taken, could have alleviated the harm done to people infected and affected in Scotland. Instead, that harm was compounded. As the late Philip Dolan described, "For years, every time we have reached the top of a mountain, we have found that, when the cloud lifts, there is another mountain to climb." 1306

1306 Scottish Parliament Health and Community Care Committee Official Report on Hepatitis C 11 December 2002 p13 SCGV0000250\_019

# 7.7 Northern Ireland and Wales

This chapter considers the response of the Northern Ireland Office and the Welsh Office to people infected and affected and whether the response changed after the enactment of the Northern Ireland Act 1998 and the Government of Wales Act 1998.

### **Key Dates**

**1990s** David Hunt, Secretary of State for Wales, recalls there was no distinctive "*Welsh dimension*" when discussing the approach to infected blood.

**May 1995** Welsh Office and Northern Ireland Office express concern about financial implications of making payments for Hepatitis C.

**May 1995** Welsh Office follows the Department of Health line on payments in respect of Hepatitis C.

**June 1995** Northern Ireland Office follows the Department of Health line on payments in respect of Hepatitis C.

**July 1999** transfer of responsibility for health to the National Assembly for Wales.

**December 1999** transfer of responsibility for health to the Northern Ireland Assembly.

**March 2001** Jane Hutt, Minister for Health and Social Services in the Welsh Government, maintains the Westminster line that there will be no compensation because the NHS was not at fault.

**August 2003** Northern Ireland and Wales are not consulted in advance about the decision to reverse the line on Hepatitis C payments.

### **People**

John Breen Health Promotion Branch, DHSSNI

Peter Davenport Health Services Division, Welsh Office

**David Hunt** Secretary of State for Wales (1990 - 1993 and 1995 - 1995)

Jane Hutt Minister for Health and Social Services, Welsh Government (1999 - 2005)

**Malcolm Moss** Parliamentary Under-Secretary of State for Northern Ireland (1994 - 1997)

#### **Abbreviations**

**DHSSNI** Department of Health, Social Services and Public Safety for Northern Ireland **DHSS** Department of Health and Social Security

#### Northern Ireland

Just as the Northern Ireland Department of Health and Social Services ("DHSSNI") followed the policy decisions made by the Department of Health and Social Security ("DHSS") in London in relation to the risks of viral transmission by blood and blood products, with little observable influence from the DHSSNI on those decisions, 1307 so too did the response of the DHSSNI in the 1990s and 2000s (both before and after the enactment of the Northern Ireland Act 1998) largely echo the response of the Department of Health in Westminster. On matters relating to the infection of people with hepatitis and HIV through blood and blood products, the relationship largely remained one of "mirrored subservience". 1309

A submission from (probably) November 1986, discussing AIDS in general, recorded that the measures taken in Northern Ireland to prevent the spread of infection "mirrored initiatives which have been introduced at national level" including the introduction of screening within the Northern Ireland Blood Transfusion Service and participation by officials or ministers from Northern Ireland in the various national AIDS committees, such as the Expert Advisory Group on AIDS and the Home and Social Affairs Committee (as the Cabinet's Sub-Committee on AIDS was known). AIDS – The position in Northern Ireland 18 November 1986 p1 DHSC0046919\_006

It is notable that at the first meeting of the Ministerial Steering Group on AIDS in December 1985 there were (junior) ministerial representatives from the DHSS, Welsh Office and Scottish Office (as well as other departments), but the sole attendee from the Northern Ireland Office was a civil servant, Dr Robert McQuiston: Memo from Chris France to J Chilcott 19 December 1985 p2 CABO0000221. Dr McQuiston was again the sole attendee from the Northern Ireland Office at the second meeting of the Ministerial Steering Group on AIDS in April 1986: Minutes of the Ministerial Steering Group on AIDS meeting 15 April 1986 p1 SHTM0001036. It is unclear if a third meeting took place: having been scheduled for June 1986 and then July, it was postponed until November. Letter from Linda Oliver to John Peet 19 May 1986 HMTR0000007\_025, Letter from Linda Oliver to Penny Boys 27 May 1986 HMTR0000007\_031, Letter from Linda Oliver to Angus Macpherson 2 July 1986 SCGV0001172\_034, Letter from Linda Oliver to diary secretary to John Mackay 29 August 1986 SCGV0001171\_086. Handwritten notes recorded "It is difficult to believe that such a meeting has to be so long deferred in present circumstances" and "I agree ... that DHSS don't seem to be trying very hard to bring the Ministerial Cttee into play." Letter from Linda Oliver to diary secretary to John Mackay 29 August 1986 SCGV0001171\_086.

The Sub-Committee on AIDS of the Cabinet's Home and Social Affairs Committee first met on 11 November 1986 and was attended by the Minister of State or Secretary of State for Northern Ireland. Minutes of Cabinet Home and Social Affairs Committee Sub-Committee on AIDS meeting 11 November 1986 p2 CABO0100010, Minutes of Cabinet Home and Social Affairs Committee Sub-Committee on AIDS meeting 20 November 1986 p1 CABO0100009

<sup>1307</sup> See the chapter on Role of Government: Response to Risk.

<sup>1308</sup> Renamed the Department of Health, Social Services and Public Safety in December 1999; now the Department of Health.

<sup>1309</sup> The phrase used by Richard Needham to describe the position in the 1980s. He was Parliamentary Private Secretary to the Secretary of State for Northern Ireland 1983-1984 and Parliamentary Under-Secretary of State for Northern Ireland 1985-1992. Written Statement of Sir Richard Needham para 31 WITN5595001.

#### Thus, by way of example:

- (a) There is no evidence to suggest any substantive involvement in the decision-making that led to the decision to make a payment of £10 million to what became the Macfarlane Trust, save that Dr Brian Mawhinney was present, in his capacity as Parliamentary Under-Secretary of State in the Northern Ireland Office, at the meeting of the Sub-Committee on AIDS which met on 10 November 1987 and agreed that a payment should be made.<sup>1310</sup>
- (b) There is little evidence of any meaningful involvement of ministers within the Northern Ireland Office in the decision-making that led to the announcement of an additional payment to the Macfarlane Trust in November 1989, although (for example) the Secretary of State for Health's (Kenneth Clarke) minute to the Prime Minister of 22 November 1989 was copied to the Secretary of State for Northern Ireland, Peter Brooke.<sup>1311</sup>
- (c) There is little evidence relating to the involvement of the Northern Ireland Office in the settlement discussions relating to the HIV haemophilia litigation. In January 1991 John Canavan, a civil servant within the Department of Health in London, wrote to Jack Scott (assistant secretary) at the DHSSNI with a copy of the latest draft of the proposed terms of settlement, stating that "we think the document is now very close to reflecting our policy aims" and suggesting that the DHSSNI "might, therefore, wish to use it as a basis to begin discussions with the representatives of your HIV infected haemophiliacs." Jack Scott was (along with representatives of the Scottish Office and the Welsh Office) copied into some Department of Health communications regarding the litigation. 1313
- (d) When the position of the Secretary of State for Health regarding the provision of ex gratia payments to people infected with HIV through blood transfusion changed in November 1991 (William Waldegrave now being in post), communications between William Waldegrave and the Chief Secretary to the Treasury, David Mellor, were copied to the Secretary of State for Northern Ireland, Peter Brooke.<sup>1314</sup> The latter responded by supporting the proposal, expressing the view that "there is little public

<sup>1310</sup> Minutes of Cabinet Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p1, pp6-10 CABO0100016 011

<sup>1311</sup> Memo from Kenneth Clarke to the Prime Minister 22 November 1989 p1 HMTR0000001\_013. Further correspondence with the Chief Secretary to the Treasury was also copied to the Secretary of State for Northern Ireland. Letter from Kenneth Clarke to Norman Lamont 23 November 1989 p2 DHSC0002536\_027, Letter from Norman Lamont to Kenneth Clarke 23 November 1989 DHSC0002536\_032

<sup>1312</sup> Memo from John Canavan to Jack Scott 9 January 1991 DHSC0003657\_108

<sup>1313</sup> See by way of example: Memo from David Burrage to Charles Dobson and others 15 May 1991 MACK000042, Memo from David Burrage to Charles Dobson and others 14 June 1991 p1 BNOR0000357, Memo from Charles Dobson to Stephen Alcock 2 May 1991 p1 DHSC0002433\_023, Memo from Charles Dobson to Stephen Alcock 1 May 1991 DHSC0003398\_026, Memo from Charles Dobson to Stephen Alcock 19 April 1991 DHSC0003662\_089, Memo from David Burrage to Charles Dobson and others 20 March 1991 DHSC0041209 148

<sup>1314</sup> Letter from William Waldegrave to David Mellor 2 December 1991 p2 DHSC0002921 009

understanding or sympathy for the Government's position on this matter and that the campaign for a settlement is likely to gather momentum in the months ahead." <sup>1315</sup>

When, in the 1990s, the focus of attention shifted to the suffering of those infected with Hepatitis C and the question of making ex gratia payments to them, 1316 the DHSSNI took the same line as the Department of Health. On 6 April 1995 Eddie McGrady (the then Member of Parliament for South Down) wrote to Malcolm Moss (the Parliamentary Under-Secretary of State in the DHSSNI) in relation to the Haemophilia Society's recently launched compensation campaign, explaining that several constituents had been in contact about the need for compensation awards to be made available to those with haemophilia infected with Hepatitis C.<sup>1317</sup> Following a response from Malcolm Moss which was regarded by Eddie McGrady MP as disappointing, John Breen, a civil servant who worked in the Health Promotion branch, prepared a submission dated 31 May 1995 which noted that many similar representations could be expected over the coming months. The submission suggested that preliminary estimates would put the number infected with Hepatitis C through blood transfusions or blood products in Northern Ireland at about 100, of whom approximately 50 had haemophilia. Reference was made to the Department of Health in London's "standard response indicating that the Government does not propose to pay compensation since there was no question of negligence on the part of the NHS and that it believes that the most effective use of resources is to seek to improve the understanding, management and treatment of the disease". 1318 This standard response had formed the basis of the Minister's reply to the MP. The submission continued:

"Although this continues to be the line taken by all UK countries, Ministers in the Department of Health (London) have asked for a plan for some sort of compensation scheme to be prepared but without any presumption that such a scheme would be desirable or inevitable.

It is likely that Health Ministers are acutely aware that when previous campaigns were run firstly in support of haemophiliacs who were infected with the HIV virus and then on behalf of those infected by HIV through blood transfusion, the Government eventually did agree to make such payments.

Officials are presently considering the feasibility of such a compensation scheme but it is a complex matter with political, legal, medical, ethical and financial considerations which will take some time to resolve. It is likely to be the subject of Ministerial correspondence in the near future. In the meantime it would be premature to make any concession to Mr McGrady and it is recommended that Minister should hold to the standard response." 1319

<sup>1315</sup> Letter from Peter Brooke to William Waldegrave 27 December 1991 HMTR0000003 047

<sup>1316</sup> See the chapter on Government Response to Hepatitis C Infections.

<sup>1317</sup> Letter from Eddie McGrady to Malcolm Moss 6 April 1995 DHSC0006522 059

<sup>1318</sup> Memo from John Breen to PS/Malcolm Moss 31 May 1995 p1 DHNI0000054 040

<sup>1319</sup> Memo from John Breen to PS/Malcolm Moss 31 May 1995 pp2-3 DHNI0000054 040

John Breen told the Inquiry that he passed on the line approved by ministers in London and that "The policy in Northern Ireland, as I understood it, was to follow the policy adopted in London." He felt it was premature to make any concessions in respect of compensation "because the matter had not been firmly decided by the Department of Health in London." 1321

An attempt was made by the Department of Health in mid 1995 to "establish the views of the Territorial Health Departments". 1322 A handwritten Scottish Home and Health Department file note, undated but written after 9 May 1995, refers to the author having received phone calls from John Breen (and from Peter Davenport in the Welsh Office) regarding the issue of compensation for those infected with Hepatitis C. The note records that "Both Wales and N.I. were concerned about the financial implications of what seems to be a marked softening in the DoH attitude towards compensation. Apparently the sum of £60,000 is being considered per case and the Treasury have already made it clear that the funds must be found from within existing resources." A "council of war" with the Welsh Office and Northern Ireland Office had been agreed. 1323 The position of officials in Northern Ireland as communicated to the Department of Health in early June 1995 was that "Officials' view is that it is difficult from point of view of equity to resist comparisons with HIV compensation. But this could mean a substantial drain on health resources. The views of Ministers have not been sought yet." 1324

There was no change in the DHSSNI position during the years that followed and the lines to take that were deployed by the Department of Health in London were used in Northern Ireland. Thus, for example, a letter sent by John Breen on behalf of the Secretary of State for Northern Ireland in June 1995, explained that there was no plan to make payments to those infected with Hepatitis C and that "All patients received the best treatment available in the light of medical knowledge at the time." This response was formulated using a template draft letter provided by the Department of Health in London. and reflected the fact that "DHSSNI's policy was to follow the Government position in London." 1327

When, in June 2003, the new Secretary of State for Health, John Reid, decided to reverse the Department of Health's line and opt for some form of ex gratia payment to people infected with Hepatitis C through blood and blood products, Scotland having already decided in principle in January 2003 to do so, no attempt was made to discuss this in advance with

<sup>1320</sup> Written Statement of John Breen para 26.2 WITN7515001

<sup>1321</sup> Written Statement of John Breen para 26.3 WITN7515001. He asked to be kept informed of any developments on the question of compensation. Memo from John Breen to Roger Scofield 4 May 1995 DHSC0002556 003

<sup>1322</sup> Memo from Gerald Malone to Graham Hart 1 May 1995 WITN5249050, Letter from Roger Scofield to David Hogg 9 May 1995 p3 DHSC0006946\_010

<sup>1323</sup> Note regarding phone calls from John Breen and Peter Davenport SCGV0000165\_055. John Breen did not recollect this call and could not say if the note was a fair characterisation of the position. Written Statement of John Breen para 31.1 WITN7515001

<sup>1324</sup> Memo from Paul Pudlo to David Abrahams 5 June 1995 p1 DHSC0004428\_152

<sup>1325</sup> Letter from John Breen to Ann McIlwrath 30 June 1995 DHNI0000054\_008. See similar letters: Letter from Malcolm Moss to Dr Ian Paisley 18 July 1995 DHNI0000054\_006, Letter from Malcolm Moss to Peter Robinson 18 July 1995 DHNI0000054\_013

<sup>1326</sup> Letter from Leonard Levy to John Breen and others 26 April 1995 DHSC0006946 046

<sup>1327</sup> Written Statement of John Breen paras 28.1-28.2 WITN7515001

Northern Ireland. Indeed even as at 21 July 2003, neither Northern Ireland or Wales had been informed of this development. John Reid's reasoning was that the quickest and most coherent way of getting "an English scheme" was "to do a deal with the Scots and then invite the other two nations to join us, which they did, and they did in very short order."

The Department of Health, Social Services and Public Safety's position on the holding of a public inquiry likewise reflected the Department of Health line. 1330

#### **Wales**

The response of the Welsh Office and, post devolution, the Welsh Assembly Government in the 1990s and 2000s to the position of those infected with hepatitis and HIV through blood and blood products largely echoed the approach taken by the Department of Health in London.

David Hunt (later Lord Hunt) was the Secretary of State for Wales between May 1990 and May 1993 (and again for a very short period from late June to early July 1995). He told the Inquiry that he was nominally in charge of, and accountable for, health policy in Wales but that the discretion (or "room for manoeuvre") that he enjoyed as Secretary of State was "in practice very limited in most instances, except at the margins of policy":

"Where there was any significant departure from England policy ... there was always a clear 'Welsh dimension' to justify the difference of approach (and in many instances the expenditure involved was relatively low). I have no recollection of there being any distinctive 'Welsh dimension' when discussions about Infected Blood took place. As Infected Blood affected the whole of the UK, the matter was dealt with on a UK basis, with the lead taken by the Department of Health, with financial support schemes (and any other initiatives requiring additional public expenditure) dependent upon agreement from HM Treasury." 1331

Whilst the Department of Health would take the lead "the health departments of the other territories would be kept abreast of developments and, ideally, consulted in a timely fashion on policy." 1332

As with Northern Ireland:

<sup>1328</sup> Notes of meeting between the Scottish Executive and the Department of Health 30 July 2003 p1 DHSC0004421 141

<sup>1329</sup> Lord John Reid Transcript 21 July 2022 pp40-42 INQY1000232. Northern Ireland was similarly sidelined at the time of the Secretary of State for Health's announcement in January 2011 of the response to the review of the Skipton Fund: "The Health Departments in Northern Ireland, Wales and Scotland had sight of the Government response only on the day of the Secretary of State's announcement. There was no consultation with DA [Devolved Administration] Health Ministers before the announcement, and despite written requests from the devolved administrations, officials were not kept adequately informed or given sight of the report before the announcement." Memo from Seamus Camplisson to Dr Elizabeth Mitchell and others 17 February 2011 pp2-3 DHNI0000485, Written Statement of Dr Elizabeth Mitchell para 49 WITN7542001

<sup>1330</sup> See for example Letter from Bairbre de Brún to Pat Doherty DHNI0000038\_023 and the chapter *Delay* in Holding a Public Inquiry.

