

## Infected Blood Inquiry Response Expert Group

**Final Report** 

16 August 2024



#### **CONTENTS**

Foreword by the Minister for the Cabinet Office	3
Acknowledgements & Thanks	4
Executive Summary	5
The Moral Case for Compensation	11
Principles Underpinning the Scheme	11
Sir Brian Langstaff's Second Interim Report	11
Government aspirations	12
Reflection on past schemes	12
The Task of the Expert Group	14
How we worked	14
Building on the Architecture of the Second Interim Report	15
Sense Checking	16
Taking into account other Schemes	17
Engagement meeting feedback	18
Research Ethics Failures	19
Heads of Loss	20
The principles behind a tariff approach	20
Core and supplementary awards	21
Severity Bandings for people who were wrongfully infected	23
Core Bandings	23
Enhanced, Advanced and 'Special Category' bands	24
Supplementary route health impact groups	25
Injury Awards	29
Social Impact Awards	31
Autonomy Awards	32
Care Awards	33
Estimating care needs	33
Care Bands	34
Care Profiles	37
Calculations	38
Financial Loss Awards	39
The baseline earnings assumption	39
Higher earners	40
Assessing the impact of illness	40
Financial loss for people infected with Hepatitis	40
Financial Loss for people infected with HIV	44
HIV and Co-infection of HIV and Hepatitis C or Hepatitis B financial loss award	45
Enhanced impact	45
Lifetime impacts	47



Awards for People with Acute Hepatitis B/Hepatitis C Infection	47
Awards for people affected by the wrongful infections of others	48
Injury awards for those affected	48
Social Impact awards for those affected	50
Autonomy Awards for those affected	51
Care Awards for those affected	51
Financial Loss for dependants	51
Beneficiaries with multiple claims	53
Clarifications of eligibility criteria	54
Eligibility for people wrongfully infected by contaminated blood or other products.	54
Direct Infections	55
Indirect Infections	59
Establishing eligibility as an 'affected' person	60
Conclusion	63
Annex 1: Infected Blood Inquiry Response Expert Group Terms of Reference	64
Annex A: Membership of the Infected Blood Inquiry Response Expert Group	68
Annex B: Cabinet Office contacts	70
Annex C: The Seven Principles of Public Life	70
Annex 2: Special Category Criteria used in the Support Schemes	71

## Foreword by the Minister for the Cabinet Office

I am very grateful for the specialist advice provided by the Infected Blood Inquiry Response Expert Group, offering specialist expertise to ensure the Compensation Scheme can serve the victims of infected blood. In particular, I would like to thank the chair Professor Sir Jonathan Montgomery for his clear direction of the group and willingness to facilitate the provision of wide-ranging advice.

An interim summary of the Infected Blood Inquiry Response Expert Group's work was published on <u>gov.uk</u> on 21 May 2024. Since the publication of the interim report, the Interim Chair of the Infected Blood Compensation Authority - Sir Robert Francis KC - has conducted an engagement exercise with representatives of the infected blood community to gather feedback on the proposed scheme before it is finalised in regulations.

In his recommendations, Sir Robert recommended the Expert Group to provide further detail on the rationale underpinning their advice. He also asked them to review clinical and legal practicalities for a number of areas of the proposed scheme in light of the engagement exercise outcome. The final report includes the reviewed areas of work recommended by Sir Robert.



I hope that the report provides reassurance surrounding the decisions taken in the Compensation Scheme. The Government is committed to providing fair and full compensation to victims of infected blood, and work of the Expert Group has played a critical part in delivering this.

Rt Hon Nick Thomas-Symonds MP, Minister for the Cabinet Office



## Acknowledgements & Thanks

From the Expert Group Chair, Professor Sir Jonathan Montgomery

I am extremely grateful to my colleagues on the Expert Group, and to the civil servants who have supported us, for their commitment during the intense period that is covered in this report of our work in providing advice to Ministers. Each has brought distinctive professional expertise to our deliberations. They have worked together with mutual respect and compassion for those who are entitled to justice under the compensation scheme recommended by Sir Brian Langstaff in his Second Interim Report. We have aimed to provide robust and objective advice on technical aspects of the design of the scheme. We have been acutely aware that justice demands fair compensation and that the very long delays that victims have already suffered mean that it must now be delivered as soon as is practicable. We hope that our advice will assist the Government in that task.

Our terms of reference did not permit us to take evidence directly from members of the infected community. We have done our best to take note of evidence received by the Inquiry and we have drawn on members' insights from their professional work. Had time and the restrictions of confidentiality permitted wider consultation, then we would have found that helpful. The Government decided to tender for legal expertise from a single firm rather than to invite representatives from a number of different lawyers. This has precluded the collaborative approaches that solicitors aim to adopt. I have been deeply impressed by the care taken by all those involved to consider not just their own judgements but also the range of views they know others might suggest.

We have benefited from feedback from the Engagement Events that were convened by Sir Robert Francis KC in his capacity as Interim Chair of the Infected Blood Compensation Authority. The Expert Group is grateful to him for allowing me to attend those meetings and convey the insights to the Expert Group to refine its advice. Many very helpful and constructive points were made that needed to be taken into account.

Membership of the group is set out in Annex A.



## **Executive Summary**

The moral case for compensation for the victims of the infected blood scandal is compelling. The impact of the wrongful infection on their lives is substantial and far-reaching. They have been let down by the NHS, in whose care they trusted. Information to which they were entitled has been withheld or lost, both by the health service and Government. They have suffered terrible stigma when they deserved support. Justice has been long delayed. Issues about research misconduct have been identified more strongly in the final report than we anticipated and we have added some observations on the implications for the compensation scheme to our initial advice.

In his Second Interim Report, Sir Brian Langstaff set clear expectations for the scope and shape of the compensation scheme that described who should be eligible and the categories of loss that should be reflected in the awards. He recommended that it should be based on a tariff approach and that it should be characterised by speed of provision, simplicity of process, accessibility, fairness and efficiency. Sir Brian also recommended that proactive support would be needed for people claiming the compensation to which they are entitled.

It will be for His Majesty's Government to determine the details of the final scheme, through the Regulations that will be laid before Parliament within three months of the Royal Assent to the Victims and Prisoners Act. Our task has been to advise on how Sir Brian's recommendations could be implemented. In particular, we have been asked to ensure that compensation should be deliverable rapidly; that the scheme would be worthy of the trust of the communities which have been infected (and also affected), so that they would prefer it to litigation through the courts; that there should be a simple and sensitive application process (that avoids re-traumatisation), that requires of applicants minimal time, effort or stress. Sir Brian recommended that the development of the scheme should involve the infected blood community. We support that principle, but our terms of reference precluded public engagement in our work. We have revised our initial advice in a number of respects based on the feedback from the Engagement events convened by Sir Robert Francis KC as Interim Chair of the Infected Blood Compensation Authority.

