Summary of responses to the Infected Blood Inquiry's consultation seeking views on terms of reference

Introduction

In March 2018, a consultation was launched to seek views on the terms of reference for the Infected Blood Inquiry. The Inquiries Act 2005 requires that the Minister should set the terms of reference before the Inquiry can receive or call for evidence. Sir Brian Langstaff was appointed as Chair of the Inquiry on 8 February 2018 and decided to consult widely to ensure all who wanted to engage with the process had the opportunity to do so.

The consultation paper sought views on a variety of topics so as to assist with the identification of the areas and issues on which the Inquiry should focus. The consultation received almost 700 responses and considered the following:

- 358 online responses;
- 185 responses made by email;
- 91 items of written correspondence;
- 24 responses by telephone; and
- points made in discussions during 15 meetings with groups and individuals.

Respondents included people infected and their families, campaign groups and organisations including those listed below. The Inquiry team is extremely grateful for all the engagement with the consultation.

Birchgrove Group
Bloodloss Families
Contaminated Blood Campaign
Contaminated Blood Public Inquiry Group
Contaminated Whole Blood UK
Factor 8 Campaign UK
Fatherless Generation
Forgotten Few
Haemophilia and Contaminated Blood All-Party Parliamentary Group
Haemophilia Northern Ireland
Haemophilia Scotland
Haemophilia Society
Haemophilia Wales
Hepatitis B Trust
Hepatitis C Trust

Justice For All: Contaminated Blood Products
Manor House Group
Positive Women
Scottish Infected Blood Forum
TaintedBlood
Tainted Blood Widows
The Truth About Hepatitis C
Welsh Assembly Cross-party Group on Haemophilia and Contaminated Blood
West of Scotland Group Haemophilia Group

Responses were also received on behalf of:

NHS Blood and Transplant
Northern Ireland Blood Transfusion Service
Scottish National Blood Transfusion Service
UK Haemophilia Nurses Association
Welsh Blood Service

The Inquiry team heard from firms of solicitors who represent both campaign groups and individuals (Collins Solicitors; Hodge, Jones & Allen; Leigh Day; Thompsons Solicitors; and Watkins & Gunn Solicitors). Collins Solicitors proposed draft terms of reference. Written submissions on the consultation were received from Hodge Jones & Allen, Leigh Day and Watkins & Gunn Solicitors.

It was common for campaign groups to submit a collective response as well as responses on behalf of a number of their individual members. The Inquiry is also aware that in some cases individuals who belong to such groups submitted their own personal response. The Inquiry welcomes the fact that people wanted to share their own experience and have their own input about issues that had particularly affected them.

All responses were considered in full. They covered many issues. Some responses concentrated on a specific issue, whilst others covered all the themes and proposals set out within the consultation. This paper does not seek to provide details of each response, but rather seeks to reflect the key themes that emerged from the body of responses as a whole. This summary is structured by the areas set out in the consultation paper and has been divided into sections dealing with key themes that emerged.

Key themes

The period of time to be considered by the Inquiry

The consultation sought views on the timeframe on which the Inquiry should focus. A general message that came through many responses was that the Inquiry should go back as far as necessary and up to the present day in order to get to the truth. Despite many responses not specifying an exact time period, a common suggestion was that the focus should begin from the early 1970s while being able also to look back at the earlier provision of blood and

blood products in the United Kingdom. A small number of responses spoke of cases of infection that had occurred earlier than the 1970s.

The campaign group TaintedBlood said that the history of contaminated blood to the current date should be recognised and documented. Those represented by Collins Solicitors recommended that the Inquiry should consider all relevant issues on a timeline from the introduction of the National Health Service in 1948 to the present date. The campaign group TaintedBlood indicated that the history of contaminated blood to the current date should be recognised and documented. The Haemophilia Society suggested that the Inquiry should focus on when blood and blood products were first used within the United Kingdom and examine viral transmissions from the time of their earliest introduction, particularly in respect of hepatitis B infection, to set the context for what followed. They pointed out that different time periods were relevant for different viruses.