<sup>1331</sup> Written Statement of Lord David Hunt para 23 WITN5583001

<sup>1332</sup> Written Statement of Lord David Hunt para 35 WITN5583001

- (a) The evidence does not point to any meaningful involvement in the decision-making that led to the decision to make a payment of £10 million to what became the Macfarlane Trust, save that Peter Walker, the Secretary of State for Wales, attended the meeting of the Sub-Committee on AIDS which met on 10 November 1987 and agreed that a payment should be made. 1333
- (b) Ministers within the Welsh Office had little, if any, direct involvement in the decision-making that led to the announcement of an additional payment to the Macfarlane Trust in November 1989, although (for example) the Secretary of State for Health's (Kenneth Clarke) minute to the Prime Minister of 22 November 1989 was copied to the Secretary of State for Wales.<sup>1334</sup>
- (c) There is little evidence relating to the involvement of the Welsh Office in the settlement discussions relating to the HIV haemophilia litigation, 1335 although officials within the Welsh Office were copied into various Department of Health communications regarding the litigation. A letter in January 1990 from a lawyer within the Welsh Office's Legal Division to the Treasury Solicitor indicates that the Welsh Office was involved in assembling documentation relevant to the litigation and sought to explain the Welsh Office's position in relation to the allegations in the claim. 1337
- (d) When William Waldegrave concluded that ex gratia payments to people infected with HIV through blood transfusion should be made, in November 1991, communications between William Waldegrave and the Chief Secretary to the Treasury, David Mellor, were copied to the Secretary of State for Wales, by then David Hunt. The latter supported the proposal. 1339

<sup>1333</sup> Minutes of Cabinet Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p1 CABO0100016\_011

<sup>1334</sup> Memo from Kenneth Clarke to the Prime Minister 22 November 1989 p1 HMTR0000001\_013. Further correspondence with the Chief Secretary to the Treasury was also copied to the Secretary of State for Wales. Letter from Kenneth Clarke to Norman Lamont 23 November 1989 p2 DHSC0002536\_027, Letter from Norman Lamont to Kenneth Clarke 23 November 1989 DHSC0002536\_032

<sup>1335</sup> The steering committee of plaintiffs' representatives covered both England and Wales, and the negotiations conducted by the Department of Health appear to have encompassed both the Welsh and English cases, which were said to be much further down the track, but not the cases in Scotland or Northern Ireland. Memo from Strachan Heppell to Stephen Alcock 14 December 1990 p1 DHSC0003664\_173

<sup>1336</sup> In July 1991 a civil servant within the Welsh Office expressed concern to the Treasury that the Secretary of State for Wales had not been consulted with regarding the funding arrangements for people with haemophilia infected with HIV following the settlement of the HIV litigation; the specific issue about which complaint was made was regarding the expectation that the health departments might have to contribute financially to the settlement if the amount being made available by the Treasury was insufficient. Letter from Jon Shortridge to Joe Grice 2 July 1991 HMTR0000003\_022

<sup>1337</sup> Letter from John Evans to Jayant Desai 16 January 1990 p1 DHSC0044895. It appears from earlier correspondence that the position of the Welsh Office was generally perceived as "being on all fours with that of the Department of Health" in relation to the litigation. Letter from John Evans to Jayant Desai 25 October 1989 p1 DHSC0019634 001

<sup>1338</sup> Letter from William Waldegrave to David Mellor 2 December 1991 p2 DHSC0002921 009

<sup>1339</sup> Letter from David Hunt to David Mellor 2 January 1992 DHSC0002717 014

The Welsh Office took its lead from the Department of Health on the guestion of financial support for those infected with Hepatitis C. In May 1995 Peter Davenport, an official within the Welsh Office, sent a submission to ministers explaining that although the Government had, to date, "firmly resisted claims for compensation", the Department of Health had now "canvassed territorial departments" for their views on the Haemophilia Society's campaign. He reported that the Department of Health's lawyers "advise that there is little valid or sustainable distinction between those infected with HIV and those infected with hepatitis C and that there would be a significant risk of Judicial Review should such a distinction be maintained by the Government." Present evidence suggested that about 350 people might be affected in Wales. The Treasury was said to have indicated that additional resources would not be made available. Peter Davenport concluded that "DoH [Department of Health] are in the lead; the issue is likely to go to Cabinet."1340 The Secretary of State was asked to approve the sending of a letter which suggested that further discussions would be needed with the Treasury, expressed concern about potential serious difficulties in delivering other Government health priorities but accepted that "Some form of 'No fault' compensation, probably administered as a hardship fund very generally along Macfarlane Trust lines may be inevitable."1341 The latter acceptance does not appear in the final version of the letter that was sent following review by the Secretary of State for Wales, John Redwood. 1342

The position of officials in Wales as communicated to the Department of Health in early June 1995 was that "Legal advisers are of the view that it would be difficult to sustain rejection of claims for compensation on the grounds of a distinction between those infected with HIV and HCV. Such grounds are considered insufficiently robust to resist judicial review." 1343

In June 1999, shortly before devolution took effect, Welsh Office Minister Jon Owen Jones, responding to a written parliamentary question, maintained that "Government policy remains that those infected with hepatitis C through NHS treatment should not receive special treatment, as the same considerations would apply to patients infected with another illness or otherwise harmed as a result of medical or surgical procedure not resulting from negligence."<sup>1344</sup>

This line was maintained following the transfer of responsibility to the National Assembly for Wales on 1 July 1999. In August 1999, not long after taking executive responsibility for public health as the new Minister for Health and Social Services in the Welsh Government, Jane Hutt received a submission about the issue of Hepatitis C compensation. Officials had previously been asked to explore the possibility of a special payment scheme for Wales, but this was said not to be a viable proposition due to its financial and practical implications. The submission asserted that most patients were infected before blood products were heat

<sup>1340</sup> Letter from Peter Davenport to Roger Williams and others 25 May 1995 DHSC0002549 154

<sup>1341</sup> Letter from Welsh Office Health Service to Roger Scofield 26 May 1995 p2 DHSC0003552 164

<sup>1342</sup> Letter from Roger Williams to Roger Scofield p2 DHSC0006946\_006. John Redwood was Secretary of State for Wales 1993-1995.

<sup>1343</sup> Memo from Paul Pudlo to David Abrahams 5 June 1995 p1 DHSC0004428 152

<sup>1344</sup> Written answers on Hepatitis C 30 June 1999 NHBT0134319

treated and that "As this<sup>1345</sup> was the best practice available at the time, claims of negligence have not been accepted"; the briefing reiterated that government policy remained that compensation or financial help was only paid out "where individuals working on [sic] the NHS have been at fault"; the position in relation to people with haemophilia infected with HIV was said to be different in light of the stigma and "the fact that the infection was rapidly fatal, associated with sexual transmission and that haemophiliacs could inadvertently infect their partners." In conclusion, "We strongly advise that Wales maintains the Government position on no-fault compensation." <sup>1346</sup>

A later submission, dated 20 December 1999, suggested the following line to take: "We believe that haemophiliacs in Wales who developed hepatitis C as a result of NHS treatment did so before blood products were heat treated from 1985; this heat treatment counters the hepatitis C and HIV virus. While we have every sympathy with those infected there are no plans to make special payments to these individuals on the grounds that they received the best available treatment at the time." This position was communicated in a letter in February 2000: "there are no plans to make special payments to these individuals on the grounds that they received the best available treatment at that time."

In her written statement to the Inquiry Jane Hutt said that this position was maintained in light of the UK Government's policy on compensation and the advice which she had received. Her main focus at this time was on the care being provided to those in Wales with haemophilia and Hepatitis C.<sup>1349</sup> In the Assembly debate on 8 March 2001 Jane Hutt explained that "Assembly and central Government policy remains that compensation or other financial help to patients is only paid when the NHS or individuals working in it are at fault." That "many haemophiliacs were inadvertently infected by a treatment designed to improve their quality of life" was "not a justification for special payments" and a public inquiry "would probably not provide a satisfactory answer."<sup>1350</sup>

In March 2002 the Minister provided a paper entitled *Safety of Blood and Blood Products* to the Health and Social Services Committee. The paper stated, in relation to calls for a public inquiry "into why so many haemophiliacs have been infected with Hepatitis C", that: "It is a global problem linked to developing science and technology and it was not confined to the UK or linked to some local breakdown in blood product development. A public inquiry has been rejected by the UK Government and the Assembly Government as it is unlikely to provide a satisfactory answer." On the issue of compensation, the paper, referring to the Haemophilia Society's campaign, explained that "Assembly Government and UK Government policy

<sup>1345</sup> It is not entirely clear what "this" refers to – presumably treatment with blood products.

<sup>1346</sup> Memo from Sue Paterson to Tim Kirby and Jane Hutt 4 August 1999 HSSG0000140 076

<sup>1347</sup> Memo from Sue Paterson to Julie Gregory and Jane Hutt 20 December 1999 p4 HSSG0000140 074

<sup>1348</sup> Letter from Jane Hutt to Jan Wallace 3 February 2000 p2 HSSG0000140 047

<sup>1349</sup> Written Statement of Jane Hutt para 30 WITN7293001

<sup>1350</sup> Welsh Assembly debate on Compensation for Haemophiliacs Infected with Hepatitis C 8 March 2001 p4 GLEW0000437\_002

remains that compensation or other financial help to patients is only paid when the NHS or individuals working in it are at fault." <sup>1351</sup>

In April 2002, writing to Assembly Member Dai Lloyd, Jane Hutt recognised the steps that had been taken in Scotland to set up an expert group to consider financial and other support, but "Welsh Assembly Government policy remains that compensation or other financial help to patients is only paid when the NHS or individuals working in it are at fault ... The fact is that the technology to make blood products free from Hepatitis C, in sufficient quantities to treat all Haemophiliacs in the UK, was simply not available prior to 1985."<sup>1352</sup>

Following the decision to establish the Skipton Fund, a letter to campaigner Haydn Lewis following a meeting in November 2003 reiterated the lines to take discussed elsewhere in this Report:

"The inadvertent infection of many thousands of people with hepatitis C as a result of treatment with NHS blood and blood products in the 1970s, 80s and 90s remains a tragic event in the UK and in many other countries around the world. These patients were at the time given what was felt to be the best treatment available. It was a great shame that medical advances in virology could not keep pace with those being made in transfusion and blood technology, – technology which continues to save, prolong and improve lives today." 1353

The Welsh Assembly Government also repeated the Department of Health line regarding the position in Ireland: a letter from Jane Hutt to Haydn Lewis in April 2004 referred to the Irish scheme being set up following evidence of negligence and said "the fact remains that blood services in the UK have not been found to be similarly at fault." The decision not to support a public inquiry was maintained: thus, in December 2004, writing again to Haydn Lewis, Jane Hutt was satisfied that "all the information available is already in the public domain and that a public inquiry would not provide any additional information." 1355

Jane Hutt's statement explains the influence of UK Government policy in shaping the position of the Welsh Government on the response to the those infected and affected:

"Infection via contaminated blood had been UK wide (and indeed much wider than that) and had taken place prior to devolution. It is also relevant that the period 1999 to 2004 was in the very early days of devolution. Welsh Government powers were much more limited at that time ... the advice I had received is that

<sup>1351</sup> Health and Social Services Committee Safety of Blood and Blood Products 13 March 2002 p5 GLEW0000568

<sup>1352</sup> Letter from Jane Hutt to David Lloyd 26 April 2002 HSOC0000405. This line was repeated in October 2002 to Haemophilia Wales: "The Welsh Assembly Government has no plans to review or extend the special payments scheme that currently operates". Letter from Jane Hutt to Jan Wallace 24 October 2002 GLEW0000271

<sup>1353</sup> Letter from the Welsh Assembly Government to Haydn Lewis GLEW0000134. See the chapter on *Lines To Take*.

<sup>1354</sup> Letter from Jane Hutt to Haydn Lewis 8 April 2004 GLEW0000140

<sup>1355</sup> Letter from Jane Hutt to Haydn Lewis 22 December 2004 p2 GLEW0000143

it would have been inappropriate for Wales to take a separate position to the other three nations in respect of financial assistance. In the circumstances, my view as I recall was that the most appropriate approach was to work as closely as possible with the other administrations on a four nations basis and act where we considered it appropriate, within the constraints of the Welsh Government's powers at the time." 1356

On the question of a public inquiry:

"the advice remained that a public inquiry was unlikely to serve any useful purpose and that it was important for those infected that we focused on ensuring that those concerned received the best treatment, advice and support that could be provided. It was also relevant to any consideration by the Welsh Assembly Government of the case for holding a public inquiry that ... the events took place prior to devolution when the NHS across the UK was the responsibility of the UK Government and so any public inquiry which was a UK matter would have needed to be a UK inquiry." 1357

# Commentary

In theory, devolution of health powers to Wales meant that Wales was free to take its own decisions on the issue of payment to people with bleeding disorders who had suffered Hepatitis C infection from blood products, as well as others who had been transfused with blood and became infected. In practice, Wales did not take a separate line; nor did Northern Ireland. Before devolution, powers rested with the Welsh Office, and in the case of Northern Ireland with the Northern Ireland Office. In both cases, it was the Department of Health in England which effectively determined the policy, and settled how to articulate it. It is a sad commentary on the effectiveness of these arrangements (at least in respect of infected blood) that no-one involved in health policy and administration sought to query the policy once the decision in *A and Others v National Blood Authority* was published in 2001<sup>1358</sup> – for this on any fair reading cast a very different light on the facts of what had taken place from that presented by the Department of Health in London – and that no-one in the Northern Ireland Office, despite the links that would have existed with counterparts in the Irish government, sought to check what was actually the position in Ireland as to whether payments made in that jurisdiction were on the basis of fault or not.<sup>1359</sup>

What has been said about the response of the government in England thus applies to Northern Ireland and Wales too, and needs no further comment here – save that there is

<sup>1356</sup> Written Statement of Jane Hutt para 35 WITN7293001

<sup>1357</sup> Written Statement of Jane Hutt para 47 WITN7293001. See the chapter *Delay in Holding a Public Inquiry.* 

<sup>1358</sup> A and Others v National Blood Authority Judgment 26 March 2001 PRSE0003333

<sup>1359</sup> It is an ex gratia scheme which requires no proof of negligence or fault. It began paying sufferers "long before" findings of fault were made in either of two tribunals – the Finlay Tribunal (reporting in 1997) and the Lindsay Tribunal (reporting in September 2002). R (March) v Secretary of State for Health Judgment 16 April 2010 para 34, para 45, para 52 DHSC0003819\_011

the added criticism that health policy, insofar as it related to infected blood in both Northern Ireland and Wales, was determined with a lack of curiosity as to whether the English position was actually justified.

# 7.8 The Government's Response to Calls for Compensation 2020-2024

This chapter considers the calls for compensation for people infected and affected since 2020 and the Government's response.

#### **Key Dates**

- 13 July 2020 Penny Mordaunt writes to the Chancellor about compensation.
- 21 September 2020 Penny Mordaunt writes again to the Chancellor.
- 25 March 2021 Penny Mordaunt commissions a Compensation Framework Study.
- 21 May 2021 Matt Hancock gives evidence to the Inquiry.
- **14 March 2022** Sir Robert Francis QC delivers the Compensation Framework Study to the Government.
- **15 March 2022** Michael Ellis says (and again on **22 March, 31 March** and **27 April**) he will publish the Study and the Government's response before Sir Robert Francis QC gives evidence to the Inquiry.
- **7 June 2022** Compensation Framework Study is published.
- 11 12 July 2022 Sir Robert Francis QC gives oral evidence to the Inquiry.
- **29 July 2022** the Inquiry's First Interim Report is published recommending interim compensation payments.
- 17 August 2022 Government accepts the Inquiry's recommendations for interim payments.
- **5 September 2022** Michael Ellis indicates that the Government will not respond to the Compensation Framework Study until the final report of the Inquiry is published.
- **30 November 2022** senior officials across government meet for the first time to consider compensation.
- **15 December 2022** the Government accepts the moral case for compensation.
- **3 February 2023** Inquiry indicates that a second interim report will be published.
- 22 February 2023 Small Ministerial Group meets for the first time to discuss compensation.
- **5 April 2023** the Inquiry's Second Interim Report is published with full and final recommendations on compensation.
- **12 June 2023** UK, Scottish and Welsh Ministers and the Northern Ireland Department of Health Permanent Secretary hold first meeting to discuss compensation.
- **July 2023** government ministers give oral evidence to the Inquiry.
- **4 December 2023** House of Commons votes in support of an amendment to the Victims and Prisoners Bill which would require the government to establish a body to administer a compensation scheme within three months of the passing of the Act.

#### **People**

Michael Ellis Paymaster General (2021 - 2022)

Sir Robert Francis KC author of the Compensation Framework Study

John Glen Paymaster General (2023 - )

Penny Mordaunt Paymaster General (2020-2021)

Jeremy Quin Paymaster General (2022-2023)

# The Compensation Framework Study

On 13 July 2020 the then Paymaster General Penny Mordaunt wrote to the then Chancellor of the Exchequer, Rishi Sunak, on the subject of "Compensation for victims":

"Following the stakeholder meeting in January, Minister [Oliver] Dowden wrote to the Prime Minister setting out agreed actions to address the most pressing issues of support, including consideration of a framework for compensation.

I fully expect the Inquiry Chair, Sir Brian Langstaff, to make recommendations about levels of financial support, and I believe it to be inevitable that the Government will need to provide substantial compensation. The costs are likely to be high; for example, the compensation tribunal established in the Republic of Ireland paid out €743m between 1996 and 2018.