Sir Brian recommended that the compensation scheme should provide for awards based on five components and that their quantification should reflect different impacts on people who were infected and on those who were close to them (described by Sir Brian as 'affected') and also take into account differences between the diseases caused by HIV (human immunodeficiency virus), HCV (Hepatitis C virus) and HBV (Hepatitis B virus) and the impact of co-infections. Sir Brian explained that the components of compensation need to address:

- The Injury suffered
- The Social Impact of that injury
- The interference with people's Autonomy



- The additional Care costs that people incurred as a result of the injury, and
- The Financial Loss that was suffered from being unable to work



#### Awards for people who were wrongfully infected

Sir Brian recommended, building on the Compensation Study undertaken by Sir Robert Francis, that the scheme should reflect the different impacts of infection by developing severity bandings but did not define them. The clinical members of the Expert Group have proposed the following bandings, beginning with those who have experienced the most significant impacts:

- People who have been co-infected with HIV and/or HCV and/or HBV
- People who have been infected with HIV
- People who have been infected with HCV or HBV who have progressed to liver cancer, decompensated cirrhosis and/or those who have needed to receive a liver transplant,
- People who have been infected with HCV or HBV who have progressed to cirrhosis
- People whose HCV and HBV infection is chronic (lasts more than 6 months) but has not progressed to cirrhosis
- People who have been acutely infected with HCV (but did not develop chronic infection)
- People who died or received a liver transplant because of an acute HBV infection
- These bandings are based on clinical markers. The Expert Group considered that it was important to ensure that the evidence required from people claiming their right to compensation should be readily available to them, be verifiable in order to enable objective assessment of their entitlement, be proportionate to the need to operate the scheme and that inappropriate intrusive questions should be avoided.

For people who have been infected, this enables an injury award for each band to be calculated by reference to judicial guidelines on the damages that are appropriate in personal injury cases. This has been done by taking the descriptions developed by clinicians of the symptoms that are typical of people with these diagnoses and examining case law and judicial guidelines for comparable cases. These injury awards would be uplifted where people suffered more than one infection as the clinical advice is that co-infections are significantly more harmful.

Following the Engagement Events, we reflected on the feedback that insufficient recognition was given to the impact that some victims experienced. We revised our advice to add six supplementary health impact groups where adjustments would be made for additional care needs or financial loss. These cover:

- Severe visual impairment
- Neurological disorders which result in long term severe physical/mobility disability
- Neurological disorders which result in long term severe neurocognitive impairment
- Severe psychiatric disorders



- Other Hepatitis C associated extra hepatic disorders resulting in long term severe disability (including those on current support scheme enhanced payments)
- End stage kidney disease requiring renal replacement therapy

The Expert Group believes that social impact awards should not differ as much across the bandings as injury awards because the stigma suffered is usually as a result of societal prejudice rather than knowledge of the clinical symptoms or specific infection. We recommend that there is a flat rate for most beneficiaries that is fixed at the upper end of the band suggested in the report from Sir Robert Francis. This would be reduced for those in the HCV acute band, as they most likely will not have been aware of their infection and the likelihood of stigma is reduced, and increased for those who were infected by more than one virus as the impact is likely to have been more obvious and there was therefore a greater risk of stigma.

There are limited comparators for the autonomy awards that Sir Brian Langstaff recommends as a new head of loss. They need to reflect the aggravated distress caused by interferences in people's autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. Awards should also include the effects of lack of candour and inadequate responses by authority. These may not have all applied to every victim but they will all have experienced a lack of respect for their autonomy in some of these ways. The Expert Group has found elements of the Windrush Compensation Scheme to be the most useful guide to the quantification of this category of award, although it is not a direct comparator.

Care awards aim to compensate for the cost of care that has been received, or its value if it has been given without charge. The clinical experts have set out a typical pattern of care needs after infection in the different clinical bands. Where the wrongful infection was likely to have caused death (or is likely to do so for those still living with the infection), then it would be expected that these awards need to cover a period of end-of-life care, some months of high care, and some years of moderate care, with (for those who survive longer) periods with clearly defined lower care needs. These patterns are typically different for those with HIV from those with Hepatitis alone. People with decompensated cirrhosis or liver cancer will typically face greater care needs for longer periods than those with cirrhosis or chronic infections. These care needs have been costed by experts who are experienced in commissioning and delivering care to severely injured people as well as costing care regimes, both in practice and for the purposes of legal cases. This approach means that once the date and nature of the infection and the clinical banding is known, a formula can be used to calculate the award due for a typical pattern of care needs. This can be paid without the need for further evidence, thereby reducing delay. Where people's care needs have exceeded the typical pattern, additional payments could be made to cover the actual costs after assessment by the Infected Blood Compensation Authority. Care Awards should be paid to the estates of those infected persons who are deceased to cover the cost of care



between the date of infection and death. For those living with wrongful infections a choice should be available between a lump sum to cover the anticipated costs over their expected years of life or periodical payments.

Sir Robert Francis suggested that the calculation of financial loss awards should provide people who were wrongfully infected with compensation based on the assumption that they would have earned 5% more than an average salary if they had not been infected. The Expert Group recommends a formula based on this approach that also takes into account that the impact on a person's ability to work will vary over time. There will be stages in a person's life where they cannot work at all because of their infection. At other times, possibly for a long period, their ability to do work will be impaired. The clinical experts have estimated the degree of impairment, taking into account that this would have sometimes been greater prior to improvements in available treatment than it would be in the present day. We have revised our advice based on feedback from the Engagement Events to limit the assumption that victims of the infected blood scandal would have experienced the benefits of improvements in treatment.

Many people who have been wrongfully infected will have the length of their working life reduced and this is a loss that must be compensated. The Expert Group proposes that for those who are deceased, awards should include compensation for earnings lost until retirement age based on annual earnings plus 5% and for financial loss between their retirement and their death at half that rate (as would be typical for defined benefit retirement schemes). Compensation for financial losses up to the date of death would be paid to the estate of the deceased. Where there are dependants of the deceased, they should receive further compensation related to lost earnings between death and the date when the death of the deceased might have been expected in the absence of the wrongful infection. This should be paid directly to the dependants. For those living with wrongful infections a choice should be available between a lump sum to cover the anticipated financial loss during the remaining expected years of life or periodical payments.

#### Awards for people affected by the wrongful infections of others

Sir Brian Langstaff was clear that awards to people who were affected by the infections of those close to them should be made on the basis that they are entitled to compensation in their own right. The Expert Group considers that this means that the awards should primarily reflect the relationship between the person affected and the person infected rather than which virus or viruses were involved.

We recommend that injury awards should reflect the quantum of damages that would be ordered by courts in respect of psychological damage, distress, anxiety and emotional upset that are likely to have been caused. No specific or additional evidence of such impacts should be required beyond establishing the relationship of the person who is affected to the infected person. The scale for injury awards should vary according to the



closeness of the relationship, with the largest awards for partners, reducing for parents who have lost children, then children who have lost parents, with others getting a lower rate. For immediate family members, where the law provides for loss of society or bereavement awards, then this should lead to an increase in injury awards in cases where the infection was likely to have contributed to an early death (cirrhosis, decompensated cirrhosis, liver cancer and HIV).

The Expert Group advises that there should be a flat rate of social impact award as all those close to people who are infected will have been affected by societal stigma without variation by virus, disease condition or relationship. As Sir Robert Francis noted, awards under this head should be proportionate to those made to people who were infected as it would be inappropriate for those affected to receive more than they did. The recommendation is that the Social Impact award for affected persons should therefore be a proportion of the award for persons with chronic infections.

It is recommended that autonomy awards for those affected by another's wrongful infection broadly reflect court awards for the intrusion into privacy. These awards should be made to the partners, parents and children of the infected person. For partners, it is recommended that a comparator of judicial awards for very serious intrusions is adopted. For parents and children, it is recommended that the benchmark should be the mid-point of awards that have been made as aggravated damages in privacy cases.

The Expert Group advises that care costs should be part of the awards to infected persons rather than those who are affected. These costs are related to the services required by the person who is infected. They are calculated by reference to their needs and paid directly to them (or if they have died to their estates). It will be for the infected person or those administering the estate of the deceased to choose how to divide the funds between those who provided the care in order to provide fair recompense. It would not be appropriate for the compensation scheme to take away the control from the infected person. There would therefore not be separate care awards for those who are affected by the wrongful infection of others. Rather, the costs incurred by them, and which Sir Brian Langstaff recognises must be met by the compensation scheme, would be reflected in the care awards for the persons who are infected. The Compensation Authority could be asked by beneficiaries to pay awards directly to others on their behalf.