78 respondents suggested that the Inquiry should begin from when UK authorities started to import blood products from other countries. Those individuals who could pin point the actual incident by which they were first infected mentioned this as being a significant starting point for them.

The history as to how blood screening evolved was seen as very relevant by some. For instance, several respondents noted September 1991 as a key date in the chronology of events for hepatitis C (HCV) as this was the year that screening for the virus was introduced in England. It is also used by the Trusts and Schemes as a cut-off when determining eligibility for payments, though some respondents believed they had been infected after this date.

Length of the Inquiry

Some respondents saw this question as asking how long the public inquiry should last. For example, one online respondent remarked, "*I really hope this Inquiry does not drag on and on as I would like to live long enough to see the result*". There was a general concern that the Inquiry should be quick, rather than drawn out, though one respondent observed that it was important that the thoroughness of the Inquiry should not be sacrificed for speed saying, "*I myself may not see the result of the Inquiry but it must get to the truth and name all the guilty parties*".

Respondents who were older or particularly unwell or frail were likely to place importance on the Inquiry not taking too long. Some were concerned that the Penrose Inquiry had taken too long and produced only a single recommendation. Nearly all who responded to the consultation by phone hoped for a quick inquiry. Similarly, many of those who had experienced financial problems or saw compensation as a key issue called for a quick inquiry so that they or family members might see the benefits of any compensation or assistance. Some nonetheless placed emphasis on the thoroughness of the inquiry.

Some respondents suggested the Inquiry should consider reporting in stages so that as many people as possible live to see progress and results.

Delay in establishing a statutory Inquiry

Some responses referred to the delay in setting up a statutory public inquiry and thought the Inquiry should consider why it had taken so long to do so. It was noted by others that consecutive Governments had refused an inquiry, or even to acknowledge that a "*human disaster was occurring*".

Provision of blood and blood products

There was very strong agreement with the provisional view of the Inquiry that it should aim to find out:

- why patients were given infected blood and blood products when treated by the NHS;
- the extent to which this continued after the NHS and/or Government was or should have been alerted to the risks, and why it continued to happen;
- why it was that blood products had to be purchased abroad rather than sourced locally;
- whether there was a deliberate attempt to conceal details of what had happened, both at the time it occurred or later.

A significant majority of online responses (307) not only agreed but 'strongly agreed' with the consultation statement. Only nine responses disagreed. Of those respondents who disagreed, some emphasised the need to have a stronger focus on particular points of inquiry, such as the role of pharmaceutical companies, while others felt that an inquiry would be a painful experience for those who had lost close relatives.

Knowledge of risks

A significant number of respondents (375) supported the Inquiry looking to see what was known of the risks of infection associated with blood products and blood donations, and the failures of those with responsibility to respond to those risks. Many respondents explained that they wanted the Inquiry to establish when Government first knew people were being given infected blood. Many individuals wanted to know why people had not been informed of the risks and why it was that, when people had been infected, many had not been told. These were all important points for the campaign groups and campaigners, as well many individuals. The Contaminated Blood Campaign wanted the Inquiry to consider the justification for treating people with mild, moderate and severe bleeding disorders with pooled factor products and how any "risk to life" balanced against the risk of using the products.

Self-sufficiency in blood and blood products

85 respondents raised the United Kingdom's failure to become self-sufficient in blood products. Those represented by Collins Solicitors questioned why self-sufficiency was not achieved earlier in light of a commitment to self-sufficiency made by David Owen, the Minister of State for Health and Social Security, in 1973. Factor 8 Campaign UK wanted the Inquiry to look at the policies that applied to donor selection and to the screening of blood and

blood products. Some respondents drew attention to UK donated and manufactured blood products carrying a risk of infection, while many responses highlighted concern over the use of imported blood products from high-risk and paid donor groups from the United States.