I believe we should begin preparing for this now, before the Inquiry reports, and my officials are working with DHSC [Department of Health and Social Care] colleagues to consider approaches to compensation. Any decision on compensation will require careful consideration." 1360

The question of compensation was not new in 2020. An awareness that compensation might be recommended was a central factor in the unwillingness of successive governments to establish a public inquiry earlier than 2017. In April 2017 Andy Burnham MP had called for "full, fair compensation now." Following the Inquiry's first day of evidence in 2019, Diana Johnson MP said: "Yesterday saw the first harrowing testimonies of those who were infected in the infected NHS blood scandal. Since the Prime Minister announced the public inquiry in July 2017, one victim has died every four days. Delay is not acceptable. In the Republic of Ireland, it was accepted that it was known that there were risks, and in the 1990s it paid full compensation. Why can we not do the same in the United Kingdom?" 1363

<sup>1360</sup> Letter from Penny Mordaunt to Rishi Sunak 13 July 2020 p2 EIBS0000706. Penny Mordaunt was Paymaster General between 13 February 2020 and 16 September 2021. She was also the sponsor minister for the Inquiry. The suggestion of undertaking work on a compensation framework had been put forward by a campaigner, Jason Evans, at a meeting at the Cabinet Office on 28 January 2020. Minutes of Infected Blood Roundtable meeting 28 January 2020 p5 RLIT0002344. The then Paymaster General and Minister for the Cabinet Office, Oliver Dowden, explained the Government's position on compensation as being: "While the Inquiry could not make a finding of legal liability, it could make a recommendation that the government fundamentally increases what it pays to the infected and affected, and that it does so on a different basis. For this reason, the government has decided to wait for the Inquiry to conclude." Minutes of Infected Blood Roundtable meeting 28 January 2020 p2 RLIT0002344. Following the meeting Oliver Dowden wrote to the Prime Minister, Boris Johnson, explaining that he had asked officials in the Cabinet Office and the Department of Health and Social Care ("DHSC") to consider the proposal for a compensation framework. Letter from Oliver Dowden to Boris Johnson 12 February 2020 p3 WITN7702002

<sup>1361</sup> See the chapter Delay in Holding a Public Inquiry.

He added: "I say to the Government, do not delay, do what Ireland and other countries have done. They should do that now." Hansard extract on Contaminated Blood 25 April 2017 p7 RLIT0001578

Hansard extract on Engagements 1 May 2019 p13 RLIT0002073. She, and others, have returned to this issue repeatedly in Parliament. See for example:
 Diana Johnson on 21 May 2019: "Has the time not come for the Chancellor to heed the call from the Westminster leaders of seven Opposition parties to fund proper compensation for those infected and affected by the NHS blood scandal across the whole United Kingdom?" Hansard extract on Topical Questions: Treasury 21 May 2019 p8 RLIT0002054

Penny Mordaunt told the Inquiry that she would expect anyone in Government with a working knowledge of the infected blood scandal to understand that people were continuing to suffer and continuing to die – that this was not only a matter of historical injustice. One purpose of raising at that stage the "inevitable outcome" of compensation was so that the Treasury could start to make appropriate provision and so that all Government departments were "aware of what is likely to need to happen and prepare for that." She wanted to give the Treasury "some encouragement to grip the issue". 1366

There were discussions between officials but no written response to this letter. 1367

The Paymaster General wrote again to the Chancellor on 21 September 2020. She repeated her expectation that the Inquiry would make recommendations about levels of financial support. It was, she said, "inevitable that the Government will need to provide substantial compensation." She indicated that the costs were likely to be high and she firmly believed that the Government should "begin preparing for this now – before the Inquiry reports." She expressed a wish to meet with the Chancellor or the Chief Secretary to the Treasury to discuss the approach to compensation, and said "I cannot stress enough the urgency of taking long overdue action on financial support and compensation." 1368

No substantive written response to this letter was received. On 25 March 2021, however, Penny Mordaunt was able to announce that: "To meet the Government's commitment to consider a framework for compensation, we can confirm our intention to appoint an independent reviewer to carry out a study, looking at options for a framework for compensation, and to report back to the Paymaster General with recommendations, before the Inquiry reports." This study would, she said, provide the Paymaster General with advice on "potential compensation framework design and solutions which can be

Diana Johnson on 27 June 2019: "Along with seven Opposition party leaders, I have requested the Prime Minister, and the two people who are standing to be the next Prime Minister, to commit to providing compensation now rather than waiting for two years, when we know that so many more people will die." Hansard extract on Business of the House 27 June 2019 p15 RLIT0002093

Dr Philippa Whitford MP on 23 October 2019: "One hundred and eighty-one victims have died since the start of the contaminated blood inquiry, so when will this Government accept the responsibility for the worst scandal in the NHS and pay compensation to surviving victims and bereaved families?" Hansard extract on Topical Questions: Cabinet Office 23 October 2019 p2 RLIT0002085

- 1364 Penny Mordaunt Transcript 24 July 2023 p14 INQY1000279. "I have been a Member of Parliament", she said, "since 2010, and in that time we have had all kinds of inquiries into people with learning disabilities in care homes, or the Hillsborough disaster, many tragic things that Parliament has had to grip, but I think this is absolutely unprecedented, the length of time that people have had to wait ... and things that people have had to deal with that are very difficult to understand." Penny Mordaunt Transcript 24 July 2023 p27 INQY1000279
- 1365 Penny Mordaunt Transcript 24 July 2023 pp17-18 INQY1000279
- 1366 Penny Mordaunt Transcript 24 July 2023 p19 INQY1000279
- 1367 Penny Mordaunt Transcript 24 July 2023 p20 INQY1000279. It is right to note that this was taking place during the COVID-19 pandemic and it was, as Penny Mordaunt said, "a pretty chaotic situation in Government".
- 1368 Letter from Penny Mordaunt to Rishi Sunak 21 September 2020 pp1-2 EIBS0000705. The letter also addressed the issue of disparities between the four national support schemes. See the chapter on *National Support Schemes*.
- 1369 A holding response was received. Written Statement of Rishi Sunak para 3 WITN7712001. Penny Mordaunt made the point in her evidence that she was able to progress the issues that she had raised in her letter. Penny Mordaunt Transcript 24 July 2023 pp24-25 INQY1000279

ready to implement upon the conclusion of the Inquiry, should the Inquiry's findings and recommendations require it." <sup>1370</sup> It was her expectation in commissioning the study that the Government's response would be published and shared with the Inquiry so that the Inquiry would have the benefit of considering it. <sup>1371</sup>

On 20 May 2021, the day before the Inquiry heard evidence from the then Secretary of State for Health and Social Care, Matt Hancock, it was announced that Sir Robert Francis QC had been appointed to carry out this study "to provide the Government with advice and recommendations on a potential compensation framework." <sup>1372</sup>

In his evidence to the Inquiry on 21 May 2021 Matt Hancock agreed that there was a moral responsibility on the Government to address the impact of what has happened to those infected and affected.<sup>1373</sup> He added:

"I respect the process of the Inquiry and I will respect its recommendations, and should the Inquiry's recommendations point to compensation, then of course we will pay compensation and Sir Robert Francis's Review on compensation is there in order that the Government will be able to respond quickly to that ... what I can say to you is that we will respect the outcome of the Inquiry and if the Inquiry points to compensation, as opposed to a support scheme, in the future then the Government will pay compensation." 1374

Given the principles of collective responsibility, the only reasonable conclusion to draw is that the then Secretary of State for Health and Social Care was speaking on behalf of the Government.

Following a period of consultation, Sir Robert wrote to Penny Mordaunt on 16 August 2021 with proposed terms of reference for the study. On 23 September 2021 Michael Ellis, who had taken over as Paymaster General on 16 September, accepted Sir Robert's recommendations as to the key issues which the study should consider and the terms of reference were published without amendment. In a Parliamentary written statement, Michael Ellis acknowledged that "The infected blood scandal continues to claim the lives of infected people, and those directly affected have waited too long for answers, and for justice." 1376

<sup>1370</sup> Parliamentary written statement on Infected Blood Update 25 March 2021 p2 WITN4066017

<sup>1371</sup> Penny Mordaunt Transcript 24 July 2023 pp39-40 INQY1000279

<sup>1372</sup> UK Government Press Release Appointment of Sir Robert Francis QC to undertake the infected blood compensation framework study 20 May 2021 p2 RLIT0002057

<sup>1373</sup> Matt Hancock Transcript 21 May 2021 p126 INQY1000121

<sup>1374</sup> Matt Hancock Transcript 21 May 2021 p151 INQY1000121

<sup>1375</sup> Letter from Sir Robert Francis to Penny Mordaunt 16 August 2021 RLIT0002056

<sup>1376</sup> Hansard parliamentary written statement on Infected Blood Compensation Framework Study: Terms of Reference 23 September 2021 p3 RLIT0002083. Michael Ellis was Paymaster General between 16 September 2021 and 6 September 2022; he also held the role of Minister for the Cabinet Office between 8 February and 6 September 2022.

Sir Robert delivered his report *Compensation and Redress for the Victims of Infected Blood*– *Recommendations for a Framework* to the Paymaster General on 14 March 2022.<sup>1377</sup>

In a statement to the House of Commons the following day, Michael Ellis explained that: "It is my intention to publish the Study and the Government response, in time for the Inquiry and its core participants to consider them before Sir Robert gives evidence to the Inquiry." On 22 March he gave the same message in response to a question from Dame Diana Johnson:

"It is my intention to publish Sir Robert Francis' study alongside the Government's response. Before I am able to do so, you will understand that work must be undertaken within Government to formalise our response. That work is already underway. I recognise how important it is for the Inquiry and its core participants to have sufficient time to consider the study before Sir Robert gives evidence to the Inquiry. It is my intention to publish the study alongside the Government's response as soon as possible." 1379

He said again, on 31 March 2022, in reply to a question from Dr Philippa Whitford MP, that: "It is my intention to publish the compensation framework study alongside the Government's response as soon as possible, and in sufficient time for the infected blood inquiry and its core participants to consider them before Sir Robert gives evidence to the inquiry." Likewise, on 27 April and in response to a question from Ian Lavery MP, Michael Ellis reiterated his intention "to publish the Study and the Government response, in time for the Inquiry and its core participants to consider them before Sir Robert gives evidence to the Inquiry." 1381

Despite the Government making it clear, in these various statements, (a) that it would publish its response to Sir Robert's study at the same time as the study itself and (b) that it understood the importance for those infected and affected to be able to consider the Government's response before Sir Robert gave evidence to the Inquiry, on 7 June 2022 the Government published the study but **no** response from the Government to that study. What was said on this occasion by Michael Ellis was that: "There is a great deal of complexity to the issues that the study covers and a wide range of factors to be taken into account in considering Sir Robert's recommendations. This analysis cannot be completed hurriedly but officials across government are focussing on this so that the government can be ready to respond quickly to the Inquiry's recommendations, as was intended when the study was commissioned." 1382

<sup>1377</sup> Infected Blood Compensation Study Compensation and Redress for the Victims of Infected Blood – Recommendations for a Framework 14 March 2022 RLIT0001129

<sup>1378</sup> Parliamentary written statement on Study of Infected Blood Compensation Framework 15 March 2022 p1 RLIT0001137

<sup>1379</sup> Parliamentary written answer on Blood: Contamination 17 March 2022 p1 RLIT0001133

<sup>1380</sup> Hansard extract on Contaminated Blood Products: Sir Robert Francis Report on Compensation for Those Affected 31 March 2022 p1 RLIT0002052

<sup>1381</sup> Parliamentary written answer on England Infected Blood Support Scheme 21 April 2022 p1 RLIT0001134

<sup>1382</sup> Parliamentary written statement on Publication of Sir Robert Francis QC's infected blood compensation study 7 June 2022 p1 RLIT0001136

On 9 June, the Paymaster General told the House of Commons that the Government was considering Sir Robert's recommendations, that he would update the House as the work progressed, and that "Sir Robert will give evidence to the Inquiry on 11 and 12 July, so just a few weeks from now, and the Government will need to reflect very carefully on his evidence to the Inquiry in considering his study." 1383 In response to further questions, 1384 the Paymaster General said that Sir Robert's recommendations needed "careful consideration", which it would be "remiss" of the Government to "rush": "It is most important that we are able to reflect on his evidence, which he is due to give in four or five weeks' time, and we will do so after that." 1385 The Government would, he indicated, "want to hear what [Sir Robert] has to say. We will study it very carefully and will act as expeditiously as possible after that." 1386

This statement would be reasonably understood as the Government indicating that it **would** respond to the compensation framework study once it had considered Sir Robert's oral evidence (on 11 and 12 July 2022).

On 20 June 2022 Michal Ellis, in response to a question from Lisa Nandy MP, explained that: "The government is considering Sir Robert's recommendations and it is most important that the government is able to reflect upon Sir Robert's evidence and the evidence of others to the Inquiry as part of that consideration." He did not identify the "others" whose evidence the Government apparently now needed to be able to reflect on in order to respond to Sir Robert's study.

On 14 June 2022, Martyn Day MP raised the question of the potential impact on mental health "of the lengthy waiting times for compensation in relation to contaminated blood". The Secretary of State for Health and Social Care, Sajid Javid, acknowledged in response that he had raised "a very important issue." 1388

Sir Robert gave oral evidence to the Inquiry on 11 and 12 July 2022. On 14 July Dame Diana Johnson reminded Michael Ellis how many people had died since the announcement of the Inquiry ("*Time is pressing*"). In response the Paymaster General assured her that the matter

<sup>1383</sup> Michael Ellis in response to questions from Duncan Baker MP. Hansard extract on Infected Blood: Compensation 9 June 2022 RLIT0002068

Dame Diana Johnson asked, pertinently, this question: "I just want to make it clear that the Government's approach to the study conducted by Sir Robert Francis was to publish it at the same time as their own response. That is what we were told – although the all-party parliamentary group on haemophilia and contaminated blood and many campaign groups had asked the Government for openness and transparency, and for the report to be published when it was given to the Government. Given that two people are dying every week as a result of the contaminated blood scandal, may I press the Minister on this issue? Do the Government accept that there is a strong moral case for compensation to be paid, irrespective of any legal liability, and for interim payments of at least £100,000 per individual to start now?" A similar question was posed by Ian Lavery MP: "the victims of the scandal need reassurance ... When will the interim payments be made, and do the Government support recommendation 14 of Sir Robert Francis's report?" Recommendation 14 was for interim payments. Hansard extract on Topical Questions: Cabinet Office 9 June 2022 p5 RLIT0002067

<sup>1385</sup> Hansard extract on Topical Questions: Cabinet Office 9 June 2022 p5 RLIT0002067

<sup>1386</sup> Michael Ellis in response to a question from Chris Stephens MP. Hansard extract on Topical Questions: Cabinet Office 9 June 2022 p3 RLIT0002067

<sup>1387</sup> Parliamentary written question on Infected Blood Inquiry 20 June 2022 p1 RLIT0001135

<sup>1388</sup> Hansard extract on Topical Questions: Health and Social Care 14 June 2022 p3 RLIT0002088

was being given "expeditious consideration" and that the Government would respond to Sir Robert's recommendations "just as soon as possible." 1389

On 18 July 2022 Michael Ellis, responding to a question from Drew Hendry MP, said that the issues arising from the Compensation Framework Study were "under active consideration across government, including consideration of Sir Robert's evidence to the independent Inquiry on 11-12 July."<sup>1390</sup> On 19 July, in response to an Urgent Question from Dame Diana Johnson MP, he stated that officials across Government were "making haste to address this as quickly and thoroughly as possible ... it will take a little more time for the work to be completed." The matter was being given "the fullest, speediest and most expeditious consideration". Time was, he acknowledged, "of the essence."<sup>1391</sup>

Over two years after Sir Robert delivered his study to the Government, those infected and affected **still** do not know the Government's response to his recommendations.

# The Inquiry's First Interim Report July 2022

On 29 July 2022 the Inquiry's First Interim Report was published. This recommended that an interim payment, of no less than £100,000,<sup>1392</sup> should be made without delay to all those infected and all bereaved partners.<sup>1393</sup>

The Government **did** respond promptly to this recommendation, announcing on 17 August 2022 that interim payments of £100,000 would be made to infected individuals and bereaved partners.<sup>1394</sup>

That swift action can be taken, with the right political will and leadership, is apparent from the evidence available to the Inquiry. Kit Malthouse, the then Chancellor of the Duchy of Lancaster, told the Inquiry that: "we took the view that we should make fulfilling Sir Brian's recommendations a priority ... At the time the IBI [Infected Blood Inquiry] was being dealt with by Minister for the Cabinet Office. I took the view he needed more political assistance to get it over the line. Prospective recipients were dying all too frequently, and I could see no good reason for delay; rather there was a moral imperative for speed. I decided therefore to assume the lead." His statement describes promptly held meetings, the exertion of pressure on the Cabinet Office "to make an announcement as soon as possible", and the support of the then Prime Minister, Boris Johnson, such that: "Following an intense period of work by

<sup>1389</sup> Hansard extract on Topical Questions: Cabinet Office 14 June 2022 pp5-6 RLIT0002090

<sup>1390</sup> He added that he would "*update the House as this work progresses*". Parliamentary written answer on Infected Blood Inquiry 13 July 2022 p1 RLIT0002091

<sup>1391</sup> Hansard extract on Contaminated Blood Scandal: Interim Payments for Victims 19 July 2022 p2, p4, p9 RLIT0002109

<sup>1392</sup> As also recommended by Sir Robert.