Financial loss awards should be paid to dependants of an eligible deceased person in order to compensate for the support that they will have lost due to the death. These should reflect the deceased's lost earnings between the actual and expected date of death, discounted by 25% to recognise that some of those earnings would have been spent by the deceased person on their own account. As noted above, compensation for financial losses up to the date of death would have been paid to the estate.



The Expert Group notes that for most people an acute HCV infection was without enduring consequences (that is it was not in the 'chronic' severity band) and was often not identified at the time. This means that there would have been very limited impact on those around the person who was acutely infected. It therefore recommends that no awards should be payable to those affected by a person who was acutely but not chronically infected. The Expert Group recognises that some people have developed significant post-viral symptoms following infection and such individuals and their partners may choose to present evidence of impact to the Infected Blood Compensation Authority and seek a further supplementary award.

#### **Clarifications of eligibility criteria**

Sir Brian Langstaff set out the eligibility categories for the new compensation scheme. The Expert Group has advised on clarifications required to ensure that in practice the scheme will operate in accordance with the principles that have been set out above.

All those registered with current or previous support schemes will be eligible. Some further information may be requested to enable the calculation of their compensation but not to assess whether or not they are eligible. The Expert Group has identified relevant clinical parameters that should be recorded in medical records that show disease progression. It has also identified imaging and biopsy results that can be used to assess severity banding.

For those persons infected but not previously accepted on to a scheme, evidence of infection and receipt of a contaminated product will be needed. The Expert Group has identified relevant clinical markers of infection that ought to be documented in and accessible from medical records. The Expert Group recommends that mention of HIV, HCV and HBV on a death certificate should suffice as evidence of infection (although its absence would not be taken to exclude it). Further clarification and examples might emerge as the compensation scheme becomes operational. Where there is an absence of clear medical records of receipt of a contaminated product, the Expert Group recommends that the likelihood of receipt of a blood product could be inferred, for example from major surgical procedures, even if it is not specifically recorded in notes. Patient and Carer narratives similar to those used by the different National Infected Blood Support Schemes could be no rigid cut-off that precludes claims in relation to receipt of products after any specific dates. However, this may make the causal link between their receipt and the infection unlikely and require further inquiry.

Persons who are 'affected' become eligible under Sir Brian's recommendations because of their connection with a person who was eligible for compensation due to their wrongful infection. The Expert Group has recommended definitions of partner, parent, child, sibling to reflect the range of family relationships as well as formal legal status. It suggests that where eligibility is based on having provided care the threshold should be the same as that



used for the 'low' banding of provision that is used to calculate the care awards made to persons who are infected. This marks a difference between occasional support and regular care. The Expert Group has not been able to identify ways to make workable the category of affected individuals who were 'so close that it could reasonably be expected that their mental or physical health would be seriously affected by the consequences of the disease, and who have suffered emotionally, mentally and/or physically as a result'.

The Expert Group believes that the approach set out in its advice will enable the Infected Blood Compensation Authority to calculate the awards to which people would be entitled under Sir Brian Langstaff's recommendations promptly and without disproportionate requests for complex or inaccessible evidence.



## The Moral Case for Compensation

The moral case for compensation for the victims of the infected blood scandal is compelling.

The demands that justice makes arise from particularly cruel circumstances, in which there is more than a specific injury because whole lives have been ruined. The impacts are often lifelong and they permeate all aspects of life. This applies not just to infected persons but also to those around them. The impact of infection has often led to the denial of financial security usually available to citizens such as insurance, pensions, and mortgages. Societal stigma attached to infections has further exacerbated this suffering. The moral case is based on the cumulative effect of a number of grounds that make the call for justice exceptional, possibly uniquely so. Not every victim would be able to prove in legal proceedings that they have suffered each of these injustices but the absence of formal proof of injustice is not proof that they have been treated fairly. The scheme should avoid penalising people for lack of specific evidence when the case for compensation is so overwhelming. Records of treatments that should have been maintained are too often no longer available as the NHS failed to maintain the integrity of patients' records so that documents were destroyed or lost.

The injustices have been compounded by the fact that many of those infected have not been fully informed about the risks of treatment or always told about their diagnoses. The general failure to respect patients' autonomy sometimes led to further wrongs; patients being denied care/treatment because their health condition was not acknowledged, being denied the chance to manage risks of infection to others, or the chance to make informed choices about family life. The Expert Group has offered advice on the basis that the NHS has failed in its ethical responsibilities to all victims, making it unnecessary and inappropriate to separate out elements of these wrongs. It also considers that it is inappropriate to make fine distinctions when successive Governments have falsely represented that no wrong had been done to victims, falsely asserted that the treatment they received had in fact been the best available, and failed to secure the relevant paperwork to enable the history to be understood.

## Principles Underpinning the Scheme

In this section, we set out the principles that we used to guide our work. These were set by Sir Brian Langstaff, and adopted by the Government in the work programme that it gave us, and through our discussion of the challenges to be addressed.

#### Sir Brian Langstaff's Second Interim Report

In his Second Interim Report, Sir Brian Langstaff set clear expectations for the scope and shape of the compensation scheme that described who should be eligible and the



categories of loss that should be reflected in the awards. We have aimed at all times to follow that structure and advise on how it can effectively be implemented. We have used the recommendations as our starting point and used the text of his report to guide our understanding of the rationale behind them. We have also used the Compensation Study to help that understanding, while noting that the Second Interim Report sometimes diverged from the suggestions that it made. We have also relied upon its rich details on options for consideration that go beyond the specific recommendations and assisted us in developing details in a way that was consistent with the underlying principles.

Sir Brian recommended that the Scheme should be based on a tariff approach at least for injury, social impact and autonomy awards. We have sought to extend that approach into care and financial loss awards so that the key objectives that he set can be achieved. These were that the compensation scheme should be characterised by speed of provision, simplicity of process, accessibility, fairness and efficiency.

One of the principles that Sir Brian Langstaff recommended should underpin the scheme was community involvement. The engagement events convened by Sir Robert Francis provided us with important feedback that we have taken into account to revise some of our advice. We would have benefited from such feedback at an earlier stage. However, our terms of reference did not enable us to take direct evidence.

Sir Brian made a number of additional and important points of principle in Recommendation 14 about how the scheme would operate in practice, once the design was agreed by the Government. These include that proactive support would be needed for people claiming the compensation to which they are entitled, and that the Compensation Authority would have access to the records of previous support schemes. We agree that this will be very important. For the purpose of our work, we have assumed that it will be available.

#### Government aspirations

As part of our induction, the Expert Group was informed of the Government's intention to agree a Scheme with a number of features, which were consistent with the desire to implement the recommendations in the Second Interim Report. The first was compensation should be deliverable rapidly. Second, it must be trusted by the community and preferred by those seeking redress to court actions. Third, minimal time, effort and stress should be required for eligible parties to participate in the scheme. In particular, there should be a simple and sensitive application process (with the risk of re-traumatisation recognised and avoided). Applicants should automatically be eligible if already a member of a previous scheme. Advice and support should be available for applicants not already registered on scheme.



#### Reflection on past schemes

As we began our work, we discussed what we could learn from the difficulties that had been experienced by beneficiaries of previous schemes. We could not take direct evidence on this but we were able to note issues that were recorded in evidence to the Inquiry, noted by the All Party Parliamentary Group, chronicled by reporters, or known by expert members from those they look after or worked with. We identified the following additional principles.