A joint response from Haemophilia Scotland, the Scottish Infected Blood Forum and independent campaigners in Scotland urged the Inquiry to investigate why decisions were taken in Scotland to pay for, and treat patients with, commercial products from abroad rather than use the locally available alternative. They suggested the Inquiry might usefully investigate why spare Scottish capacity was not more effectively used to meet demand south of the border.

Licensing

Issues relating to United Kingdom licensing of blood and blood products were raised as being of significant concern in 126 responses. Comments centred on those responsible for the procurement and distribution of blood and blood products. An important focus of the responses were questions as to when, and to what extent, it was known that the blood and blood products they were distributing were infected. If initially there was no knowledge, was this lack of knowledge reasonable and what degree of regulation was in place to monitor the quality and contents of the products? Also, what did the Government do in the light of such knowledge to mitigate the effects of infected blood? Some raised whether Crown Immunity was used to prevent manufacturing standards being upheld.

Commercial and financial interests

Many respondents wanted the Inquiry to investigate the role played by pharmaceutical and blood product companies and their knowledge of the risks attached to their products. Some who raised concerns about commercial or financial motives called for the Inquiry to examine whether the interests of the Department of Health and pharmaceutical companies might have taken precedence over public safety. Some respondents also noted that no one within Government ever publicly criticised the US pharmaceutical companies that produced infected products.

One response stated that vested interests should be a significant consideration when looking at "*who knew what, where and when and to what extent the commercial companies and ministers were working together and what gains there may have been to individuals who knew about the risks*."

The Haemophilia Society's response to the consultation raised the question whether commercial interests influenced decision making on the availability of products, whilst several people referred directly to the Haemophilia Society's position in the 1970s and 1980s regarding pharmaceutical companies, questioning the Society's acceptance of donations from such companies during this period.

Allegations of a cover-up

Nearly 200 responses stated that there had been attempts to cover up what had happened by ministers, officials, or by the medical establishment or medical professionals. For instance, it was suggested that official ministerial papers and patients' medical notes had been destroyed or had somehow been allowed to go missing. Leigh Day recommended that the Inquiry should not confine itself to whether there was a deliberate attempt to conceal details of the provision of contaminated blood and blood products but should also investigate the lack of openness or failure to be honest about what had happened. Echoing this, one respondent remarked: "*I have always trusted the NHS doctors and still do, they have saved my life countless times, but something went wrong back then and it would be nice to know the truth.*"

Incidence of infections

Many respondents wanted investigation of the impact of contracting HIV and HCV through infected blood and blood products. Many wrote about the effects of liver damage developing over several years and the risk of liver cancer, as well as the side effects of early treatment for HIV and HCV, with suffering lasting over decades. One respondent said, "*The whole process from when I was infected has been torturous mentally and physically. The effects of Interferon and the lack of specific and appropriate care by health professionals is indescribable.*"

Some called for an investigation into the rate of vCJD (variant Creutzfeldt–Jakob disease) infection. Several submissions urged the Inquiry not to underestimate the impact and consequences of this disease and expressed concerns that it might be overlooked.

The Inquiry was also asked to look into the rate and numbers of those infected from blood and blood products, to establish exactly how many people have been affected. Haemophilia Wales and the Cross-party Group in the Welsh Assembly on Haemophilia and Contaminated Blood raised variances in infection and mortality rates across the United Kingdom. Specifically, they asked why there had been a higher rate of infection of haemophiliacs in Wales than in England and, secondly, why there had been a higher death rate from hepatitis C in Wales than in England.

Look-back testing

A number of responses asked the Inquiry to review any look-back testing that had occurred including any reasons for delay in doing this and failures to engage with people who have been unknowingly infected.

The care and support provided after infection

The consultation canvassed opinion as to what extent the Inquiry should examine the adequacy of the provision of care and support after infection and the extent of any differences in such care and support between England, Scotland, Wales and Northern Ireland, and between the United Kingdom and similar countries overseas. The majority agreed that this issue should be investigated by the Inquiry. All campaign groups and campaigners raised a

range of issues and concerns relating to care and support that they wanted covered by the Inquiry's terms of reference.