<sup>1393</sup> Infected Blood Inquiry First Interim Report 29 July 2022 p17 INQY0000367. On 31 July 2022 Rishi Sunak, voicing support for the making of the interim payments, said "The contaminated blood scandal is a tragic injustice and we must now match words with action ... Survivors and their families need to have certainty now". The Sunday Times Urgent Blood Payouts Backed 31 July 2022 p1 JEVA0000258

<sup>1394</sup> UK Government Press Release *Infected Blood victims to receive £100,000 interim compensation* payment 17 August 2022 p2 RLIT0002086

officials ... including expediting obtaining the relevant clearances and approvals and we were in a position to make an announcement." 1395

# September 2022 to April 2023

On 5 September 2022, and contrary to what had been said both explicitly and implicitly earlier in the year, the Paymaster General, Michael Ellis, indicated that the Government did not intend to respond until the final report of the Inquiry was published.<sup>1396</sup>

At a Westminster Hall debate on 24 November 2022, Dame Diana Johnson observed as follows, referring to the Compensation Framework Study:

"Unfortunately, although the study results were sent to the Cabinet Office in March, the Government refused to publish it at that time. Instead, they promised to publish it alongside a full Government response, but the study was leaked to the press and the Government were then forced to publish the report in June. However, there is still no official response to Sir Robert's study. Five months on, we are still waiting for that full Government response. We very much look forward to what the Minister has to say today about Sir Robert's study, as the Government have had a total of eight months to review the findings of the study. I hope the Minister will be able to provide a detailed response and firm commitments ... What comes next from the Government should be marked by openness and a full commitment to deliver justice to everyone affected by this scandal." 1397

The response of the Cabinet Office Parliamentary Secretary, Alex Burghart, was to recognise that there was no doubt that the Inquiry would make recommendations about compensation for a wider group of people<sup>1398</sup> and to confirm that officials were "now working together across Government to produce options for compensation that can be quickly matched to the Inquiry's recommendations." He was pressed by various MPs as to when the Government would respond to Sir Robert's report. No direct answer was provided to this

<sup>1395</sup> Written Statement of Kit Malthouse paras 9-13, para 19 WITN7713001. See also the statement of Nadhim Zahawi MP, then Chancellor of the Exchequer, which demonstrates that Treasury approval was given for the interim payments within eight days of approval being sought. Written Statement of Nadhim Zahawi paras 5-8 WITN7715001

<sup>1396</sup> His precise words were: "Sir Robert's study has been warmly welcomed by the Inquiry and, without prejudging the findings of the independent Inquiry, I fully expect his wider recommendations to inform the Inquiry's final report when it is published in mid-2023. Until that time, the government will continue work in consideration of the broader recommendations in the Compensation Framework Study so that we are ready to respond promptly when the Inquiry concludes its work." Parliamentary written statement on Infected blood – Interim Compensation 5 September 2022 p2 RLIT0002094. See further the press release of 22 October 2022. UK Government Press Release Infected blood £100,000 interim compensation payments to be made this month 22 October 2022 p3 RLIT0002106

<sup>1397</sup> Hansard extract on Infected Blood Inquiry and Compensation Framework 24 November 2022 p2 RLIT0002107

<sup>1398</sup> Jeremy Quin confirmed in his evidence to the Inquiry that it was the Government's expectation that the compensation recommendations, when they came, would go beyond the cohorts of individuals to whom the interim payments had been directed. Jeremy Quin Transcript 25 July 2023 p28 INQY1000280

<sup>1399</sup> Hansard extract on Infected Blood Inquiry and Compensation Framework 24 November 2022 p15 RLIT0002107

question: the ministerial position was that there was work being undertaken to enable a very quick response to the recommendations expected from the Inquiry. The implication was that the Government would not be providing any response to the Compensation Framework Study itself.

This was subsequently confirmed by Jeremy Quin, who had taken over as Paymaster General in October 2022. In a statement on 15 December 2022 he admitted that the Government "had intended to publish a response alongside the study itself, ahead of Sir Robert's evidence to Sir Brian Langstaff's inquiry." However, "as the then Paymaster General explained, the sheer complexity and wide range of factors revealed in Sir Robert's excellent work meant that when the study was published by the Government on 7 June, it was not possible to publish a comprehensive response."<sup>1401</sup>

This is a somewhat surprising explanation, for three reasons. First, the Government was at all times aware of – indeed had approved – the terms of reference for Sir Robert's work. Its "complexity" and breadth should not have come as any surprise. Second, this does not explain why, **after** receiving Sir Robert's study, the Government stated on four separate occasions that it **would** publish its response, alongside the study and in advance of Sir Robert's evidence to the Inquiry. Thirdly, a claimed inability ("not possible") to publish a "comprehensive" response does not explain a failure to provide any kind of response at all. And even if that complexity and breadth meant that the Government could not furnish its response prior to the evidence of Sir Robert on 11 and 12 July 2022, it does not explain the failure to publish the response in the nearly two years that has since elapsed.

The Paymaster General added that he intended to update the House of Commons on progress and "where it is possible" to provide "greater clarity on the Government's response to Sir Robert's recommendations" prior to publication of the Inquiry's Report. He informed the House that a cross-government working group, co-ordinated by the Cabinet Office, was "taking forward work strands informed by Sir Robert's recommendations" and that a cross-departmental group at permanent secretary level had been convened to oversee the work. There was one recommendation which was being accepted then: the "moral case for the payment of compensation." In response to questions from MPs, Jeremy Quin declined to commit to a timetable but reiterated his intention to update the House as progress was made "in order to ensure that those infected and affected are fully apprised of the progress

<sup>1400</sup> Hansard extract on Infected Blood Inquiry and Compensation Framework 24 November 2022 pp15-20 RLIT0002107

<sup>1401</sup> Hansard parliamentary statement on Infected Blood Inquiry 15 December 2022 p1 COLL0000022. Jeremy Quin was Paymaster General and Minister for the Cabinet Office between 25 October 2022 and 13 November 2023. He was preceded (briefly) by Chris Philp (14-25 October 2022) and Edward Argar (6 September-14 October 2022), who had succeeded Michael Ellis.

<sup>1402</sup> On 15, 22 and 31 March and on 27 April 2022. Parliamentary written statement on Study of Infected Blood Compensation Framework 15 March 2022 p1 RLIT0001137, Parliamentary written answer on Blood: Contamination 17 March 2022 p1 RLIT0001133, Hansard extract on Contaminated Blood Products: Sir Robert Francis Report on Compensation for Those Affected 31 March 2022 p1 RLIT0002052, Parliamentary written answer on England Infected Blood Support Scheme 21 April 2022 p1 RLIT0001134

we are making."1403 As will be apparent from the narrative below, it does not appear that that intention has been fulfilled.

Whilst the Inquiry has an incomplete picture as to the extent of the Government's activity up to this point, 1404 it is apparent that: as at November 2022 no decision had been taken on what a final scheme might look like; no options had yet been presented to the Paymaster General; 1405 and it was only on 30 November 2022 that the **first** meeting of senior officials to consider matters across government took place. 1406

The Government was anticipating at that stage that it would see the Inquiry's recommendations on compensation in around mid 2023, and its plan was "to have done everything it needed to do to be able to respond very swiftly to those recommendations." That being the case, it might be expected that by mid 2023 the Government would have reached some decisions and be in a position to communicate those decisions to the infected and affected, to Parliament and to the Inquiry. As explored below, however, it did not do so.

On 11 January 2023, in answer to a question from Taiwo Owatemi MP as to when the Government would establish an arm's-length body, Jeremy Quin's response was "A cross government working group coordinated by the Cabinet Office is taking forward work informed by the Study's recommendations, including the establishment of an arm's length body." 1408

On 19 January 2023, in answer to a question from Barbara Keeley MP asking how many times the cross-government working group had met, Jeremy Quin's response was: "A cross government working group of officials meets formally on a regular basis to take forward the work of the infected blood Compensation Framework Study." He added that meetings also took place on an ad hoc basis and that he had regular meetings with officials to receive updates.<sup>1409</sup>

In early 2023 it was decided that the Department of Health and Social Care ("DHSC") would establish a new team to undertake an analysis of cost and scale of implementation. Jeremy Quin told the Inquiry that he was not aware of that analysis having been undertaken prior to that time "other than a very, very top-level view." He was not able to say why this work, which he thought was necessary and important, had not been commissioned earlier.<sup>1410</sup>

<sup>1403</sup> Hansard oral statement on Infected Blood Inquiry 15 December 2022 p2, p4 COLL0000022

<sup>1404</sup> The Government has relied on the principles of collective responsibility and a safe space for policy-making as the basis for declining to provide a fuller account.

<sup>1405</sup> Written Statement of Jeremy Quin para 11 WITN7526001

<sup>1406</sup> The second meeting was on 2 February 2023. By July 2023, there had been meetings at permanent secretary level on 2 and 27 March 2023 and 26 April 2023. Written Statement of Jeremy Quin paras 8-9 WITN7526002. Jeremy Quin told the Inquiry that following the Westminster Hall debate on 24 November 2022 he took the view that "we needed to increase senior attention, increase resources on the issue". Jeremy Quin Transcript 25 July 2023 p22 INQY1000280

<sup>1407</sup> Jeremy Quin Transcript 25 July 2023 p29 INQY1000280

<sup>1408</sup> Hansard written question on Blood Contamination 11 January 2023 p1 RLIT0002095

<sup>1409</sup> Hansard written question on Blood Contamination 19 January 2023 p1 RLIT0002089

<sup>1410</sup> Jeremy Quin Transcript 25 July 2023 pp40-42 INQY1000280

On 9 February 2023, in answer to a request from Caroline Lucas MP for publication of a plan for the delivery of compensation to the infected blood community, Jeremy Quin repeated that work was underway across Government and that he intended to update Parliament "as we make progress in consideration of compensation."<sup>1411</sup> This was consistent with the intention that had been expressed by the Paymaster General in a Cabinet Committee writeround on 5 December 2022: "to update Parliament as this work progresses, providing as much detail as I can on specific areas of work, including, where possible, formal acceptance of other recommendations, as workstrands are completed, seeking collective agreement where necessary."<sup>1412</sup> Jeremy Quin confirmed in his evidence to the Inquiry that his thinking was that, as and when decisions were made on particular issues or recommendations, he would be able to make announcements on a rolling basis rather than a single announcement at the end of all the work.<sup>1413</sup> It remains unclear why the Government has not done so.

The Paymaster General also indicated in the Cabinet Committee write-round in December 2022 that work was underway with the intention of completion by May 2023. 1414 That being the position, the fact that those infected and affected are, as at May 2024, none the wiser is difficult to comprehend – or justify.

On 3 February 2023 the Inquiry confirmed that a second interim report would be published. 1415

On 22 February 2023, nearly a year after the Government had received the Compensation Framework Study from Sir Robert, a Small Ministerial Group met for the first time to discuss compensation. No good reason for this having taken so long has been made public.

On 16 March 2023 Dame Diana Johnson asked the Paymaster General to set out how he could best engage with those infected and affected in the coming months to show that progress was being made and to set out a plan for that involvement. His response was that he was focused on the anticipated interim report from the Inquiry: "When we see the interim report, it will be incumbent on us to give an immediate reaction – a reaction as soon as is practical – to it, and then to set out what we will be doing to build towards the final report." 1417

On 5 April 2023 the Inquiry published its Second Interim Report. It was made explicitly clear that the recommendations of the Inquiry relevant to compensation were contained within

<sup>1411</sup> Hansard written question on Blood Contamination 9 February 2023 p1 RLIT0002096. On 24 February 2023 he answered a question from Mark Pritchard MP by stating that the cross-government work underway was likely to be significantly assisted by the Inquiry's further interim report in making "preparations to act swiftly in response to [the Inquiry's] final report." Hansard written question on Blood Contamination 24 February 2023 p1 RLIT0002129

<sup>1412</sup> Letter from Jeremy Quin to Jeremy Hunt 5 December 2022 p4 WITN7526003

<sup>1413</sup> Jeremy Quin Transcript 25 July 2023 p35 INQY1000280. As he put it, "if I could set out building blocks which would help ... towards the Government's response on compensation, then that's something I would like to do and would then make statements accordingly." Jeremy Quin Transcript 25 July 2023 p39 INQY1000280

<sup>1414</sup> Letter from Jeremy Quin to Jeremy Hunt 5 December 2022 p3 WITN7526003

<sup>1415</sup> Sir Brian Langstaff Transcript 3 February 2023 p130 INQY1000276

<sup>1416</sup> Written Statement of Jeremy Quin para 9 WITN7526002. By July 2023, it had met again on 8 March 2023, 3 May 2023, 23 May 2023 and 14 June 2023.

<sup>1417</sup> Hansard parliamentary question on Infected Blood Inquiry Compensation 16 March 2023 RLIT0002121

that second report.<sup>1418</sup> The recommendations were based on wrongs done "at individual, collective and systemic levels", though the precise detail of these was not at that stage set out in greater detail. The principal recommendation was that a compensation scheme should be set up "now" and should begin work "this year" (ie 2023). A number of more detailed recommendations regarding compensation were made, largely reflecting the recommendations of Sir Robert, with a further recommendation that an interim payment should be paid "to recognise the deaths of people to date unrecognised and thereby alleviate immediate suffering." This reflected the fact that "some people have died as a result of infected blood and blood products without any payment being made in respect of their death, leaving bereaved parents, children or siblings who have suffered profound distress and loss which has to date been unremedied."<sup>1419</sup> The Second Interim Report also recommended that steps be taken "without delay" to provide a bespoke psychological service in England. <sup>1420</sup>

# The Government's response following publication of the Second Interim Report April-July 2023

In a statement on 19 April 2023 Jeremy Quin told Parliament that work was underway "at pace" across all relevant departments "to respond fully": "while the Government are progressing work to ensure that we are in the best possible position to respond fully at the end of the inquiry, every recommendation by Sir Brian, including in relation to timing and a further interim payment, is receiving intense focus." 1421 In the debate which followed, he was asked to commit to more regular updates on progress and the direction of travel ("We should not have to keep squeezing this information out of the Government, because it compounds the pain of the victims" 1422). The Paymaster General also told Parliament that "We will bring forward a response as soon as we can" and that although the focus was on the Inquiry's conclusion "that does not preclude coming forward before then if we are able to do so and we decide that that is the right course of action." 1423

In a series of questions in late April and early May 2023 Dame Diana Johnson asked the Paymaster General for details about the cross-departmental meetings which he had said were taking place. The responses referred in general terms to a range of meetings and

<sup>1418</sup> Infected Blood Inquiry Second Interim Report 5 April 2023 p3 INQY0000453

<sup>1419</sup> Infected Blood Inquiry Second Interim Report 5 April 2023 p13, p5, p60 INQY0000453

<sup>1420</sup> Infected Blood Inquiry Second Interim Report 5 April 2023 p15 INQY0000453. Such a service being already available in Northern Ireland, Scotland and Wales.

<sup>1421</sup> Hansard Update on Infected Blood Inquiry 19 April 2023 pp1-2 RLIT0002126

<sup>1422</sup> Fleur Anderson was Shadow Paymaster General between 4 December 2021 and 4 September 2023. Hansard Update on Infected Blood Inquiry 19 April 2023 p3 RLIT0002126

<sup>1423</sup> Hansard Update on Infected Blood Inquiry 19 April 2023 p6 RLIT0002126

emphasised the Government's continued "working at pace". 1424 She also posed questions to the Chancellor of the Exchequer in mid May 2023 and received similarly general responses. 1425

On 12 June 2023 UK, Scottish and Welsh Ministers, and the Northern Ireland Department of Health Permanent Secretary, met for the first time to discuss the position regarding compensation. A joint communique following the meeting recorded agreement that working together to enable a response as soon as possible after the Inquiry concludes did "not preclude earlier announcements as work progresses." There have, however, been no such announcements.

On 9 May 2023 the *Financial Times* carried a story that speculated, based (it was reported) on information from officials, on the size of a compensation bill, describing it as a "further blow to the UK's stretched public finances" and reporting an official as saying "People are very worried about the cost." On 2 July The Sunday Telegraph reported that: "The figures have caused concern in Whitehall because the potential amounts involved are so large that they would affect the Government's wider fiscal plans. And ministers do not know where the money is coming from, with the compensation at present 'completely unfunded', The Telegraph has been told." One concern about these figures — quite apart from the motivation of those who leaked them to the press — is that they may overlook the importance of the Government's decision being made on the basis of a realistic understanding of the likely numbers who may be in a position to apply for compensation. Many of those infected with Hepatitis C are likely to have died without them or their family ever knowing that they were infected. So whilst the statistics expert report indicates the numbers who may have been infected, it is important to bear in mind that the actual number of those who may realistically claim compensation is likely to be significantly lower.

- Dame Diana Johnson raised it with the Leader of the House, asked to see his ministerial diary and received a general response, raised a point of order, and got a slightly more detailed answer. "To reassure the right hon. Lady, I chaired a meeting with Ministers from across Government last week. I have a bilateral meeting next week and I anticipate having more ministerial meetings, which I will chair, the week after. She has asked me to set out every single internal meeting I have on this subject, which is not normal in the formulation of policy. I do not intend to list every single meeting that I have internally or with other Ministers, but I assure her that we are working at pace to come up with a constructive response to the report." Hansard written question on Blood Contamination 26 April 2023 p1 RLIT0002125, Hansard extract on Business of the House 27 April 2023 p10 RLIT0002128, Written Question on Cabinet Office Diaries 3 May 2023 RLIT0002114, Hansard Points of Order 9 May 2023 RLIT0002117, Hansard extract on Topical Questions: Treasury 9 May 2023 p6 RLIT0002134, Hansard extract on Topical Questions: Cabinet Office 11 May 2023 p94-5 RLIT0002124
- 1425 Written Question for the Treasury on Infected Blood Compensation Framework Study and Infected Blood Inquiry 10 May 2023 RLIT0002115, Written Question for the Treasury on Blood Contamination 10 May 2023 RLIT0002120, Written Question for the Treasury on Blood Contamination 11 May 2023 RLIT0002116. Her questions were answered by John Glen who was Chief Secretary to the Treasury between 25 October 2022 and 13 November 2023.
- 1426 Joint Communique on the Infected Blood Inquiry 12 June 2023 RLIT0002157
- 1427 Financial Times *Blood-scandal compensation scheme expected to cost taxpayer up to £10bn* 9 May 2023 RLIT0002137. The article reported that Government officials had told the *Financial Times* that the compensation scheme might cost £5bn-£10bn.
- 1428 The Sunday Telegraph *Payouts for infected blood scandal could reach £20bn* 1 July 2023 p1 RLIT0002136
- 1429 By way of illustration, there were 4,496 interim payments made in the first year. Written Statement of Brendan Brown para 9 WITN4496048, Written Statement of Martin Bell p2 WITN4728059, Written Statement of Alison Ramsey p2 WITN4506039, Written Statement of Karen Bailey p2 WITN4936041

In July 2023 the Inquiry heard oral evidence regarding compensation from Penny Mordaunt (by then Leader of the House of Commons), from the then Paymaster General (Jeremy Quin), from the Chancellor of the Exchequer (Jeremy Hunt) and from the Prime Minister (Rishi Sunak). It was told that work was "ongoing", "not complete", with "a significant number of issues to resolve". 1430 The Government was, however, "now in a position where some significant decisions need to be made ... we have the building blocks that are required for those decisions to be made in Government." 1431 Jeremy Quin could not give a timescale or deadline for the Government's response, but could only say that the Government "is committed to responding as soon as they can after the final report." 1432

The Prime Minister told the Inquiry that the work was not concluded and that no decisions had been made: the Government did not yet have options that were ready to implement upon the conclusion of the Inquiry. 1433 Jeremy Hunt told the Inquiry that "we are genuinely in a situation where no decisions have been made about the level of compensation or how it will be funded." He could not say where the funding would come from or what the timescales were. He did think that "good progress has been made" but there was more work to do. The Small Ministerial Group had not made its final recommendations. 1434

Asked whether – given the recognised "need for pace" and the knowledge that "people die every week" and the fact that people still have no idea of the shape, form or scope of any compensation scheme or of timescale, the Government's response was "good enough" – Jeremy Quin's answer was as follows:

"The Government, from the outset, has said that they would want to respond swiftly to – in terms of the substance of the compensation scheme – Sir Brian's final report, and I appreciate that Sir Brian and the Inquiry has said that that is their final word on compensation. As I said in the House of Commons before now, I have absolutely no doubt that those compensation proposals will be put into very upsetting context when the full findings of the report are released." 1435

That is not an answer to the question posed.