First, compensation must become a matter of entitlement rather than charity. The APPG had described previous schemes as requiring the 'worst form of modern-day begging'. To avoid this, we think discretion should be kept to a minimum. Where discretionary judgements are required, these should relate to specific components of assessment not total amounts, reasons should be recorded for such the exercise of such discretion so that challenge/appeal can be made when errors or unreasonable judgements have been made. We also noted that subsequent good fortune does not negate entitlement to compensation for past wrongs, noting that it was reported that the MacFarlane Trust had used this as a reason for declining support.

Second, entitlements must be secure and not ad hoc. The past use of loans, sometimes with equity in houses being taken, had created unacceptable vulnerability. The aim should be to resolve claims fairly once and not to require multiple applications based on extreme need.

Third, the process must not be demeaning for applicants and intrusive inquiries should be avoided (such as asking about sexual relationships to exclude other possible sources of infection).

This led us to identify some principles governing evidence requirements that we have used to guide the eligibility descriptions. Any evidence required should be:

- Accessible to claimants (and assessors) so that we ask for information that we can reasonably expect to be available;
- Assessable so that the relevant question about eligibility can be answered
- Verifiable, so the integrity of the scheme is maintained;
- Proportionate to the need to answer the question to determine eligibility or quantify awards, so that:
  - Privacy is maintained but applicants can be asked to consent to access to medical records; and
  - Excessive detail is not sought as it is unnecessarily time consuming (leading to delay and expense in processing cases).



## The Task of the Expert Group

It is for His Majesty's Government to determine the details of the final scheme, through the Regulations that will be laid before Parliament within three months of the Royal Assent to the Victims and Prisoners Act. Our task has been to advise Ministers and civil servants in the Cabinet Office on how Sir Brian's recommendations could be implemented. Our independent advice on the work that has been done by the Government on its proposals is set out in this report, which elaborates and develops the earlier Summary Report.

We were not asked to make recommendations on the architecture of the Scheme. That had already been done by Sir Brian Langstaff. He, and Sir Robert Francis, had recommended that two panels, one clinical and one legal, be set up to develop that architecture further. We have worked as a single group rather than separating the tasks. This has been very helpful in bringing together the insights of the various experts rather than working in parallel. We have understood that our role was to take on the tasks that were suggested for those panels as well as to respond to any other requests for support in developing the details of the scheme. It has not been our role to make recommendations for changes to the fundamental design, which would be a policy matter for the Government. We have provided advice on the technicalities of implementation.

Sir Brian recommended that the development of the scheme should involve the infected community. We support that principle, but our terms of reference have precluded public engagement in our work. The speed with which we have needed to work in order to meet the Government's schedule and later statutory deadlines has made this task particularly challenging. We hoped that our advice could be validated by wider discussion before the Regulations were drafted. We have not been able to do this directly, but we have been briefed on issues that have been raised during the engagement meetings convened by Sir Robert Francis as interim chair of the Infected Blood Compensation Authority and have revised our advice to reflect the feedback on matters that are within the scope of our Terms of Reference.

#### How we worked

The Expert Group met virtually and held over 30 plenary meetings between the beginning of February and the end of July 2024. Additional meetings were convened on specific issues that involved relevant members of the Expert Group. These included defining clinical parameters and giving advice to the Communications team within the Cabinet Office on appropriate terminology. Other sessions addressed actuarial considerations such as expected lifetimes, consistency with the Ogden tables used to calculate awards in personal



injury litigation, the fair design of periodical payments. In addition, there were discussions with modellers to assist their understanding of the number of people likely to fall within severity bands.

We began by reviewing the Interim Reports of the Inquiry and the Compensation Study by Sir Robert Francis. We were briefed on the extensive work that had already been done by civil servants on the implementation of the recommendations. This had identified a series of questions on which advice was sought to progress the detailed design. These provided the initial agenda for our work.

The Chair also met with Sir Robert Francis to clarify the Group's understanding of some of the issues his report examined and with Professor Christopher Hodges, chair of the Horizon Compensation Advisory Board to understand learning from the Post Office scandal.

In order to address questions about eligibility we were provided with documentation on the operation of existing support schemes, and had the opportunity to discuss issues they raised for us with assessors and administrators from the England Infected Blood Support Scheme (some of whom also worked with the Scotland Scheme). We were grateful for the opportunity to explore some issues of evidence and prevalence with experts from the Advisory Committee on the Safety of Blood, Tissues and Organs (SABTO) that helped us appreciate what material was available and accessible. Social Care issues were explored in separate virtual workshops with the social care experts which some clinical members as well as the chair attended.

Our advice informed and helped to shape the proposals that Ministers agreed and which were published by the Government on 21 May 2024. Once the process of drafting the Regulations began, we responded to a series of requests from the drafters for clarification and specification that they needed.

#### Building on the Architecture of the Second Interim Report

The first stage in developing the detailed framework of the Compensation Scheme was to specify the severity bandings that had been proposed by both the Second Interim Report and the Compensation Study. The clinicians developed these by reference to disease impact and clinical markers that should be available and accessible in health records, in accordance with the principles of evidence that we adopted (see above). They were then asked to provide summary descriptions of the impact of each of these bands on the people who were infected, which were used by the legal experts to identify comparators in case law, judicial council guidelines on compensation tariffs, and from the Compensation Study. This was an interactive process in which further clarification was requested by lawyers of the clinicians in order to refine the range of likely court awards, and in which clinicians



probed the basis of the legal advice to avoid misunderstandings. This process led to the quantification of the injury awards.

We then sought to understand how care and financial loss awards could be quantified from the descriptions of the impact of different viruses and severity of impact. This led to a description of the likely care needs for each of the bands, which was refined in discussion with the care experts. The care experts then identified the care provision that would be needed to meet those needs drawing on their experience in commissioning and delivering care to severely injured people. The patterns of care provision were then costed in the way the experts would have done if commissioning the care or assisting in the preparation of litigation. We have been able through this process to devise a way of calculating the value of care awards that does not require specific evidence from beneficiaries beyond that needed to ascertain the appropriate severity banding.

For financial loss awards, we similarly sought to develop an approach that would not require detailed evidence from beneficiaries of loss of earnings. To demand this would delay the assessment of awards and would disadvantage those who did not have comprehensive financial records, including people in insecure employment or out of the workforce who would struggle to evidence their potential earnings. We took the lead from observations of Sir Robert Francis on the calculation of support scheme payments and developed a tariff approach based on the likely impacts of infections and their severity on people's ability to work.

This process enabled us to advise that a scheme of core awards could be designed that required only a limited amount of evidence from infected persons. We believe that this will enable appropriate compensation for the majority of beneficiaries much more quickly than a scheme based on specific assessment. It will need to be supplemented with additional amounts for those for whom the assumptions underpinning the calculations can be shown to be false (for example greater than usual care needs, or higher than average earnings) or where there are specific impacts that go beyond those identified by the clinicians as shared by most people with a particular severity of impact. Since the publication of our summary report and the Government's proposals in May 2024, we have been able to develop more detailed advice on the supplementary awards. This element of our work has been helped considerably by the feedback that we received from the infected community through the engagement events. We describe the conclusions of this further below.

For social stigma awards and autonomy awards we have drawn from components of court awards that correspond to the elements that were described in the Compensation Study and Second Interim Report as falling under these Heads of Loss. We also examined the approaches to quantification taken in other compensation schemes that were mentioned in the Compensation Study. We also looked for comparisons from other areas of law such as privacy litigation. We explain this further below.