Standards of care

Nearly 300 responses mentioned standards of clinical care and medical support as an issue for investigation. Many of these described negative experiences of care and referred to hostile and indifferent attitudes by some medical staff managing their care and also occasions of being treated "*like pariahs*". On the other hand some responses provided positive examples of being treated respectfully and compassionately by staff at both hospitals and specialist centres.

In relation to informing people of life-changing medical results, a campaigner referred to a large group meeting where a doctor had announced, '*some of you are infected, some are no*t', leaving those present "*with no idea of*" their own diagnosis. Positive Women recalled how no counselling or support had been offered when being informed of their results.

Professional conduct

237 responses referred to professional conduct. This included medical professionals and others not passing on results, not explaining risks, making inappropriate and disproportionate medical interventions, failing to seek patient consent, and deliberately testing blood products and treatments on patients without consent. Several people described treatment out of proportion with a condition and not being listened to when this was questioned (for example, people with mild haemophilia, including children, being administered blood products despite only very minor injuries).

Public perception and communication

Over 200 responses highlighted communication and information sharing. Concerns included a lack of respect, sensitivity and confidentiality when doctors and others communicated results, the NHS's failure to contact at-risk groups, a lack of Government awareness campaigns and the stigmatising effects of the Government's AIDS campaign in the late 1980s.

A recurring question raised by many was if Government knew of the disaster, why did they not attempt to contact everyone who could have been infected during the relevant period? The Contaminated Blood Campaign questioned why people were not called back after a transfusion to have a blood test. Similarly, several respondents asked why GPs were not actively instructed by the health authorities to identify at-risk patients.

Psychological and physical impacts

176 responses highlighted the mental and physical effects on people's lives and how the treatment of infections affected individuals. A respondent spoke of how more than 30 years later a friend was still in a "*living hell […] they are inconsolable over the tragedy because it should have been preventable*". Other responses recounted how the stigma and fear that came with HIV and

AIDS was extremely hard to live with. Another had been left isolated and feeling abused by the "*so-called*" support and care system.

The Fatherless Generation group asked the Inquiry to look into the psychological and mental impact of losing a parent to infected blood products, children being taken into care, and the adequacy of the bereavement and psychological support that had been, and was now, on offer. Many others recalled the impact on their lives of a partner's condition or being infected by a partner. Respondents also expressed sadness and regret at not being able to have children or a family of their own, being advised not to conceive or to have a termination.

Social and economic effects

Many respondents wanted the Inquiry to go beyond the medical evidence and look at the social and economic effects on the families, not only of those still living but also the families of those who have died. 249 responses noted the impact their circumstances and health had had on their own and their family's wellbeing. Many talked about lower life expectancy, debt, no pension, the loss of a job and being denied a fulfilling career.

Many respondents commented on a wider social impact on their lives, the stigma attached to their conditions, negative attitudes, and ignorance of hepatitis and HIV infections.

Financial support

Over half of all responses (357) raised financial support and the question of compensation as a priority issue. Many people mentioned that they struggled with day-to-day living expenses, others pointed to the inequity of the Schemes, and many said that the level of financial support was too low and out of kilter with that in other countries. One response noted that while money could not compensate for the loss of life and health, the provision of compensation and support for people with young families should continue following the loss of a parent or carer. A respondent said that the "*compensation*" offered felt "*tokenistic rather than based on need*". Many of those who contacted the Inquiry team by telephone during the consultation thought that financial support was important for the Inquiry to consider.

Trusts and Schemes

Many responses wanted the Inquiry to look at the difficulty people encountered when seeking to establish their entitlement to financial support under the Trusts and Schemes. A recurring theme was the humiliation of repeatedly being assessed and asked to prove a long-term medical condition. The UK Haemophilia Nurses Association stated that there was a complete lack of equity in the Schemes' application processes and they were concerned for vulnerable patients who lacked the ability to apply. The Association also reported that the claims process for financial support had made people feel '*ashamed*' or '*dirty*' and one of their patients had likened their experience in dealing with the Trusts to being '*interrogated*'.