The Prime Minister, asked the same question, said that "the Government at the time having decided to establish an independent inquiry to make recommendations on compensation, fully funding it, recognising that this was a complex and sensitive issue that required

<sup>1430</sup> Written Statement of Jeremy Quin paras 4-7 WITN7526002

<sup>1431</sup> Jeremy Quin Transcript 25 July 2023 p53 INQY1000280. Shona Dunn, the Second Permanent Secretary in the DHSC, agreed in her evidence to the Inquiry that "the building blocks are there." Shona Dunn Transcript 25 July 2023 pp112-113 INQY1000280

<sup>1432</sup> Jeremy Quin Transcript 25 July 2023 pp52-53 INQY1000280. It is right to note that he did also say that he had no doubt that compensation would be paid – "the form and the shape of that compensation are decisions that have to be made." Jeremy Quin Transcript 25 July 2023 pp72-73 INQY1000280

<sup>1433</sup> Rishi Sunak Transcript 26 July 2023 pp27-29 INQY1000281

<sup>1434</sup> The Chancellor said that he appreciated that, from the outside, that "it feels like the Government is working painfully slowly" but was satisfied as Chancellor that the Government "is working very fast to try and resolve this as quickly as possible." Jeremy Hunt Transcript 28 July 2023 p5, p13, p35, p40 INQY1000282

<sup>1435</sup> Jeremy Quin Transcript 25 July 2023 Transcript 25 July 2023 pp45-46 INQY1000280

independent and thorough investigation, as is happening, it is reasonable to allow that inquiry to conclude its work." 1436

That **might** be an answer to the question, had the Inquiry not set out its recommendations on compensation clearly and fully in its Second Interim Report in April 2023.

The Government declined to share with the Inquiry and its participants detailed information regarding its decision-making, relying on the principles of collective Cabinet responsibility and safe space decision-making.<sup>1437</sup>

# September 2023 onwards

Parliamentarians have continued to press the Government to share information as to its work on compensation. On 7 September 2023 Dame Diana Johnson asked what progress had been made on the recommendation in the Second Interim Report for interim payments for those not previously included. The response was "we are working through this. There is more work to be done. It is a mammoth undertaking ... and we are looking forward to the final report and putting our response into that context." Jeff Smith MP relayed the concern of constituents: "The lack of transparency is causing great stress and anxiety to those of us at the heart of this NHS treatment disaster who have already waited decades for our loss and suffering to be recognised." Asked by Jessica Morden MP "why will the Government not get on with extending the interim payments now ...?", the Paymaster General's response included that "we paid interim compensation last year". However, the interim compensation paid in 2022 was, as detailed above, to those infected and to bereaved partners only, and did **not** include those many people affected who were the subject of the interim payment recommendation in the Second Interim Report.

As at October 2023, no final decision had been made on the nature of compensation payments, according to Shona Dunn, Second Permanent Secretary at the DHSC.<sup>1440</sup>

On 25 October 2023, asked why the Government insisted on postponing its response until after publication of the final report, when the Inquiry's recommendations on compensation had already been published, the Prime Minister said that "extensive work has been going on in Government for a long time, co-ordinated by the Minister for the Cabinet Office, as well as interim payments of £100,000 being made to those who were affected." As with the

<sup>1436</sup> Rishi Sunak Transcript 26 July 2023 p22 INQY1000281. This was part of a longer answer; see: Rishi Sunak Transcript 26 July 2023 pp18-25 INQY1000281

<sup>1437</sup> Written Statement of Jeremy Quin paras 19-23 WITN7526005. As to these principles, see: Note from Counsel to the Inquiry: Collective Responsibility/Safe Space for Policy Making 21 July 2023 INQY0000455

<sup>1438</sup> To which the Paymaster General's response was that the Government committed to responding "as swiftly as we can" after the final report is published. Hansard House of Commons debate on Infected Blood Inquiry: Interim Recommendations 7 September 2023 RLIT0002342

<sup>1439</sup> Hansard House of Commons extract on Topical Questions: Cabinet Office 7 September 2023 p6 RLIT0002347

<sup>1440</sup> Written Statement of Shona Dunn para 2.4 WITN7714003

<sup>1441</sup> Hansard House of Commons Prime Minister Engagements 25 October 2023 p9 RLIT0002336

Paymaster General's comment on 7 September 2023, a listener might well have understood that latter remark to indicate that **all** those affected had received interim payments. It is, of course, the position that only those infected and bereaved partners have received interim payments: all others have received nothing. On 26 October 2023 Dame Diana Johnson raised a point of order in the House of Commons; referring to the Prime Minister's statement she said: "That is factually incorrect ... as not all those affected have received interim payments. A parent who lost a child or a child who lost a parent in the scandal has received no such interim payment". She continued, referring to the Inquiry's recommendation that a scheme should be set up and begin work in 2023:

"We are nearly in November, very close to the end of 2023, and there is still no clarity from the Government. We have no idea what progress the Government have made on their work, despite being told repeatedly that it was at pace and they were working towards the original November deadline for the publication of the final report ... The Government have also failed to explain why victims of the infected blood scandal are being treated differently from the victims of the Post Office Horizon scandal, who rightly have received compensation before the public inquiry into their scandal has concluded." 1442

On 23 November 2023 the new Paymaster General, John Glen, in response to questions as to the progress being made on implementing the recommendations in the Second Interim Report, sensed the "palpable frustration" and stated that he was doing everything he could "to move things forward and to gain assurances from across Whitehall so that I can update the House as quickly as possible." 1443

On 4 December 2023 the House of Commons voted in support of an amendment ("New Clause 27") to the Victims and Prisoners Bill which would require the government to establish a body to administer a compensation scheme, ensure that the body is chaired by a High Court or Court of Session judge, and set up the scheme within three months of the passing of the Act. The amendment was opposed by the Government, but passed with votes of 246 to 242.<sup>1444</sup>

On 18 December 2023 John Glen made a statement in Parliament, in which he repeated the Government's acceptance of the moral case for compensation. His statement included the following: "With the interim compensation payments issued last October, the Government

<sup>1442</sup> Hansard House of Commons Points of Order 26 October 2023 p1 RLIT0002345

<sup>1443</sup> Hansard parliamentary answer on Infected Blood Inquiry 23 November 2023 p2 RLIT0002340. John Glen was appointed Paymaster General and Minister for the Cabinet Office on 13 November 2023.

<sup>1444</sup> A number of Conservative MPs voted in support of the amendment notwithstanding the use of the whip. A new Clause 42 was also put forward, to establish a deadline of 25 sitting days from the publication of the final report for an oral statement to be made to the House. In response, the Government committed to updating Parliament with an oral statement on next steps within 25 sitting days of the final report being published. Hansard House of Commons parliamentary debate on Victims and Prisoners Bill 4 December 2023 p13 RLIT0002349

<sup>1445</sup> John Glen also announced that a bespoke psychological support service for people infected and affected would be implemented, to be delivered by NHS England.

recognised the immediate and urgent needs of those most severely impacted."<sup>1446</sup> The boundary separating those who were "most severely impacted" from others was not set out. But the profound distress and loss of parents who watched their children die of AIDS or children who grew up without a parent or who watched their parents die can surely not be in doubt. <sup>1447</sup> In any event the recommendation made in the Second Interim Report was in respect of recognising the death of the child or parent concerned, upon whom the impact could hardly have been more severe.

Referring to the recommendations of the Inquiry on compensation, John Glen said: "The inquiry's recommendations are not without complexity, and it would be inappropriate for the Government to prejudge the findings of the final report." The Government was not, therefore, "yet in a position to share any final decisions on compensation." It was, however, "urgently appointing clinical, legal and social care experts to advise the Cabinet Office on detailed technical considerations" to ensure that the Government "have the relevant expertise to make informed choices in responding to the inquiry's recommendations on compensation." These experts' roles would be, he said, "the calibration of tariffs and allocation of compensation". 1448

Two matters by way of comment. Firstly, if such advice is required to enable the Government to make informed choices as to how to respond, it is difficult to understand why it took until December 2023, over a year and a half since Sir Robert submitted his study to the Paymaster General and eight months on from the Inquiry's Second Interim Report, for that advice to be sought. Secondly, if it is anticipated that the newly appointed experts will undertake the calibration of tariffs and allocation of compensation, that does not reflect this Inquiry's recommendations in the Second Interim Report – which were, in relation to expertise, that there should be expert panels to advise the chair, such panels to be appointed by the chair, so as to help secure a proper independence of the scheme, and that the panels should be expected to talk to, engage with and consult widely with beneficiaries. To take decisions behind closed doors would be to repeat the mistakes made with regard to financial support, which resulted in injustices and compounded the psychological impact of the original infections. 1450

It is open to the Government to decide to do something different from that which this Inquiry has recommended – but given the repeated lack of candour and transparency that has been displayed by successive governments, that is something which should be made

<sup>1446</sup> Hansard House of Commons debate on Infected Blood Inquiry: Government Response 18 December 2023 p1 RLIT0002341

<sup>1447</sup> This point was powerfully made in an email from Jason Evans to John Glen on 19 December 2023: Email from Jason Evans to John Glen and others 19 December 2023 JEVA0000278

<sup>1448</sup> Hansard House of Commons debate on Infected Blood Inquiry: Government Response 18 December 2023 pp1-2, p6 RLIT0002341

<sup>1449</sup> And unidentified, with the exception of one (Professor Sir Jonathan Montgomery).

<sup>1450</sup> On 12 March 2024 John Glen wrote to Diana Johnson explaining that the names of the expert group whom he has appointed would not be disclosed (other than the name of its chair) "to safeguard the privacy and ability of experts to continue their frontline clinical roles whilst advising on Government policy." Letter from John Glen to Diana Johnson 12 March 2024 p1 RLIT0002364

explicitly clear, and the public and participants in the Inquiry should, in justice, be told what the reasons are for taking a different course.

On 18 January 2024 the Paymaster General told the House of Commons that the Cabinet Office was "moving forward with the appointment of the clinical, legal and care experts" and that he would continue to have meetings with colleagues "to move this forward as quickly as I can." 1451

On 6 February 2024 the Chancellor of the Exchequer, in response to a question from Dame Diana Johnson, said that "the Government have already given £100,000 to the families affected." The Chief Secretary to the Treasury on the same date said "I am pleased that the interim payments at least have been paid." These statements ignore the fact that, of "families affected", only bereaved partners received the interim payment.

On 21 February 2024, the Prime Minister, referring to John Glen's 18 December statement, said that: "the Minister for the Cabinet Office updated Parliament with the latest Government position just before the Christmas recess. He announced that the Cabinet Office was appointing an expert group of clinical, legal and social care experts so that it had the relevant expertise to make informed decisions, responding to the inquiry's recommendations on compensation when they come." This answer suggests that the Cabinet Office has still not made "informed decisions" regarding the question of compensation. Furthermore, the Inquiry has already made its recommendations on compensation. There are no further recommendations on compensation to come.

During the 26 February 2024 consideration of the Victims and Prisoners Bill in the House of Lords Earl Howe, the Deputy Leader of the House of Lords, explained the role of the expert group was "to enable Ministers to understand certain technical issues and thus enable decisions to be taken more quickly." He also informed the House of Lords that the government would propose amendments at the report stage of the Bill that "will have the desired effect of speeding up the implementation of our response to the inquiry's findings." "There are", he said, "still a number of decisions to be made on the government response".1455

Earl Howe also advanced – for the first time, more than a year and half since the First Interim Report said that I would be considering submissions about interim payments to be reaved

<sup>1451</sup> Hansard House of Commons extract on Topical Questions: Infected Blood Inquiry 18 January 2024 p2 RLIT0002339

<sup>1452</sup> Hansard House of Commons extract on Topical Questions: Treasury 6 February 2024 p7 RLIT0002348

<sup>1453</sup> Hansard House of Commons answer on Infected Blood Compensation: Funding 6 February 2024 pp1-2 RLIT0002338

<sup>1454</sup> Hansard House of Commons answer on Infected Blood: Prime Minister Engagements 21 February 2024 p4 RLIT0002337. Further information regarding the appointment of an expert group was provided by the Paymaster General on 29 February 2024, when he indicated that the group was to advise the Cabinet Office on "detailed technical considerations" and to "advise on how to implement the recommendations of the report." Hansard House of Commons answer on Infected Blood Inquiry: Recommendations 29 February 2024 p2 RLIT0002343

<sup>1455</sup> Hansard House of Lords debate on Victims and Prisoners Bill 26 February 2024 pp15-17 RLIT0002350

parents and bereaved children – a reason why further interim payments could not be made: that it was not possible so to do, because "the legal powers to register, and make payments to, the new cohorts do not exist" within the existing schemes, and the alternative to making payments would have to be through a new arm's length body. 1456 It would have been helpful to the Inquiry to have understood before then what exactly the problem was, and what stood in the way of it being solved, not least because it is not apparent to the Inquiry why the same powers to issue directions that were used to set up the national support schemes in the first place could not be used again.

On 6 March 2024 the Chancellor delivered the Budget. It contained no reference to any compensation. There was, said Dame Diana Johnson, "not even an allocation for further interim payments to alleviate the immediate suffering of parents who have lost children, and children who have lost parents. Let me give the House an example of what that looks like. Sam Rushby, whose entire family – mum, dad and three-month old baby sister – all died of AIDS by the time he was three, has received no compensation, and would benefit from the interim payments" recommended in the Second Interim Report. 1458

The Office for Budget Responsibility ("OBR"), in its *Economic and fiscal outlook* report published on 6 March, referred to the interim payments made in 2022 and then recorded that "we will incorporate the impacts of any further recommendations into our forecast once they are sufficiently certain." Richard Hughes, chair of the OBR's Budget Responsibility Committee, has told the Inquiry that "Infected blood compensation payments are an area where the Government has committed to some future payments but has not yet provided sufficient detail, inter alia regarding their magnitude, timing, or source of funding, to enable us to include them in our central economic and fiscal forecast. He explained that for the fiscal consequences of compensation payments to be sufficiently certain for the OBR to include in its forecast, it would need: the estimate of the precise amounts; the timing of when payments are to be made; whether payments will come from within existing spending plans or from new spending; the spending classification of the payments; and how the payments will be treated in the National Accounts. He in may be that some of these matters have already

<sup>1456</sup> Hansard House of Lords debate on Victims and Prisoners Bill 26 February 2024 p16 RLIT0002350

<sup>1457</sup> The Financial Times, reporting on 1 March 2024 that nearly 120 MPs from all the major political parties had written to the Chancellor urging him to allocate funding for compensation in the Spring Budget, noted that "Privately, ministers noted that it was convenient for the government that the compensation bill would not be finalised until after the Budget, meaning that the Office for Budget Responsibility cannot score the compensation payments in its economic forecasts." Financial Times Cross-party plea made for infected blood victims to get Budget payout 1 March 2024 RLIT0002361

<sup>1458</sup> Hansard House of Commons debate on Budget Resolutions 6 March 2024 p32 RLIT0002333, Written Statement of Sam Rushby WITN7122001

<sup>1459</sup> The OBR asked the Treasury for details on infected blood compensation payments before it published its March report and received the following response: "The government is considering the existing recommendations made by the Infected Blood Inquiry in its interim reports. The Inquiry has also announced that its final report will be published on 20 May, and the government will need to consider the final conclusions carefully. The government will therefore respond to the Inquiry's recommendations following the final report". Written Statement of Richard Hughes para 1, para 3 WITN7749001

<sup>1460</sup> Written Statement of Richard Hughes para 3 WITN7749001

been determined, as far as they reasonably can be: but it follows as a matter of certainty that all had not yet been settled sufficiently for the OBR to be notified by 6 March 2024.

On 7 March 2024, Penny Mordaunt told the House of Commons that it is not the intention of the Government "to kick the can down the road on this issue", that it is a moral issue which the Government has taken seriously, and that she did not think the House would have to wait long before being updated by the Paymaster General.<sup>1461</sup>

The latest information that the OBR has supplied shows that their state of information had not changed in the (albeit short) period between budget day and 14 March 2024, the day on which a written statement was received from Richard Hughes of the OBR.<sup>1462</sup>

On 30 April 2024 the Victims and Prisoners Bill, which has at the date of writing reached the report stage, was considered further in the House of Lords: it provides for the establishment of an Infected Blood Compensation Authority and an amendment requiring the scheme to be set up within three months of the Bill receiving Royal Assent was accepted.