#### Sense Checking

As part of our way of working, we 'sense-checked' the emerging advice by developing a set of scenarios and comparing the likely outcome of successful litigation with the awards that the proposed scheme would provide, and also with the payments that would be made through the existing support schemes. The legal experts identified illustrative circumstances from contributors to the Infected Blood Inquiry, to include Treloar College victims and their families; single child and multiple sibling families. Clinical experts commented on draft scenarios to ensure that they were realistic and they were revised accordingly. Then the legal experts prepared the comparisons for discussion. This process reassured the Expert Group that the proposed scheme could be efficiently and effectively applied to common scenarios to generate proposed awards without detailed inquiry. It also showed that awards would be similar to or larger than the predicted litigation outcomes. It was noted that there were some scenarios in which the different basis on which the Support Scheme payments were calculated might lead to more generous amounts. We advised that on the basis of the ministerial commitment that no one should be worse off, there might be a need to consider transitional protections.

#### Taking into account other Schemes

In the Second Interim Report's Recommendation 8, Sir Brian Langstaff proposed that the tariff should be set broadly taking into account, but not limited by, current practice in courts and tribunals across the UK and sums payable in other UK compensation schemes. Bearing this in mind, we have disregarded the ruling of the UK Supreme Court in *Paul v Wolverhampton NHST* [2024] UKSC 1 which was decided after the report was published. It was clear that Sir Brian believed that affected persons (who had not suffered a bereavement) were directly entitled to compensation. Given the overwhelming moral case to compensate those affected by the infected blood scandal, we felt that it would be inappropriate to take into account the Supreme Court's position as it would exclude most affected persons from claiming in their own right.

We have also disregarded the fact that the parties in litigation will usually settle out of court and in doing so will take into account uncertainties of evidence and will be advised to accept a discounted award that reflects the risk of losing the case. The uncertainties of litigation will be high in infected blood cases due to the problems of evidence that we discuss above. However, we did not think it appropriate to apply any litigation-risk discount in our advised awards. We have, however, adopted some conventions from litigation, such as in relation to how awards for past gratuitously given care would be reduced to reflect the



fact that no tax or national insurance would have been paid. We have not made any deduction for the costs of earning a wage (such as work clothes and commuting) even though this is commonly deducted in judicial awards.

Where there are differences in the approaches taken in the four UK legal jurisdictions we have aimed to use the one that best reflects the requirements of justice in the view of the expert group.

We have generally used the illustrations in the Compensation Study as a starting point in looking for appropriate comparators and then reviewed outcomes from litigation brought by infected blood victims (updating the award values for inflation). This could not be definitive as the awards reported in the judgments were often only provisional and we did not regard ourselves as limited to them. We have considered the Judicial College Guidelines, themselves developed from the precedents of the courts, as providing indicative levels for the injury award tariffs. However, these guidelines are organised by the body part that is damaged rather than infections and do not specifically address HIV, HCV, or HBV. It is therefore not straightforward to determine which aspect of the guidelines provides the most appropriate comparator. We found it more helpful to consider reported cases concerning conditions where the impacts on people's lives were in some ways comparable, such as cancer, mild brain damage, extrapolating from them where possible.

#### Engagement meeting feedback

Although our terms of reference preclude taking evidence directly from members of the infected communities or their representatives, we have benefited from feedback from the engagement meetings convened by Sir Robert Francis in June 2024. These very constructive and informed observations were helpful and have led to us modifying some elements of our proposals and clarifying the rationales of others. We would have found this useful at an earlier stage in our work.

We have made a number of modifications to our advice, of which the most important concerned the the feedback that we had 'downgraded' the 'Special Category Mechanism' (SCM, using the English Infected Blood Support scheme terminology) that had been developed to recognise that some beneficiaries with chronic hepatitis had significantly greater needs than others. We reviewed the criteria used in the four nations' schemes and considered how to incorporate them into a supplementary award category. We also considered what other conditions were equivalent as the support schemes only addressed these issues in relation to HCV. The advice set out below reflects this further consideration.

We noted the feedback that people were not able to return to work after treatments for hepatitis C and B improved as the proposed scheme anticipated. Following the evaluation



of this evidence and relevant clinical studies, we propose to disregard the increased potential for work when beneficiaries either suffer from chronic fatigue or are aged 55 or more (to reflect the fact that re-entering the workforce at an older age is significantly more difficult). We believe that this should cover the examples raised at the meetings. While the expert group's review of the evidence shows that most people are able to return to work after modern treatments this is clearly not always the case.

There were some important matters raised in the feedback that have not led us to revise our advice as we considered them to be outside our remit. This includes the issue of exemplary or punitive damages, which Sir Brian Langstaff's Second Interim Report, Recommendation 7, said should be a matter for the courts. He did not revise that recommendation in his final report and we do not think it is an issue for the Expert Group.

We do not believe that the concerns that awards that are made to estates might not be shared in the way some participants hope can be resolved by revisiting the design of the Scheme. This is a policy issue that needs to be addressed elsewhere.

CJD (Creutzfeldt–Jakob disease) infections were not included within the scope of Sir Brian's recommended scheme and we have therefore not considered them. We note that this was of concern to the community but have not been asked to advise on it.

The points raised about the continuation of the Support Schemes and the proper interpretation of representations made to beneficiaries are matters of policy for the Government. We have followed Recommendation 13(c) of Sir Brian Langstaff's Second Interim report that any continued payments under the support schemes should be taken into account in assessing awards for future financial loss and care provision. We believe that the proposals based on our advice implement that recommendation.

#### **Research Ethics Failures**

A possible exception to the principle that victims share equally in their moral demands for compensation was raised in the engagement meetings convened by Sir Robert Francis. These raised the question as to whether there were additional wrongs done in respect of unethical research practices that should be treated separately. Designing the structure for such awards raises a number of complexities.

The Inquiry Report uses a number of examples to illustrate and highlight issues, but notes that these are echoed in other centres. If the unethical practices were widespread and affected all treatment centres, then this may be an example of a systemic disrespect for autonomy, such as already recognised in autonomy awards. However, if the research ethics failures affected only some victims then the Group sees a strong case for increasing autonomy awards for those who were subjected to unethical research. However, without



detailed investigations it would not be easy to assess eligibility and the criteria would need to be defined.

It will be difficult to identify who participated in which types of studies from available records. It may be appropriate to make a supplementary autonomy award to those who can show that they were entered into studies but consideration needs to be given to the sense of injustice this would create for those who believe that they were wronged in this way but cannot provide evidence.

The detailed account of the failures at Treloar College shows the extent of governance failures, but also that there were some cases where parents signed consent forms although they were not properly informed. There is some evidence of parents being consulted although the degree of consultation was inadequate. The Report notes that there are different kinds of research and some was retrospective and observational (with nothing being done that would not have happened anyway). It may be that these different studies require different levels of compensation.

We have been able to have only limited discussion of these issues and have not had time to reach firm conclusions. We have not therefore offered specific advice about compensation for victims who were part of research studies. It may be that further consideration would be beneficial and that compensation should be addressed as part of this.



## Heads of Loss

Sir Brian noted that 'the underlying principle adopted by the civil courts in awarding compensation for wrong-doing is to put a successful claimant into the same position in which they would have been had they not suffered the wrong, so far as money can achieve that object.' In order to achieve that, he recommended that the compensation scheme should provide for awards based on five components and that their quantification should reflect different impacts on people who were infected and on those who were close to them (described by Sir Brian as 'affected') and also take into account differences between the diseases caused by HIV, HCV and HBV and the impact of co-infections.