Many respondents questioned whether Governments were right in making payments on different terms depending on the way people had been infected. Some said this had led to being made to feel less deserving than others. One person said the system did everything it could to discourage people from getting help. Another described their contact with the Scheme as a battle of trying to obtain special grants and approval for minor payments. Others likened it to begging.

The Birchgrove Group questioned whether it had been appropriate for Department of Health appointed trustees to be on the board of a Scheme.

Disparities in support

64 respondents (including many of the campaign groups) referred directly to the disparity in the financial and other support provided in the countries composing the United Kingdom. Many also drew comparison with the higher levels of compensation in other countries. The financial support received in the Republic of Ireland was raised by several respondents as being fairer.

Evidence and documentation

Missing documentation was another recurring theme in the responses. The Inquiry received 105 responses asking that it investigate this issue. Some respondents alleged that records had been intentionally disposed of or destroyed whilst being held by the NHS or the Department of Health.

There were two main categories of documents: personal medical records and government or institutional documents. On the first, many respondents said that they had been informed that records were either lost or could not be located. The second category included documentation relevant to the procurement of blood and blood products; and internal memos and minutes of how those procurement decisions were reached.

One respondent asked that the Inquiry "*look at why Lord Owen's departmental papers were destroyed by a 10 year rule which does not exist*" along with "*correspondence between senior clinicians, pharmaceutical companies and the Department of Health*." Such correspondence was of interest to many respondents as they wanted to see the audit trail of who was responsible for making decisions and how various decisions were made.

Many respondents asked the Inquiry to investigate whether there were any clinical notes and outcomes from trials of blood or blood products. Some respondents alleged that people were used as guinea pigs and they wanted the Inquiry to investigate whether vulnerable people were taken advantage of by giving them untested or unregulated medical treatment, and what documentation exists with regard to this.

Responsibility and recommendations

Individual and institutional responsibility

390 responses called for the investigation of individual as well as institutional responsibility and urged the Inquiry to make recommendations to help to ensure that the decisions and actions that led to the use of infected blood are never repeated. Individuals and campaign groups alike called for the Inquiry to investigate accountability and comment on how things could have been done differently and what lessons can be learnt.

An important theme was the desire for the Inquiry to examine the systemic or institutional behaviours that influenced decision-making.

Nine responses indicated that they did not want the Inquiry to investigate those responsible, for fear of encouraging a '*witch hunt*'. These respondents were of the view that the appropriate way to run the Inquiry was to concentrate on support of the infected and affected to ensure that such events could never be repeated. As one respondent put it "*instead it should examine the events that led up to this public health disaster, to learn why it happened and how in the future we can best safeguard against a similar thing happening again.*"

Many responses discussed the concept of justice and what they would consider appropriate recommendations to be made by the Chair of the Inquiry. There were 59 responses asking for criminal proceedings to be recommended. These comments were closely linked with the allegations of a cover-up and deliberate destruction of medical records and documentation. Several submissions also suggested that the supply of infected blood products was at the very least negligent and should be investigated as a criminal offence.

Additional themes and considerations

The conduct of Government in legal proceedings was a prominent concern, particularly in the responses made on behalf of campaign groups and responses received from firms of solicitors. The Factor 8 Campaign UK asked that the Inquiry "*determine whether or not appropriate disclosure was given by the Government and other relevant bodies/persons during the 1990 HIV litigation; to determine whether or not the plaintiffs and/or defendants were in possession of the full facts*."

Five responses argued that there should be two separate inquiries: one for people with haemophilia and one for people who were not infected through factor products. The TaintedBlood campaign group said that the Inquiry needed to recognise the differences between the history of transfusion infections and infections via clotting concentrates and that it needed to be conscious from the outset that this may involve two different strands of investigation. In meetings with the Chair, a strong view was expressed of the need to take full account of the different experiences of those who were haemophiliac and those who were not, and to consider everyone who was infected equally.

Some responses to the consultation also provided views on how the Inquiry should approach its work: the Chair has considered all these comments.