# Commentary

The above narrative speaks for itself. It needs little commentary, beyond a brief highlighting of the chronology:

- (a) The Government did not do what it said it would: to publish its response to the Compensation Framework Study alongside the study itself and in advance of Sir Robert's evidence to the Inquiry.
- (b) The Government then failed to publish its response after Sir Robert's evidence, despite saying that it would "act as expeditiously as possible after that." 1463
- (c) The Government has not yet (as at today) published any response to the Compensation Framework Study.
- (d) Little appears to have been done before late 2022. The fact that the first cross-government meeting of senior officials took place in November 2022, that it was only decided in early 2023 to establish a DHSC team to undertake costs analysis, that the Small Ministerial Group met for the first time on 22 February 2023, and that the first ministerial meeting involving the devolved administrations was not until June 2023 have the appearance of working at a sluggish pace.
- (e) The Government said it was planning to be ready to respond to compensation recommendations that it expected to arrive in mid and then autumn 2023. On that timescale, its work should now be complete.

<sup>1461</sup> Hansard House of Commons Business of the House 7 March 2024 p9 RLIT0002334

<sup>1462</sup> Written Statement of Richard Hughes WITN7749001

<sup>1463</sup> Hansard extract on Topical Questions: Cabinet Office 9 June 2022 p3 RLIT0002067

- (f) Such evidence as there is suggests that this is not the case and that key decisions may still remain to be made.
- (g) At several stages Government has said that it would update Parliament with as much detail as it could as work progressed. It is a matter of regret that it has found little to report.

The effect of what has happened is that the Inquiry's own consideration of compensation has not been able to be informed by the Government's response to the Compensation Framework Study, that the Government's response has (thus far) escaped the scrutiny of the Inquiry; and that those infected and affected have felt a lack of transparency and openness characteristic of what they have had to face, and have been fighting, for nearly half a century.

The rationale of waiting for this Report, as explained to the Inquiry, begs for a better explanation. This is not a case in which the Government is expecting a report that says everything was done as it should have been. Jeremy Quin's expectation as at 22 June 2023 was that the full report would put the compensation proposals into further and – I fear in many ways – deeply upsetting context. He confirmed a month later in his oral evidence his expectation that the final report will unveil very, very significant issues that happened over many decades and should never ever have happened. Penny Mordaunt recognised in Parliament in October 2023 that people have suffered layer upon layer of injustice. The Prime Minister has acknowledged that what has happened have been an appalling scandal ... thousands of people ... have suffered for decades, and they have suffered a layer of injustices at that ... this is not just about historic wrongs, people are suffering and being impacted today.

Despite this, and the Government's acceptance of the moral case for compensation in December 2022, the Government has insisted upon waiting for this Report, despite knowing that the Inquiry's Second Interim Report contains its full recommendations on compensation.

Jeremy Quin has suggested the final report "will enable the Government to see those recommendations in their full context" and that "Being able to put the Government's response into the context of those findings is a useful and helpful thing to do in justifying our actions". 1470 Jeremy Hunt expressed the view that it was "responsible and right to the taxpayers, who are funding this, for Government ministers to see the full context of the

<sup>1464</sup> Nor can the Government claim ignorance of the evidence that has been given to the Inquiry: the DHSC has been a core participant throughout. It was in a position to suggest questions to counsel to put to Sir Robert, and to apply to examine his evidence in public themselves if those questions were not sufficiently dealt with by counsel to the Inquiry.

<sup>1465</sup> Hansard extract on the Infected Blood Inquiry 22 June 2023 p28 RLIT0002158

<sup>1466</sup> Jeremy Quin Transcript 25 July 2023 p59 INQY1000280

<sup>1467</sup> Hansard House of Commons Business of the House 19 October 2023 p16 RLIT0002335

<sup>1468</sup> Rishi Sunak Transcript 26 July 2023 p5 INQY1000281

<sup>1469</sup> Written Statement of Jeremy Quin para 27 WITN7526005

<sup>1470</sup> Jeremy Quin Transcript 25 July 2023 pp56-57 INQY1000280

horrific scandal that this was, before we make the final decision as to how the compensation will work."<sup>1471</sup> But when the Government knows, as it clearly does, that what happened was a terrible injustice, that people deserve redress, and that lack of redress perpetuates the injustice, then to delay, and thus deny, justice in order to await the "full context" seems hard to justify.

The Prime Minister's explanation was that it was "long-standing convention and precedent and advice" to wait for the conclusion of the Inquiry and that it was normal "not to make final decisions until an Inquiry has finished."<sup>1472</sup> Whilst that may well be the usual course — and will reflect the fact that inquiries do not always make interim reports, although they are expressly empowered to do so under the Inquiries Act — the Government's actions in relation to the Post Office Horizon scandal make plain that decisive, even bold, commitments can be made in advance of an inquiry's final report. <sup>1473</sup> In the exceptional present context, given the acceptance of moral responsibility, the known urgency in light of passing time, and the vulnerability of those infected and affected (and with people continuing to die without redress), let alone the fact that nearly two years ago now interim payments were made to some of those involved <sup>1474</sup> reliance on "convention" and "precedent" does not provide a sufficient justification.

Back in November 2022, Jeremy Quin told the Inquiry that work was continuing across government "so that Government can respond swiftly to any recommendations relating to

<sup>1471</sup> Jeremy Hunt Transcript 28 July 2023 p46 INQY1000282. The submissions on behalf of the Haemophilia Society aptly observe, in response to this particular evidence, as follows: "First, as to the potential for very large sums of money to be required properly to compensate the infected and affected, the government cannot have failed to have been aware of that potential when it decided, many years ago now, that a statutory public inquiry required to be held. Second, if — which is highly unlikely — it did not realise the potential for very large sums of money to be involved when it first set up the Inquiry, it must have identified that potential on receipt of Sir Robert Francis' Compensation Framework Study report, published on 7 June 2022 — over a year before Mr Hunt gave his evidence, at the very latest. As to Mr Hunt's second point, that it is reasonable for the government to delay a decision on compensation until publication of the Inquiry's final report so that taxpayers funding compensation can see the full context, the Society makes two points. First, the significant national media coverage of evidence given to the Inquiry that there has been during the course of the Inquiry means that taxpayers are already well informed about the horrific scandal, and the appalling suffering it has visited on thousands of innocent NHS patients. Further or alternatively, Sir Brian's second interim report, and Sir Robert's Compensation Framework Study, provide such additional context that taxpayers require to understand why it is appropriate for very large sums of taxpayers' money to be paid to the infected and affected." Written submissions on compensation by The Haemophilia Society 25 August 2023 paras 6-7 SUBS0000076

<sup>1472</sup> Rishi Sunak Transcript 26 July 2023 p32, p36 INQY1000281

<sup>1473</sup> The contrast between the Government's ability and willingness to act in relation to victims of the Post Office Horizon scandal (including the introduction of a bill to overturn convictions with the intention of having the bill receive Royal Assent before the 2024 summer recess) without waiting for the final report of that public inquiry and its inability and unwillingness to act in relation to those infected and affected until it has seen the final report of this Inquiry has been flagged up by Dame Diana Johnson in Parliament: see, for example, her observation on 23 October 2023 on a recent statement by the Paymaster General: "There was no detail on progress to establish a compensation scheme ... and no explanation of why contaminated blood victims are being treated differently from victims of the Horizon scandal". Hansard House of Commons Points of Order 23 October 2023 p8 RLIT0002346

<sup>1474</sup> Such that even if a final scheme were to be delayed there is no good reason why a way could not be found to pay interim payments to parents who have lost children and children who have lost their parents or families.

**compensation** in the Inquiry's final report."<sup>1475</sup> In other words, the rationale of waiting for the final report was to see what recommendations the Inquiry made regarding compensation. That rationale fell away once the Second Interim Report was published.

Three former health secretaries – Jeremy Hunt, Matt Hancock and Andy Burnham – wrote to the (then) Prime Minister on 3 August 2022, following the Inquiry's First Interim Report, to this effect:

"To refuse to do so [ie to make interim payments as recommended by the Inquiry] would simply continue the injustice thus far handed out by the state to a group of innocent victims condemned to years of suffering and neglect.

Any delay to such payments, for instance by arguing that we need to wait for the inquiry to finish, for a new Prime Minister, or for Parliament to return, will sadly almost certainly see more of the victims die before they see justice. Already more than 400 people have died since the inquiry started. With some estimating that one infected person is dying every four days waiting until even the end of the year when the Inquiry hearings are concluded would mean another 40 people would die. That number would likely be above 100 if the government waits until the inquiry has reported in full. This is simply unacceptable and will cause yet more harm to a group of exceptionally vulnerable people." 1476

These words are as true now as they were then. 1477

In May 2023 the Leader of the House of Commons, Penny Mordaunt, said this:

"I have had the privilege of meeting many of those who were infected and affected by that appealing scandal, and I went to hear some of the evidence that they gave at the inquiry. It may fall to us in this place, on our shift, to put that right, but we must put it right. There is not just the original injustice that was done to those people, many of whom were children at the time, but the further layers of injustice that have happened with regard to their financial resilience, as many of them lost their homes and were not able to work, facing the appalling stigma and hardship that came with that. We have to put that right." 1478

If the acceptance of a moral case for compensation is not followed by action in providing compensation then the Government is not "putting it right". 1479

<sup>1475</sup> Emphasis added. Written Statement of Jeremy Quin para 10 WITN7526001. See also: "the preparatory work already underway will present options to allow the Government to respond more quickly to any recommendations related to compensation in the Inquiry's final report." Written Statement of Jeremy Quin para 13 WITN7526001

<sup>1476</sup> Letter from Jeremy Hunt, Matt Hancock and Andy Burnham to Boris Johnson 3 August 2022 WITN3499035

<sup>1477</sup> As indeed Andy Burnham emphasised in a letter to the Chancellor on 27 July 2023. Letter from Andy Burnham to Jeremy Hunt 27 July 2023 HSOC0029912

<sup>1478</sup> Hansard House of Commons Business of the House 25 May 2023 p5 RLIT0002127

<sup>1479</sup> As Penny Mordaunt accepted. Penny Mordaunt Transcript 24 July 2023 p53 INQY1000279

As the above narrative demonstrates, there have been ample opportunities – and invitations – for the Government to explain what it is doing. It has chosen not to give detail. In his oral evidence to the Inquiry, Lord Jonathan Evans, then chair of the Committee on Standards in Public Life, observed that "it's central to the whole democratic process that there has to be accountability and that accountability requires openness". The importance of openness and transparency for those infected and affected, who have been denied truth and justice for decades, should be self-evident. The lack of transparency compounds the harm which has already been inflicted. 1481

It may be that a huge amount of work has been undertaken. It may be that the Government has decided to accept the recommendations. It may be that justice and redress are just around the corner – for those who are still alive. But at the time of writing this Report I have no way of knowing if this is the case. Nor, more importantly, do those infected and affected. That is a serious failing which replicates the wrongs of the past. People whose lives were torn apart by the wrongs done at individual, collective and systemic levels, and by the way in which successive Governments responded to what happened, still have no idea as to the shape, extent or form of any compensation scheme, and no idea, beyond the acceptance of the moral case for compensation and assurances that there will be more to come, of the Government's response either to the Compensation Framework Study or the Second Interim Report.

In 2017 Andy Burnham told Parliament that "victims now feel that they have been led up to the top of the hill only to be let down once again" and that the lack of substantial action "has left people feeling in the wilderness all over again." Andy Burnham's call for compensation was seven years ago.

People infected and affected continue to die.

From an early stage of the hearings before the Inquiry it became obvious to any objective onlooker that compensation was likely to be recommended. That was why it was decided to commission Sir Robert to report on what it might cover, and how. The Inquiry said all it had to say by way of recommendation concerning compensation before Easter 2023.

This chapter has been one of the very last I have written, because I had hoped to be able to discuss the Government's response to the Inquiry recommendations concerning compensation, and to be able to report that it had done right by those to whom the

<sup>1480</sup> Lord Jonathan Evans Transcript 9 November 2022 p15 INQY1000258

As the submissions on behalf of the core participants represented by Thompsons Scotland emphasised, "the evidence of government intransigeance towards the recommended financial solution serves to reinforce the argument that government inaction is current and that serious harms are being caused today, not just in the past." Written submissions on behalf of the core participants represented by Thompsons Scotland 25 August 2023 para 1.6 SUBS0000072. See also the submissions on behalf of the core participants represented by Watkins & Gunn Solicitors: "The CPs [core participants] we represent ... now feel considerable anger, frustration, distress and anxiety, caused by the unwillingness or inability of government witnesses to (i) commit to any future timetable, and (ii) to provide detailed answers to straightforward questions." Written submissions on behalf of the core participants represented by Watkins & Gunn 24 August 2023 para 4c SUBS0000074

<sup>1482</sup> Hansard extract on Contaminated Blood 25 April 2017 p1 RLIT0001578

recommendations relate. The Government has said it "accept[s] the will of Parliament that arrangements should be put in place to ensure, as far as reasonably practicable, that the victims receive justice as quickly and efficiently as possible." I urge the Government to put these words into action.

What has been set out in this chapter also led me to make the recommendation that a mechanism is needed to hold the executive to account before Parliament in relation to the recommendations of an inquiry. This must be in a way which ensures that the recommendations an inquiry makes are fully and properly considered; that if they are accepted there is a mechanism for ensuring that effect is then given to them; and that if they are rejected that a full explanation is given in public, to the public, and to Parliament, for this. I am recommending that this mechanism should involve a body which is open, independent, cross-party, and respected for its objectivity, so that government may properly be held to account for the way in which it deals with the recommendations of an inquiry.<sup>1484</sup> Those who have been infected and affected will expect it.

<sup>1483</sup> Hansard House of Lords parliamentary debate on Victims and Prisoners Bill 26 February 2024 p18 RLIT0002350

<sup>1484</sup> See the chapter on Recommendations.

# 7.9 Commentary on the Government Response

## Cover-up

The Terms of Reference of the Inquiry include "cover-up". A better expression than "cover-up" to convey the totality of what happened is "hiding the truth". Many of the people who were infected and affected rightly sense that the truth has been hidden, in various ways, for most of the time they have suffered, and before then. A lack of openness, a lack of inquiry, a lack of accountability and elements of downright deception have led to a lack of trust in those responsible for the treatment – that is, their treatment both medically and as citizens of a democratic state – and this has in turn done further damage to them.

Hiding the truth includes not only deliberate concealment (which the words "cover-up" often imply to the exclusion of more subtle processes) but also a lack of candour; the retelling of half-truths (statements which though not technically wrong might be misleading, such as the "no conclusive proof" line to take); the not telling people what they had a right to know (for instance, that there were risks to the treatment being given to them; or that there were alternatives to the treatment they were being given; or that they had been tested for infection; or that they had been used in research; or they were suffering from a potentially serious and fatal disease, and might infect those around them); the use of less informative rather than more revealing words on documents such as death certificates; and the use of inaccurate and misleading lines to take, with repeated assertions that people received the best treatment available, that infection was unavoidable or inadvertent, that everything was done as well and as promptly as it could have been. It will be apparent from much of what is set out in this Report that the truth has indeed been hidden and that there has been a lack of candour in the respects identified above.

Sometimes the truth was hidden by a treating clinician. Sometimes it was hidden by an organisation. Sometimes it was hidden by the civil service. Sometimes it was hidden by (and sometimes from) politicians. Also

#### Clinicians and the NHS

A number of individual witnesses who gave evidence, or provided statements, record that they were told by their doctors that the risks to them of their contracting non-A non-B Hepatitis were relatively unimportant – it was a minor infection which would have no significance in

<sup>1485</sup> For full details, see the chapters on *Haemophilia Centres: Policies and Practice* and on *Blood Transfusion: Clinical Practice*.

<sup>1486</sup> For a full exploration see the chapter on *Haemophilia Centres: Policies and Practice* and that on *The Haemophilia Society*.

<sup>1487</sup> See the chapters on Role of Government: Response to Risk, Document Destruction, Self-Sufficiency Report, Lines to Take and Delay in Holding a Public Inquiry.

their lives. Some people who had bleeding disorders were told that the risk of AIDS was undoubtedly far less than the dangers of not being treated by concentrate. In both cases, the seriousness of what the patient was facing was underplayed. In an even greater number of cases, people were given no information whatsoever about the risks of viral transmission from transfusion, or from treatment with blood products. There is overwhelming evidence, from a large number of people, of differing backgrounds, different ages, and different ways of expressing themselves, to exactly this effect. When coupled with the evidence as to what was or should have been known about non-A non-B Hepatitis and the risks of AIDS, and what was, frankly, not yet known but was entirely possible, there can be no other conclusion save that the whole truth was not given to them. It was often the truth that clinicians, or civil servants, just did not know: but they did not admit to this, and instead assumed a more comfortable "truth" which had no adequate basis. And for some people the very fact that they had been infected, or the means by which they had been infected, was not disclosed to them, sometimes for years.<sup>1488</sup>

The evidence before the Inquiry that the truth was concealed or suppressed in this sense and in these ways is overwhelming.<sup>1489</sup>

Three further examples of a less than candid approach are described below.

The first involves the Cardiff Haemophilia Centre and illustrates the fear that some had of speaking out about the truth of what was known of the likely causes of AIDS.

The Inquiry knows very little about the personal interactions at the Cardiff centre amongst those who worked there. But it does know that one clinician who worked there was Professor Allan Jacobs. He was a scientist, rather than clinical haematologist, but headed up haematology in Cardiff. From the evidence it has the Inquiry infers that he became concerned towards the end of 1982 that AIDS might be transmitted by blood products and transfusions. Susan Douglas, a young journalist with a background in medical science, learned from a friend that he might have interesting, authoritative views on this. She spoke to him at length, in person, and later by phone. She did not at first tell him she was working for a newspaper. When she eventually came clean and did, and told him that she thought the story that blood might transmit the cause of AIDS was really important he responded "I am really concerned that you don't reveal my identity because that will cause major problems for me." 1490

<sup>1488</sup> The Inquiry heard, for example, multiple accounts from individuals who, although experiencing ill health over many years, were unaware that the cause of that ill health was Hepatitis C as a result of transfusion. Had there been greater transparency and openness about what had happened, people might have discovered this much earlier than they did, and been treated much earlier than they were.