He recommended that compensation to both infected and affected persons should be built up from awards against the following heads of loss:

- 1. **Injury Impact Award** for past and future physical and mental injury, emotional distress and injury to feelings caused by the infection and treatments for it, or being affected by them or by the death of an eligible infected person, including an award for loss of society of the deceased.
- 2. **Social Impact Award** for past and future social consequences of the infection including stigma and social isolation.
- 3. **Autonomy Award** as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life (e.g. loss of opportunity to have children). This should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent in regards to their treatment.
- 4. **Care Award** for the future care needs of the eligible infected person, and to compensate for past losses in respect of care necessitated by their infection (to be paid directly to the infected person where they have paid for care, and/or directly to an affected person who has provided care).
- 5. Financial Loss Award for past/future financial loss suffered as a result of infection.

These five heads of loss are the basis on which we have developed our advice.

#### The principles behind a tariff approach

Sir Brian Langstaff's Second Interim Report recognised that the importance of an individually assessed figure for these awards should be balanced against the importance of avoiding further delay and incurring excessive cost. He therefore recommended against the Irish Tribunal Scheme because of the delays in assessing claims that followed from the preparation required for an individually assessed award. A single lump sum figure would be quicker to administer but could not reflect the differences between cases. He proposed as



'the best compromise' a scheme in which 'banded awards' were 'set to take into account the broad features of a case, allowing for individualised assessment within those bands to the extent the bandwidth permits'. This would avoid a 'one-size-fits-all' process that would be quick but fail to recognise individual circumstances.

For injury awards, this tariff approach is familiar to lawyers and claims can be quantified using Judicial College Guidelines and reports of judicial awards and settlements. This was illustrated in the Compensation Study and the legal experts on the Group have been able to update the figures used by reference to more recent guidance. Although social impact and autonomy awards are novel heads of loss, some of the matters that they compensate for have been discussed in the case law and we have been able to advise on tariff amounts. The tariff for injury awards reflects the viruses with which people were infected and their clinical consequences. Those for social impact reflect the likelihood of stigma based on the responses of others. This may be independent of the actual virus involved. For affected persons, the closeness of the relationship with the infected person will generally be more significant than the specific virus.

Creating a tariff approach to care awards was more problematic. We have been able to advise on a way of calculating them that is based on a standardised profile of care needs for each of the severity bands. This creates a tariff formula rather than a set rate. This will reflect common experience and is banded so as to reflect the range of impacts of infection over a person's life. Individualisation would not be possible without requiring extensive evidence from beneficiaries or intrusive questioning and personal assessments. That would conflict with the principles we believe should underpin the scheme. Where the core tariff formula approach would fail to reflect actual costs, this can be addressed by allowing a supplementary claim where evidence can be supplied that actual costs have exceeded the ones the model anticipated.

We have advised that a similar tariff formula should be applied to calculate financial loss. This would be based on an annual earnings figure that would be paid for each of the years of working life that have been lost due to the infection, reduced for post-retirement years to be equivalent to a workplace pension. Both Sir Brian Langstaff and Sir Robert Francis envisaged that actual financial loss would be individually assessed. However, such assessments would take time and in order to meet the principle that the Scheme should be set up in a way that enables payments to be made quickly a different approach was adopted. The tariff formula approach was suggested by examples from the Compensation Study of how financial loss could be assessed by reference to statistics on earnings (SRF 8.5) and its discussion of how a tariff for annual support payments might be fixed (SRF 9.87- 8.93). By adapting the recommendation of Sir Robert Francis to adopt the benchmark of average earnings (net of tax and National Insurance) plus 5%, we are able to suggest an approach that would match or exceed the lost earnings of the majority of people without need for specific proof. The need for individualised assessment can be met by making



available a set of supplementary awards where the beneficiary has evidence that their earnings would have been higher.

#### Core and supplementary awards

The Expert Group's advice is therefore that core awards can be determined applying the tariff approach. There would be fixed amounts for injury, social impact and autonomy awards and formulas for calculating care costs and financial loss that would reflect the common impact of viruses on most of those infected. However, there is a range of circumstances where we believe additional impacts will be felt by some people. Where the Expert Group believes broadly equivalent burdens are borne by most victims in a severity band, then this should be factored into the core award. Where a subset of victims can be identified where the harms are greater than this, then this should entitle them to a supplementary award. The concerns raised in the engagement meetings has led us to advise that the scope of this supplementary route should be expanded from our initial expectations and we set out our revised advice below. These supplementary award calculations would remain part of the statutory scheme. It would not be a substitute for the residual right to bring legal claims, which Sir Brian Langstaff was clear should not be removed.



# Severity Bandings for people who were wrongfully infected

Sir Brian Langstaff recommended, building on the Compensation Study undertaken by Sir Robert Francis, that the scheme should reflect the different impacts of infection by developing severity bandings but did not define them. The clinical members of the Expert Group have proposed the following bandings. The Expert Group considered that it was important to ensure that the evidence required from people claiming their right to compensation should be readily available to them, be verifiable in order to enable objective assessment of their entitlement, be proportionate to the need to operate the scheme and that inappropriate intrusive questions should be avoided. Consequently, clinical markers are used to define the bandings.

#### **Core Bandings**

The below table defines the core severity bandings.

Infection severity banding	Definition
Hepatitis B - Acute (where the infection resulted in a fatality in the acute period)	Infection resulting in fulminant liver failure, usually within 6-12 months of infection.
Hepatitis C - Acute	Transient, self-cleared infection usually within 6-12 months of exposure.
Hepatitis C or Hepatitis B - Chronic	Hepatitis C - Infection with replicating HCV RNA. Hepatitis B - Infection with evidence of surface antigen positivity for longer than 6 months with detectable HBV DNA on PCR if not on treatment.
Hepatitis C or Hepatitis B - Cirrhosis (liver damage)	Serious scarring of the liver caused by long-term liver damage. Treatment of B-cell non-hodgkin's lymphoma - single round treatment (first line therapy). Type 2 or 3 cryoglobyulinemia accompanied by membranoproliferative glomerulonephritis (MPGN).



Hepatitis C or Hepatitis B - Decompensated cirrhosis and/or liver cancer and/or liver transplantation	Decompensated cirrhosis is characterised by the presence of hepatic encephalopathy (confusion due to liver damage) or ascites (accumulation of fluid in the abdomen) or variceal haemorrhage (bleeding from dilated veins in the gullet or stomach) or a Child-Pugh score greater than 7. Treatment of B-cell non-hodgkin's lymphoma - multiple round treatment (second line therapy).
HIV	Single severity banding.
Co-infection of HIV and Hepatitis C or Hepatitis B	Co-infections severity bands will reflect the severity of the Hepatitis infection as described above and the HIV infection.

#### Enhanced, Advanced and 'Special Category' bands

Feedback from the engagement meetings has prompted us to review the need for an additional banding to reflect the greater impact that some people with HCV have experienced. We therefore reviewed the criteria used in the four national Infected Blood Support schemes where beneficiaries have shown that there has been a greater than average impact on them of chronic HCV or complications of their disease (Annex B). These are similar but not identical. The Expert Group has considered the equivalent features in relation to HBV, not currently within the scope of the support schemes and also whether they should be recognised in relation to HIV.

Some of these aspects of people's experience have already been incorporated into core awards as the advice from the Expert Group is that they affect most people. This is the case in relation to chronic fatigue for all viruses. Others will be less common, but when they arise they will require compensation beyond the core awards. The Expert Group therefore proposes that there should be six groups of circumstances where the calculations of care needs and financial loss should be adjusted to recognise the increased impact that some beneficiaries experience from their disease. This should take the form of a supplementary route application and have the adjustments set out below. Those who have already been recognised as qualifying for the enhanced payment categories under the Support Schemes would not need to produce further evidence to qualify.