<sup>1489</sup> See the chapter on *People's Experiences* and the statements from individuals published on the Inquiry's website.

<sup>1490</sup> Dr John Whittaker was a reader in Haematology at the Cardiff Department of Haematology 1980-2003. He told the Inquiry that between 1971 and 1991 the Department of Haematology had only four senior members with clinical responsibilities: Professor Allan Jacobs who headed the Department, Professor Arthur Bloom who was the only one responsible for patients with bleeding disorders, Dr Charles Wardrop who was a senior lecturer and himself. He read Susan Douglas' witness statement and said that her contact was "almost certainly Professor Allan Jacobs". Professor Jacobs was interested in premalignant conditions and the epidemiology of disease and died in 1993. Susan

He was telling her, in effect, that speaking out in public about what he believed, on good grounds, to be the case would not be well received – to the extent even he, in his position, felt unable to do it.

Susan Douglas understood (correctly) from what she had been told that there was a patient at Cardiff who was suffering from AIDS, as a result of being given treatment for haemophilia with blood products from the United States. She reported this on 1 May 1983 in *The Mail on Sunday*, for which she had recently begun to work.<sup>1491</sup>

Almost immediately, Professor Jacobs' fears were proved justified. There was a hostile response, not to him but towards the newspaper report. It came from Professor Arthur Bloom in his letter of 4 May 1983 for Haemophilia Society members; and on 6 May 1983 Dr Peter Jones wrote a complaint to the Press Council. He said: "I take the gravest possible exception to this approach to reporting about illness. This sensational and highly exaggerated article has, not unnaturally, started a chain reaction involving other newspapers and radio and television, not only in this country, but abroad. As a result, this Haemophilia Centre and others throughout the country have been inundated with calls from worried families." 1494

The Press Council in due course said "the subject was one of serious concern and a proper one for newspaper inquiry and report. The article contained some inaccuracies but, more importantly, was presented in extravagant and alarmist terms which were not justified by the evidence contained in it or produced since. Its headline 'Hospitals using killer blood' was unacceptably sensational."<sup>1495</sup>

In the meantime, Susan Douglas continued as best she could against a deluge of criticism. She reported (on 2 October 1983) that a patient in Bristol had died. He had haemophilia. He had been given infected imported factor concentrate. He died of AIDS. Yet there was no inquest: his death certificate said he died "of renal failure". The Mail on Sunday spoke of this as a suppression of the facts of his tragic death: it said that, and the lack of an inquest, "point towards a conspiracy of silence."

Douglas Transcript 15 September 2022 pp9-16 INQY1000242, Written Statement of Dr John Whittaker para 4a WITN7512001, Royal College of Physicians biography of Allan Jacobs RLIT0002374

<sup>1491</sup> The Mail on Sunday Hospitals using killer blood 1 May 1983 PRSE0000199

<sup>1492</sup> Professor Bloom's letter referred to "inaccurate statements in the press" and his assertion that "we are unaware of any proven case in our own haemophiliac population" was a disingenuous half-truth, given his own knowledge of a probable case amongst patients of the Cardiff Centre. The letter was published by the Haemophilia Society with the comment that "In view of the unduly alarmist reports on AIDS which appeared in the press over the weekend, we are writing to reassure members of the Society about the true position." Letter from Professor Bloom to Reverend Alan Tanner 3 May 1983 CBLA0000060\_158, Letter from Reverend Tanner to members of the Haemophilia Society 4 May 1983 DHSC0001228. See also the chapters on the Haemophilia Society and Haemophilia Centres: Policies and Practice.

<sup>1493</sup> Director of the haemophilia centre in Newcastle.

<sup>1494</sup> Letter from Dr Jones to the Press Council 6 May 1983 p1 PJON0000001\_100

The editor, in his response to the complaint, had argued, with some justification, that the article created discomfort for medical professionals rather than patients and created "exactly the sense of emergency which was hitherto lacking." Press Council Press Release For Sunday Newspapers 18 March 1984 pp2-3 PJON0000001\_145

In a headlined box entitled "Why there must be action" Susan Douglas wrote: "In May, I pointed out the dangers of importing blood from a country with an AIDS epidemic. And I was viciously attacked for panic-mongering. Must another innocent man die before action is taken?". 1496

This evidence does not display an orchestrated conspiracy to hide the truth. It does, however, display an attitude which objected to facts, or legitimate fears based on facts, rather than false reassurances, being given out. It showed a desire to control the message which was to be given to the patients and public involved, to an extent which meant that some (such as, probably, Professor Jacobs) may have been reluctant to speak out because of the hostile response they expected; a response which Susan Douglas certainly encountered.

The second example, however, shows that some behaviour did amount to a decision deliberately to deceive.

During the Inquiry hearings in Leeds, Lesley McEvoy described what had happened to her during childbirth. She was in a hospital, since closed, in Yorkshire. She lost a lot of blood during labour. As a result, she was very fatigued and lethargic. The doctors wanted her to have a blood transfusion, but she did not want one, because she understood there might be a risk of HIV (it was late 1985). When she refused, a consultant shouted at her in front of the ward and said she was a bed blocker. She described his words: "'Just take the blood. You are being paranoid. Your fears are groundless. You are a silly woman' kind of thing." She was upset. Later that night a junior doctor took a more conciliatory tone: he said he understood her worry but that: "'some of the blood is being heat treated and if the blood is heat treated it will kill the HIV virus' so he said 'if I can guarantee you that the blood you get has been heat treated will you accept it?' and I said 'Okay' because I thought that was the best I was going to get." The following morning she was brought two bags of blood. Her account was: "They were straight out of the fridge. He held them up and there was a sticker. I remember it distinctly. There was a sticker on the bag and it said 'Heat treated'. He said ... 'It has been heat treated. Will you accept it?' I said 'Yes'."<sup>1497</sup>

It was only as she was giving evidence live to the Inquiry that she was told that blood could not be heat treated. She was describing having been told a lie. Since it could not have been the case that the blood had been heat treated, the doctor was telling her what was not true, and he or another had dishonestly labelled the blood bag to support the lie.

The implications of this suggest that others must have known that this is what the doctor was going to do: the label had been prepared and stuck onto the bag in order to convey what was a lie. Nurses, or other staff may have known. It is likely they were complicit. The bag with the evidence on the sticker across it was there for anyone in the ward to see.

This conduct thwarted the wishes of a patient for her own treatment. It was no doubt thought to be excused because the doctors thought her fears of infection from blood were groundless,

and it was convenient to them that she should not "bed block". She did not suffer infection with HIV as she had feared. She was infected with Hepatitis C instead. She described it as having ruined her life after that.

The behaviour of the doctor – or doctors – in this case was shocking. I doubt that the doctors involved were seeking actively to harm their patient. There is no evidence it was part of any wider conspiracy beyond the junior doctor concerned and any nurse or other who may have known. However, this example, drawn from the evidence, shows that hiding the truth may be done in pursuit of an aim which is thought desirable from the perspective of the person doing it. The patient's perspective, and their own view of their best interests, has been overborne.

The third example reflects this too. Mrs U gave evidence to the Inquiry in Edinburgh. Her husband was diagnosed with acute myeloid leukaemia in 1980, as a result of which he received frequent blood transfusions and was treated with platelets at Edinburgh Royal Infirmary. His treating clinician was Dr (later Professor) Christopher Ludlam.

Mrs U described her husband's condition: "he was skeletal really. His skin was a strange colour and also his eyes. He'd lost his hair ... He also had oral thrush, which was horrendous ... He also had a cough ... His nature had changed. He was very depressed."<sup>1500</sup> He died in 1984 and his death certificate gave acute myeloid leukaemia as the sole cause of death. <sup>1501</sup>

Around ten years later<sup>1502</sup> Mrs U encountered Dr Ludlam whilst visiting her mother at the Royal Infirmary, and he subsequently asked to speak to her. This was her recollection of the discussion: "When I went to see Dr Ludlam he told me that [my husband] had contracted AIDS before his death ... Dr Ludlam told me that I would have to be tested for AIDS."<sup>1503</sup> She also learned from her conversation with Dr Ludlam that vials of her husband's blood had been retained. Looking back, she thought her husband probably had AIDS in 1983, and she told the Inquiry that she now struggles with not knowing which complications resulted from leukaemia and which from AIDS.<sup>1504</sup>

In a statement to the Inquiry Professor Ludlam has explained that he was informed by the Scottish National Blood Transfusion Service ("SNBTS") in early 1986, as part of the HIV lookback, that Mrs U's husband had probably received a unit of platelets on 31 December 1984. The donor was discovered, following the introduction of screening in 1985, to be HIV positive: it appeared the donor may have been positive in 1983 at the time of the donation which Mrs U's husband received. On receipt of this information Professor Ludlam

<sup>1498</sup> ANON Transcript 8 July 2019 pp55-86 INQY1000029

<sup>1499</sup> Written Statement of ANON paras 4-10 WITN0136001

<sup>1500</sup> ANON Transcript 8 July 2019 p61 INQY1000029

<sup>1501</sup> Death Certificate of ANON WITN0136002

<sup>1502</sup> Mrs U's recollection was that this was early 1994. ANON Transcript 8 July 2019 pp72-73 INQY1000029

<sup>1503</sup> Mrs U was tested; she had not been infected with HIV. Written Statement of ANON para 14 WITN0136001

<sup>1504</sup> ANON Transcript 8 July 2019 p77 INQY1000029

arranged for retained virology samples from early 1984 to be tested for HIV and the results demonstrated that her husband had been infected with HIV.<sup>1505</sup>

Thus Professor Ludlam knew in 1986 that Mrs U's husband had been infected with HIV from transfusion. He decided not to tell Mrs U. He says that he did so on the basis of a "risk assessment" that the chance of her being infected with HIV was very small. It was, however, probable, because it would have been his "standard practice", that he shared this information about the infection with the GP. Meeting Mrs U in 1994 would "have reminded" him about her husband having been infected.<sup>1506</sup>

This amounted to hiding the truth from Mrs U. She was entitled to know, as soon as Professor Ludlam knew (on his evidence, in 1986), that her husband had been infected with HIV through transfusion, not least because she might have been infected, and, unaware of that, she might in turn have unknowingly transmitted infection to others. She might have wished to seek compensation on her late husband's behalf, or at least explore the possibility of so doing, but could not do that if she did not know. It is likely that, but for the accidental encounter a number of years later, the truth would have remained hidden from her.

As well as lacking in candour, it was profoundly paternalistic and wrong for Professor Ludlam to determine unilaterally that it was not in the best interests of Mrs U and her family to be provided with this information (whilst sharing it nonetheless with the GP).

The NHS did not respond to the infection of thousands of people with HIV and hepatitis, through transfusion or through treatment with blood products, by undertaking investigations, providing detailed explanations, making sincere apologies and doing everything that could be done to learn lessons. Instead, viewed overall, what is apparent is a defensive closing of ranks. The father of a son infected with Hepatitis C expressed the view that "the NHS should have been much more open about what was happening from the beginning. It felt like a closed shop right from the start, no one knew what was going on and there was no information out there. There was nobody willing to take any responsibility for what had happened and that's not right."<sup>1507</sup>

Two meetings of haemophilia centre directors to discuss the HIV litigation are revealing. The first, on 16 June 1989, was an extraordinary general meeting, attended by representatives of medical defence organisations, the Department of Health and legal advisers of various health authorities. The meeting was advised that, if asked, directors should agree to act as experts for the plaintiffs, because if they did not the plaintiffs would have to seek expert advice "from outside the Directors' group", which would be "undesirable and not in the best

<sup>1505</sup> Professor Marc Turner, on behalf of SNBTS, confirmed in a statement to the Inquiry that Mrs U's husband received a platelet transfusion on 31 December 1983, that the donor was identified as being HIV positive when donating following the introduction of donor testing in October 1985, and that Mrs U's husband was found to have received an infected platelet transfusion during the subsequent lookback process. As part of the lookback process Dr Jack Gillon contacted Professor Ludlam to inform him of this. Written Statement of Professor Marc Turner paras 10-12 WITN3530105, Written Statement of Professor Christopher Ludlam para 7 WITN3428038

<sup>1506</sup> Written Statement of Professor Christopher Ludlam paras 4-14 WITN3428038

<sup>1507</sup> Written Statement of ANON para 35 WITN2183001

interests of anyone."<sup>1508</sup> In answer to the question whether there could be a group of directors "looking at the problems and learning from it", the response was that "the Directors needed to spend time on more profitable matters, for example research work into HIV and AIDS in haemophilia."<sup>1509</sup> A second meeting, of the AIDS Group of Haemophilia Centre Directors, on 12 February 1990 involved awkwardness because one attendee, Dr Anthony Aronstam, was acting as an expert on behalf of plaintiffs and some directors felt "nervous discussing details of their clinical practice with a representative of the plaintiffs in the room". <sup>1510</sup>

Dr Jones told BBC Radio 4's *The Reunion* that "We've apologised and apologised and apologised, and David Cameron apologised twice", and complained that people were still angry. <sup>1511</sup> Professor Christine Lee said in an interview "Personally I don't think that faults can be attributed ... I mean cynically I think the patients – the few patients driving this are probably after money actually." <sup>1512</sup>

There have without doubt been individual apologies from clinicians that were heartfelt and sincere; and there have been, in this Inquiry, insightful organisational self-reflections, such as in the closing submissions on behalf of SNBTS and the Scottish Territorial Health Boards. But most such apologies as have been uttered have never been accompanied by any admission of wrongdoing. As explained by the expert psychosocial panel to the Inquiry, whilst an apology:

"can never undo what happened to those impacted by events ... satisfying and effective apologies do help reconciliation ... The nature of the apologies that the infected, if still alive, and affected require is multifaceted. Firstly, good practice would suggest, at the very minimum: a need for someone involved to apologise for the infected blood products or blood having been administered; an apology for testing and treating without informed consent; followed by sincere regret

- 1508 It is a noteworthy feature of the litigation that the defendants looked to the UK haemophilia clinicians for expert advice, even though the latter could not conceivably be regarded as impartial, with Dr Charles Rizza, Professor Bloom and Dr Elizabeth Mayne all providing expert reports which suggested little by way of fault. Minutes of the Extra-ordinary General Meeting of UK Haemophilia Centre Directors to Discuss Haemophilia, HIV and Litigation which was held at the Royal Free Hospital, London 16 June 1989 p5 PRSE0002656
- 1509 It was also agreed that directors should put pressure on the government to provide compensation and "should draw attention to the great amount of extra work generated by litigation and how this extra work was detracting from patient care". Minutes of the Extra-ordinary General Meeting of UK Haemophilia Centre Directors to Discuss Haemophilia, HIV and Litigation which was held at the Royal Free Hospital, London 16 June 1989 pp11-12 PRSE0002656
- 1510 Minutes of AIDS Group of Haemophilia Centre Directors 12 February 1990 pp2-3 HCDO0000271\_014
- 1511 Transcript of The Reunion: Contaminated Blood 11 September 2016 p65 MDIA0000088
- 1512 Transcript of Interview between Lynda Finn and Christine Lee 26 June 2015 p35 THOM0000001. Professor Lee was asked about this in her evidence. Professor Christine Lee Transcript 21 October 2020 pp157-163 INQY1000066. She said that she thought compensation was wrong because it suggests liability, that she felt particularly aggrieved when she made this comment because of an out-of-court settlement in a case where she didn't think there was any liability, that she thinks the idea that any decent person would give someone treatment that they knew would cause harm ridiculous, and that she feels totally hurt.
- 1513 Closing submission on behalf of SNBTS and Scottish Regional Health Boards Transcript 31 January 2023 pp1-78 INQY1000273, Closing submission on behalf of SNBTS 16 December 2022 SUBS0000044, Closing submission on behalf of NHS Scotland Territorial Health Boards 16 December 2022 SUBS0000058

for the physical and psychosocial harms caused to the infected and affected individuals' lives, careers and relationships with others. Especially striking has been the accounts of deliberate obfuscation, and missing or inaccurate hospital notes, about the sequences of events." 1514

By contrast, experience of "unsatisfactory communication, including insufficient explanation or apology, is very likely to complicate the grief process." <sup>1515</sup>

### The response of Government

Just as many within the NHS responded defensively, so too did successive governments.

This Report has found that the UK Government resolved against any form of compensation at an early stage. It mischaracterised the infection of thousands of people with fatal viruses as the unavoidable adverse effects of medical treatment. It thought at the outset that no one could or should be held responsible and that nothing had been done wrong. It assumed, without any sufficient inquiry, and without listening to, or hearing, the patients themselves, that doctors and the NHS had done nothing wrong and that the risks of treatment with blood or blood products had been explained to them.

Five striking and inter-related features stand out when assessing the government response.

The first is that when steps have been taken to make payments to those who had been infected and their families, they have been prompted by intense parliamentary, media and/ or public pressure. Thus, for example, the first payment made to the Macfarlane Trust was a response to the "considerable parliamentary and public pressure ... to do something". 1516 The second payment to the Macfarlane Trust proposed in late 1989 was made at a time when "public pressure for some further action" was "intense", 1517 and the proposals were a response to "a fast escalating campaign", "responding to the campaign in a sympathetic way while containing the consequences for the NHS generally." 1518 The change of position in 1992 on payments to individuals infected with HIV through blood or tissue transfer reflected "combined increased pressure in Parliament ... from the media campaign and from allied correspondence". 1519 Expressions of willingness by junior ministers to provide some form of ex gratia support for those infected with Hepatitis C were stymied by institutional reluctance and ministers were steered away from that course by civil servants, until such time as developments in Scotland (themselves the result of pressure from campaigners) meant that something had to be done to reflect the popular will.

<sup>1514</sup> Expert Report to the Infected Blood Inquiry: Psychosocial Issues January 2020 pp17-18 EXPG0000003

<sup>1515</sup> Expert Report to the Infected Blood Inquiry: Psychosocial Issues (Supplementary) September 2020 p18 EXPG0000042

<sup>1516</sup> Memo from Tony Newton to the Secretary of State 26 August 1987 p1 DHSC0004541\_079

<sup>1517</sup> Memo from Paul Gray to the Prime Minister 17 November 1989 CABO0100003 005

<sup>1518</sup> Letter from Kenneth Clarke to the Prime Minister 17 November 1989 p1 HMTR0000001 006

<sup>1519</sup> Written Statement of Lord William Waldegrave para 4.119 WITN5288001

The second feature is the slow and protracted nature of the government response. Decision-making regarding the establishment of each of the ex gratia support schemes took too long, with the government holding out until 2003 against the provision of any such support to people infected with Hepatitis C. Too long was taken to reform the Alliance House Organisations, and once reformed too long was taken to address the unacceptable disparity between the different schemes – a disparity addressed only after campaigners yet again had to expose the injustice of it. It took until 2017 for government to yield to political and public pressure and agree to the holding of a public inquiry.

The third feature is that governments of the past generally sought to provide the least that they could. The payments offered by the Skipton Fund were much less than had been recommended by the Ross expert group in Scotland; and the response to the Archer Inquiry was to see what the least was that was required of government. More recently, government has however uplifted levels of financial support in 2019 and 2021, and having commissioned the compensation framework study from Sir Robert Francis, and considered the First Interim Report of this Inquiry, made interim payments of compensation to some 4,500 beneficiaries in the first year. It has accepted the moral case for compensation, and said there will be more money to follow. It remains deeply regrettable that the Government has still failed to provide any substantive response to the broader recommendations made by Sir Robert and by the Second Interim Report of this Inquiry.

Though part of the context within which some of these decisions were made was the general economic position at the time, the issue was the lack of priority given to meeting the needs of people who had been infected, or affected, by treatment with infected blood and blood products – it did not meet the justice of what happened.

The fourth feature is that when steps have been taken over the preceding decades they have usually been accompanied by an insistence that nothing was done wrong. This, too, has changed since the announcement of this Inquiry in 2017. It is now accepted.

The fifth is that although the Government has admitted that wrongs have been done – the Department of Health and Social Care was clear at the outset of the Inquiry that this was the case<sup>1520</sup> – it does not yet appear to be clear what lessons it has learned, or sought to learn, from the history it now accepts. It has said that "DHSC ministers and the wider Government will, in due course, react to the Inquiry's findings and recommendations but it has not wished to pre-empt that process by offering opinions now."<sup>1521</sup> By contrast, the Blood Services, in particular SNBTS, and the Scottish Territorial Health Boards, have sought to learn during the Inquiry process. Professor Marc Turner, SNBTS Director, wrote their final submission with the assistance of the SNBTS senior management because "it was important that the organisation speak as directly as possible, not only to the infected and affected but to

<sup>1520</sup> Opening submission on behalf of the Department of Health and Social Care Transcript 26 September 2018 p15 INQY000000\_005. It is right to note that the DHSC has fully and constructively cooperated throughout with all of the Inquiry's requests for documents and statements.

<sup>1521</sup> Closing submission on behalf of the Department of Health and Social Care Transcript 18 January 2023 p4 INQY1000267

everyone affected by and having an interest in SNBTS's work." 1522 The submission for the Scottish Territorial Health Boards had significant input from the Boards.

These are two different approaches. Since before the Piper Alpha disaster in 1988, and with renewed vigour since, industries that have suffered catastrophic safety failures have sought to learn lessons rather than waiting for the outcome of external investigation. For future inquiries that are not purely historical (as this is not) I suggest that the Government's position should be, not only to support an inquiry's independent work as the Government has done in this case, but to seek to learn lessons from the moment a disaster is recognised.

Steps nonetheless have been taken (since the enormity of what had happened became obvious) which show that a number of measures, similar to those the Inquiry might have had in mind as potential recommendations, have been taken to improve, and to keep improving, safety in our health services. <sup>1523</sup> It needs to be said that if this Inquiry had been held 30 years ago, during the 1990s, the recommendations I would be making would have a different emphasis. However, the Inquiry has not been told that any changes there have been in the NHS, its practices or organisation (or in the DHSC itself) have been as a direct result of experience of lessons learned. <sup>1524</sup>

Amongst the steps taken, the reaction of government to the risk of vCJD to the blood supply stands in sharp contrast to the way in which health bodies and government reacted to hepatitis and HIV infections in blood. 1525 Proactively, appropriate protective steps were taken despite there being, at the time, no known case in which there had been actual transmission through blood transfusion or blood products. 1526

Further, the chapter on *Blood Transfusion: Clinical Practice* has described the CMOs' "Better Blood Transfusion Initiative", starting from 1998, and building since then. There has been the introduction of a statutory duty of candour on providers of NHS services and a fit and proper person test for Board-level appointments; and from 2016 measures aimed to add to the

<sup>1522</sup> Closing submission on behalf of SNBTS and Scottish Regional Health Boards Transcript 31 January 2023 pp4-5 INQY1000273

<sup>1523</sup> In relation to patient safety generally, high profile cases of failures of care led to the government of that day taking a more active approach from the late 1990s. NICE was established in 1999, to strengthen regulation and the evidence base for adopting new treatments; health and social care has been regulated since 2001, in current form since 2009 by the Care Quality Commission; a National Reporting and Learning System ("NRLS") was inaugurated in 2003, as the largest single source of patient safety incident data in England; and there have been two reviews of the regulation of medical and non-medical professionals in 2006 in the wake of the Shipman Inquiry (2005). Further developments are set out in the text below.

<sup>1524</sup> I would have wished to report that the changes had been a reaction to what was understood by government about infected blood and blood products: I cannot do so, since there is no direct evidence of this. However I recognise that it may very well be that, though unspoken and unrecorded, a desire to avoid the mistakes of the past was part of what influenced making some of these changes for the better.

<sup>1525</sup> See the chapter on *vCJD*.

<sup>1526</sup> Measures were taken such as leucodepletion, a shift to non-UK plasma (even to the extent of the government purchasing a US company to ensure a continuity of safer supplies), and (albeit somewhat slowly) with providing recombinant product. See the chapters on *vCJD* and *Access to Treatment*.

<sup>1527</sup> Following the public inquiry chaired by Sir Robert Francis into the failings at Mid-Staffordshire NHS Foundation Trust from 2005 to 2009, though there is no statutory duty of candour in Northern Ireland.

protection for whistle-blowers, by providing 'freedom to speak up' Guardians in every NHS organisation supported by a National Guardian; the establishment of the Healthcare Safety Investigation Branch ("HSIB") (now the Health Services Safety Investigations Body "HSSIB") in 2017 in England; and Patient Safety Commissioners, now in both England and Scotland. (I say more about these developments in the chapter on *Recommendations*.) It would be wrong, therefore, to think that the government has not taken some steps towards improving patient safety, and (broadly) the governments that have done so deserve credit for this.

Nonetheless, given the passage of time, there might be expected to be a clearer link between changes in practice which have already taken place and the events of the treatment disaster the Inquiry has been investigating. An industry prioritising safety would be very clear what response was needed to particular events of concern, would document that that response had been taken, and would have assessed how effective it had been in preventing recurrence. I accept that in relation to the NHS, as in the case of government, many recommendations which this Inquiry might have made had it been held 25 years ago have been rendered unnecessary because of improvements over time. Yet despite a number of politicians speaking in oral evidence of groupthink amongst civil servants, and material showing that expectations of candour have again and again been disappointed, little positive action to address this has been proposed let alone any audit to see how effective any change has been and might yet be.

The medical ethics expert group, in their report to the Inquiry, said that when harm befalls a person, there are from an ethical perspective three particularly important factors:

- "Responsibility must be attributed in order to ensure appropriate action is taken to prevent further harm and to understand who (be that individual or institution) should offer an explanation, apology and relevant redress.
- Openness and transparency are needed to ensure that lessons can be learned and so that the person harmed can assess the actions taken, understand their experience fully, and pursue further action if necessary.
- Recognition is required so that those responsible for the harm can understand its nature and the impact it will have had on the person(s) harmed." 1528

They added that "we won't learn the proper facts of the matter if people are being defensive or hiding things or even not taking it seriously enough to dig down and find the important information" <sup>1529</sup> and "these same principles apply in areas of politics." <sup>1530</sup>

There has not been a proper acceptance of responsibility. There has not been openness and transparency. And there has not been recognition and understanding of the harm done and its profound and devastating impact.

Following the public inquiry chaired by Sir Robert Francis into the failings at Mid-Staffordshire NHS Foundation Trust from 2005 to 2009, though there is no statutory duty of candour in Northern Ireland.

<sup>1528</sup> Expert Report to the Infected Blood Inquiry: Medical Ethics April 2020 p13 INQY0000241

<sup>1529 (</sup>Professor Farsides) Medical Ethics Expert Panel Transcript 26 January 2021 p65 INQY1000090

<sup>1530 (</sup>Professor Kerridge) Medical Ethics Expert Panel Transcript 26 January 2021 p68 INQY1000090

## Candour, openness and cover-up?

What of the long recognised need for openness, honesty and accountability in public service ("candour" sums it up)? Standing back, and viewing the response of the NHS and of government overall, the answer to the question "was there a cover up?" is that there has been. Not in the sense of a handful of people plotting in an orchestrated conspiracy to mislead, but in a way that was more subtle, more pervasive and more chilling in its implications. In this way there has been a hiding of much of the truth. The people most directly affected said there was more to what happened than was in the public domain and they were correct. And yet it has taken decades to get an authoritative account of what happened to cause so many deaths, prolonged and wasting illnesses, and infections: and it is still not a full account since so many key witnesses have died and documents have been lost. Mrs AJ, giving evidence in London, said: "If this had happened on one day, if a plane had dropped out of the sky killing everyone on board (only in this case it would have been six planes) or if a liner had hit an iceberg (in this case it would have been two liners), something would have been done immediately:"1531

This failure to bring the true facts to life has come partly from the inertia of groupthink; but partly, it must be recognised from instinctive defensiveness, to save face and to save expense. This is a very general observation across a long period. It does not mean that every minister and every civil servant across the very long time period under investigation contributed to hiding the truth. It should not be interpreted as putting a general question mark against the integrity of every individual. When thousands of families had their lives irrevocably changed, though, it should not have taken decades for the truth to come out. That is a collective failing of successive governments.

This Report has found that there was deliberate destruction of documents of relevance. It has found that the Self-Sufficiency Report which was published by the Government in 2006 was self-justifying and argumentative, and that its redrafting had the effect of hiding significant information, and presenting a different slant. It has found that over decades successive governments repeated lines to take that were inaccurate, defensive and misleading. And it has found that over decades successive governments refused to hold a public inquiry both because of a reluctance for the decisions, actions and omissions of the NHS and government to be assessed, and because they did not want to be in the position of having to pay compensation, and did not wish to accept that wrong had been done.

These failings should not have happened.

This persistent refusal to hold a public inquiry, coupled with a defensive mindset that refused to countenance that wrong had been done, left people without answers, without compensation and without justice. It has also meant that many have been driven to devote their time and their energies to investigation and campaigning, often at great personal cost. Jackie Britton describes that "Being a campaigner is not something I would have chosen

for myself, but it is part and parcel of how I feel let down: not only was I given dirty blood in 1983, not only did no one bother to find me for nearly 30 years, not only was I not diagnosed until 2011, but added to that is the fight for treatment, and having to watch others die, and knowing that that is my future." She describes how "the contaminated blood scandal hangs over me every day" and that campaigning "does take its toll." Andrew March explains that "it is unacceptable that individuals like myself, and many others who have been infected or affected by the Contaminated Blood Scandal, had to become researchers and/or full time campaigners in order to try and establish what happened and in order to reach the point of finally achieving a Public Inquiry in 2017 ... like many others, my quest for the truth has adversely impacted my personal life and career ambitions." 1533

Mary Grindley, whose husband was infected with HIV and died, told the Inquiry "We still have no closure, no admission of wrongdoing. Everything has been swept under the carpet and no one listened ... I haven't been able to get justice for him and the thousands of others who have died or are still alive". 1534

Although apologies have been given on behalf of government – Prime Minister David Cameron apologising "for something that should not have happened", the Department of Health and Social Care's apology in its opening submissions – the apologies that have thus far been given have not identified what government is apologising **for**. The "basic human decency of admitting failings that have had such a catastrophic effect on the lives of innocent and vulnerable people" has been lacking. 1535

Two brothers who would die only months apart, Haydn and Gareth Lewis, were spurred by the death of seven-year-old Colin Smith, to find out what had happened and why. 1536 Why did the NHS and Government not feel similarly inquisitive and determined? Why, when a transfusion following childbirth led to the infection and death of three members of the same family, 1537 did the NHS and the Government not want to explore every avenue to examine how that happened and whether it could have been avoided?

The answer, as a former Secretary of State told the Inquiry, may be that "embedded deep within the Civil Service psyche, over not just a few years in question but a number of decades ... the response to this particular issue was primarily driven by a fear of financial exposure." That, said Andy Burnham, explains "all of the responses, the lines, everything". He came to think that the UK Government "has comprehensively failed the victims of infected blood" over decades. There is room for thinking that financial reasons were not the only ones at play. The truth may be that there is not one simple motivation for what is a mix of complex factors.

<sup>1532</sup> Written Statement of Jackie Britton paras 95-96 WITN1838006

<sup>1533</sup> Written Statement of Andrew March para 3 WITN1369014

<sup>1534</sup> Mary Grindley Transcript 1 November 2019 pp162-3 INQY1000049

<sup>1535</sup> Member of the Haemophilia Society quoted in the Haemophilia Society Submission 16 December 2022 para 416 SUBS0000065

<sup>1536</sup> Written Statement of Gaynor Lewis p13 WITN2368001

<sup>1537</sup> Observer Aids victims: Pressure for action grows 26 May 1991 HSOC0001454

<sup>1538</sup> Andy Burnham Transcript 15 July 2022 pp27-28 INQY1000228

However, the undoubted fact is that the state – successive governments – failed badly in its response to people who had been harmed. It closed ranks and denied wrongdoing. It made ex gratia payments through schemes which were initially designed to operate at arms length, such that the schemes rather than central government might be blamed for their inadequacies. And for the reasons set out in the preceding chapter, it is sadly the case that – at the time of writing this Report – the Government has still not taken on board some of the lessons of the past. Having announced the Inquiry, the Government addressed my public concerns about immediate grinding hardship and also swiftly made the first set of interim compensation payments. But it has caused widespread distress through the manner of its response to the recommendations of Sir Robert Francis and of this Inquiry, with people infected and affected and their MPs repeatedly pressing to know what was happening and trying to elicit a sense of urgency.

Though the truth of what happened, and why, is a complex mix of factors which this Report has examined, the overall effect of it can be summed up in fewer words. The best way to do that is to end this Report as the Inquiry's hearings began – with the voices of people whose lives have been so irreparably and catastrophically damaged:

"one emotion that has been building and growing for over 30 years is that of anger. The rage I feel at being lied to, dismissed and pushed aside, when all we asked for is recognition of our plight and meaningful recompense for the lives we have had so cruelly stolen from us. Instead, we have been treated with disrespect, disdain, and as if we are irrelevant ... being multiply infected absolutely prevents a normal life being possible. Sufferers are consigned to the fringes of society, forever fearful of public reaction, without support from life or mortgage insurance and all the usual ways that people can protect themselves and their families from hardship through being unable to work. Desperately sick, exhausted and terrified about the future, this is the result of decisions made by those who were paid to do better. In the comfort of their offices, they pushed paper across desks, set aside the warnings and decided to gamble with people's lives for the goal of saving money. It is hard to avoid the conclusion that we were deemed expendable, collateral damage." 1539

Those were the words of Richard Warwick, giving evidence to this Inquiry.

Pete Burney, who has since died, said this:

"Every government's job is to protect their citizens, and make sure they are safe. Previous governments have let us down, as has this one. There is a slight difference, however as this government may say they have given more to our community and acknowledged there have been mistakes (why else would they have apologised?). But this government is standing by and watching victims die on a monthly basis, while at the same time trying to distance themselves

from any responsibility, both financial and humanitarian. That in itself makes this government as bad, if not worse, than previous governments because this government has been confronted with all the undeniable facts and they know that we know that it's adding insult to injury, yet they are still standing by and watching this tragedy develop and letting victims die without them knowing justice has been served. They could and should at the very least, let every victim know now that if anything happens to them, that their family's future is financially secure, and that would be a massive weight off the victim's mind. Infected and affected victims have a right to be treated with empathy and respect." 1540

And finally, Mr AM in his evidence to the Inquiry:

"what happened was the most egregious dereliction of duty by a country to its citizens in modern times. The government made us more vulnerable with deadly infections ... the government's response was worse than mere apathy ... Day after day, week after week, the Inquiry has heard accounts of people's personal battles with their viruses. In reality, we have been waging a war, not just against our viruses but against government. Government has tried to subdue us. They continue to ignore us and continue to do battle with us. Why? Where is their recognition of our struggle? ... We are tired of meaningless apologies. We are tired of platitudes in relation to this being something that should never have happened. As a community, in future we will judge you by what you do, not by what you say". 1541

Sir Brian Langstaff

Chair, Infected Blood Inquiry

Brian H. Langstaf

20 May 2024

Written Statement of Pete Burney para 57 WITN0061001. See also his powerful opening statement: Pete Burney Transcript 26 September 2018 pp51-63 INQY0000000\_004

<sup>1541</sup> ANON Transcript 15 October 2019 pp111-115 INQY1000041