The Expert Group did consider whether there should be different injury award bandings for these categories but considers that they are best understood as uncommon consequences of the same injuries rather than separate severity bands attracting a different level of injury award. It does not therefore advise any changes to the injury, autonomy or social impact awards for people in the supplementary health impact groups.



#### Supplementary route health impact groups

The below tables defines the enhanced, advanced and special category bands.

Health impact group (1)	Infection	Amendment to care award (2)	Amendment to financial award (2)	Notes
<b>1) Severe visual impairment</b> (certified and registered with severe sight impairment)	HIV	Lifetime domestic support HIV: N/A - financial loss already 100% 6 hours per week (Support with heavier domestic tasks, attendance of medical appointments and household maintenance.		Consider adjustment to low care if justified by evidence.
<ul> <li>2) Neurological disorders which result in long term severe physical/mobility disability</li> <li><i>Examples include:</i></li> <li>(I) Cerebral toxoplasmosis resulting in severe stroke</li> </ul>	HIV Hepatitis C	Lifetime low care 16.5 hours per week (6 hours per week domestic support + 1.5 hours per day personal care) - Domestic support as above plus personal care per day including washing, dressing and grooming.	HIV: N/A - financial loss already 100% <u>Hepatitis</u> : Financial loss to 100% from diagnosis of the condition regardless of liver disease stage if person can show that they have been unable to work.	Consider adjustment to moderate care if justified by evidence.
3) Neurological disorders which result in long term severe neurocognitive impairment Examples include:	HIV Hepatitis B Hepatitis C	Lifetime low care 16.5 hours per week (6 hours per week domestic support + 1.5 hours per day	<u>HIV</u> : N/A - financial loss already 100% <u>Hepatitis</u> Hepatitis B/C	Condition would only be associated with decompensated cirrhosis band.



Health impact group (1)	Infection	Amendment to care Amendment award (2) Amendment to financial award (2)		Notes
(i) HIV associated dementia (ii) HCV/HBV Chronic hepatic encephalopathy		personal care)- Domestic support as above plus personal care per day including washing, dressing and grooming.	Decompensat ed cirrhosis: financial loss already 100% for longer than 4 years.	Consider adjustment to moderate care if justified by evidence.
<ul> <li>4) Severe psychiatric disorder</li> <li>A severe psychiatric disorder diagnosed by a psychiatrist and requiring on-going (&gt;6 months) treatment (by either pharmaceutical or non-pharmaceutical interventions) under the care of specialist mental health services. This would include severe cases of psychiatric disorders significantly greater in impact than those captured in category 5.</li> <li>Such conditions would normally have resulted in episodes of inpatient psychiatric care and individuals would have been under regular psychiatric follow up for a prolonged period of time.</li> <li>Sectioning under the Mental Health Act would also qualify individuals for this category.</li> </ul>	HIV Hepatitis B Hepatitis C	Lifetime low care 16.5 hours per week (6 hours per week domestic support + 1.5 hours per day personal care)- Domestic support as above plus personal care per day including washing, dressing and grooming.	HIV and co-infection: N/A - financial loss already 100% <u>Hepatitis</u> : financial loss based on psychiatric assessment.	Assessment to confirm impact of severe depression and anxiety.
5) Other Hepatitis C associated extra hepatic	Hepatitis B Hepatitis C	Lifetime domestic support.	<u>Hepatitis C</u> Financial loss: Match to	Those registered with SCM in the current support



Health impact group (1)	Infection	Amendment to care award (2)	Amendment to financial award (2)	Notes
disorders resulting in long term severe disability. This includes those currently assessed as the following category on IBSS: • Hepatitis Special Category Mechanism (EIBSS) • 'Severely Affected' Hepatitis C (SIBSS) • Hepatitis C Stage 1 Plus (WIBSS) • Hepatitis C Stage 1 Plus (WIBSS) • Hepatitis C Stage 1 Enhanced Payments (NIIBSS) For new applicants not currently registered on support schemes, you may be eligible if due to the impact of Hepatitis C and / or its treatment you: () Have autoimmune disease due to or worsened by interferon treatment for hepatitis C, for example: • Coombes positive haemolytic anaemia; • Idiopathic fibrosing alveolitis of the lung; • Rheumatoid arthritis. (ii) have sporadic porphyria cutanea tarda causing photo sensitivity with blistering.		6 hours per week (Support with heavier domestic tasks, attendance of medical appointments and household maintenance.	award (2) cirrhosis b.	scheme would automatically be accepted. New applicants would need to provide evidence supporting. diagnosis and impact.
(iii) have immune thrombocytopenic purpura.				



Health impact group (1)	Infection	Amendment to care award (2)	Amendment to financial award (2)	Notes
(iv) have type 2 or 3 mixed cryoglobulinaemia which is accompanied by:				
<ul> <li>Cerebral Vasculitis;</li> <li>Dermal Vasculitis;</li> <li>Peripheral neuropathy with neuropathic pain.</li> </ul>				
(v) you are suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to Hepatitis C infection as a result of infected blood/ blood products, which affect your ability to perform daily tasks. This may include:				
<ul> <li>You are unable to work or have had to reduce your working hours or change your working pattern due to the impact of physical or mental health problems.</li> <li>You had to leave a better job,</li> </ul>				
<ul> <li>role or career due to physical or mental health problems.</li> <li>Your mental health problems have directly resulted in the breakdown of your marriage or other long-term relationship and this is still having significant effect on</li> </ul>				
<ul> <li>your life.</li> <li>Your mental health problems frequently make it very difficult for you to leave your home or socialise with other people</li> </ul>				
<ul> <li>You are unable to carry out day to day activities e.g. shopping, cooking, gardening or cleaning.</li> </ul>				



Health impact group (1)	Infection	Amendment to care award (2)	Amendment to financial award (2)	Notes
6) End stage kidney disease requiring renal replacement therapy	HIV Hepatitis B Hepatitis C	Duration of dialysis treatment: Low care 16.5 hours per week (6 hours per week domestic support + 1.5 hours per day personal care) - Domestic support as above plus personal care per day including washing, dressing and grooming.	HIV and co-infection: N/A - financial loss already 100% Hepatitis Duration of dialysis treatment: 100% financial loss.	

- 1. Condition as a consequence of HIV or Hepatitis B or Hepatitis C infection.
- 2. Adjustment to care profile from date of diagnosis of condition until escalation of care required as per profile for core route.

## **Injury Awards**

This award recognises the physical and mental injury, emotional distress and injury to feelings that may have been caused or will in future be felt as a result of infected blood and/or related medical treatments. This broadly reflects what is described in personal injury litigation as 'general damages' to cover pain, suffering and loss of amenity, although Sir Brian Langstaff also mentions the need to include sums for emotional distress and injury to feelings caused by the infection and treatments for it.

For people who have been infected, an injury award for each band has been calculated by reference to judicial guidelines on the damages that are appropriate in personal injury cases.

This has been done by taking the descriptions developed by clinicians of the symptoms that are typical of people with these diagnoses and examining case law and judicial



guidelines for comparable cases. The values of awards in the cases were updated for inflation and this uprating is reflected in the amounts noted below. All those infected should receive at least a sum of £10,000. Additional sums would be based on the nature and impact of the infection as follows.

**'HCV exposed**' are people exposed to the virus but who, typically, will have had no symptoms nor major interference in their quality of life. Payments reflect the acknowledgement of harm in the absence of significant impact and where the psychological distress will usually be minimal. In one 2006 case of a needlestick injury where infection did not take hold, possibly because of vaccination given against HBV, an award was made of £4,000 (current updated value). People who experience specific harms not usually suffered from exposure that does not lead to a chronic infection can seek recompense via the supplementary route. We advise that the £10,000 would be an appropriate level of injury award for this band of severity.

**Chronic viral hepatitis (HBV or HCV)** leads to stigma and autonomy loss, which is of a similar level for both infections. Both infections are associated with impaired work capacity (more marked for HCV than HBV) that usually resolves when the virus is eliminated by treatment. There is likely to be a significant psychological impact that affects people's ability to function, that should be reflected in the injury award for all beneficiaries in this category. Comparators have been taken from the National Blood Authority litigation (2001) and also from other personal injury cases involving liver damage, potential lifelong complications, stoma, and chronic fatigue. These comparators included compensation for the impact and side effects of treatment with interferon, where the awards ranged in 2001 from £17,000 to £45,000 (current updated values). We advise that an injury award of £60,000 would be appropriate.

**Cirrhosis**, regardless of the aetiology, leads to a common health impact with common needs. The impact, including psychological impact, is significantly greater than for people with chronic infection. Patients are unlikely to be able to work full time. Comparators have been taken from personal injury cases concerning severe liver damage. These awards made in the 2001 litigation ranged from £59,000 to £99,000 (current updated values). We advise that an injury award of £120,000 would be appropriate.

People with **decompensated cirrhosis**, regardless of cause, have enhanced care needs, will be unable to work, and will suffer significant fatigue. We think that those with liver cancer or who need a liver transplant should be banded in the same category. The injury award is calculated on the assumption that there are significant psychiatric symptoms in addition to the physical effects of the virus. Comparators have been taken from personal injury cases involving terminal cancer. For example, the proposed level of injury award is slightly above that in a 2021 case where the claimant was awarded £178,000 (current updated value) when she lost the opportunity to prevent cervical cancer, had to undergo a radical laparoscopic hysterectomy, experienced urinary incontinence, bowel problems,



radiotherapy, stoma, chemotherapy, and was left with a very limited life expectation. In a 2001 case that was part of the litigation against the National Blood Authority an award of  $\pounds$ 99,000 (current updated value) was made to a claimant who had received a liver transplant as well as having received interferon earlier in her treatment. We advise that an injury award of  $\pounds$ 180,000 would be appropriate.

The estates of people who **died during an acute Hepatitis B infection** should receive the same injury award as those with decompensated cirrhosis or HIV as the impact of the infection was so great.

**HIV mono infection** is a single severity band because HIV is a lifelong infection and the vast majority of people infected with HIV through blood products will have experienced progression to advanced symptomatic HIV disease including AIDS conditions and will have died as a consequence of their infection. This group will comprise a relatively small number of people, many of whom will be deceased and relevant evidence for different subdivisions will be difficult to access. Those who have survived will continue to be severely impacted by their infection. In these circumstances, it would be disproportionately complex and onerous to disaggregate the category even if some victims might get greater compensation than they would if a detailed inquiry was carried out. The injury award is calculated on the assumption that there are significant psychiatric symptoms in addition to the physical effects of the virus. We advise that this should be the same as for those with decompensated cirrhosis, &/or liver cancer &/or liver transplantation and therefore suggest the injury award should be £180,000.

Head of Loss	HCV - Acute/Exposed	HCV/HBV - Chronic	HCV/HBV -Cirrhosis	HCV/ HBV- Decompensated cirrhosis, &/or liver cancer &/or liver transplantation	HIV
Injury Award	£10,000	£60,000	£120,000	£180,000	£180,000

Where people have more than one infection, these injury awards need to be increased. Co-infections cause significantly greater harm. As HIV is considered the primary infection in terms of impact, injury awards are quantified on the basis of full HIV award plus a percentage uplift of the relevant severity of Hepatitis infection, with the percentage increasing with severity. For those infected with both HBV and HCV (but not HIV), they should get a 25% uplift on the award for the most serious impact.

Head of Loss	HIV & Acute HCV	HIV & Chronic HCV/HBV	HIV & Cirrhosis HCV/HBV	HIV & Decompensate d cirrhosis HCV/HBV	HIV & liver cancer &/or liver transplantation HCV/HBV or HBV acute where the infection resulted in a death in the acute
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					period
Injury Award	25% uplift on HCV/HBV acute + full HIV £182,500	25% uplift on HCV/HBV chronic + full HIV £195,000	50% uplift on HCV/HBV cirrhosis + full HIV £240,000	50% uplift on HCV/HBV decompensated cirrhosis + full HIV £270,000	50% uplift on HCV/HBV + full HIV <b>£270,000</b>

Head of Loss	Hepatitis C	Hepatitis C	Hepatitis C and Hepatitis B
	and	and	(Decompensated cirrhosis, and/or
	Hepatitis B	Hepatitis B	liver cancer and/or liver
	(Chronic)	(Cirrhosis)	transplantation)
Injury award	£75,000	£150,000	£225,000

## Social Impact Awards

The Expert Group believes that social impact awards should not differ as much across the bandings as injury awards because the stigma suffered is usually as a result of societal prejudice rather than knowledge of the clinical symptoms. We advise that there should be a single rate of  $\pounds$ 50,000 across all chronic single infections. That is fixed at the upper end of the band suggested in the report from Sir Robert Francis, who proposed a severity linked range of figures for social impact award of  $\pounds$ 10,000 for mild diseases of 0-4 years up to  $\pounds$ 51,500 for co-infected for 15+ years. The Social Impact Award would be reduced to  $\pounds$ 5,000 for those in the HCV acute band, as they most likely will not have been aware of their infection and the likelihood of stigma is reduced. It should be increased to  $\pounds$ 70,000 for those who were infected by more than one virus as the impact is likely to have been more obvious and there was therefore a greater risk of stigma.

Sir Brian Langstaff initially described this head of loss as 'a Social Impact Award for past and future social consequences of the infection including stigma and social isolation, loss of educational opportunity, and loss of congenial employment' (p42). The Expert Group noted that financial losses were covered separately and therefore focused on stigma and social isolation when looking for comparators for quantifying these awards. This is consistent with the formulations in the recommendations of both the Compensation Study (R8) and Second Interim Report (R6), which cover 'past and future social consequences of the infection including stigma and social isolation.'



Head of Loss	HCV - Acute / Exposed	HCV/HBV - Chronic	HCV/HBV - Cirrhosis	HCV/ HBV - Decompensated cirrhosis, &/or liver cancer &/or liver transplantation	HIV
Social Impact Award	£5,000	£50,000	£50,000	£50,000	£50,000

Head of Loss	HIV & Acute HCV/HBV	HIV & Chronic HCV/HBV	HIV & Cirrhosis HCV/HBV	HIV & Decompensated cirrhosis HCV/HBV	HIV & liver cancer &/or liver transplantation HCV/HBV	HBV & HCV - All chronic infections
Social Impact Award	£70,000	£70,000	£70,000	£70,000	£70,000	£70,000

## Autonomy Awards

There are limited comparators for the autonomy awards that Sir Brian Langstaff recommends as a new head of loss. They need to reflect the aggravated distress caused by interferences in people's autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. They should also include the effects of lack of candour and inadequate responses by authority. These may not have all applied to every victim but they will all have experienced a lack of respect for their autonomy in some of these ways.

The Expert Group found elements of the Windrush Compensation Scheme to be the most useful guide to the quantification of this category of award, although it is not a direct comparator. Awards under that Scheme at Level 5 were for lump sums of £100,000. These include injury to feelings, anxiety and distress, family separation (social impact effect) and impact on physical and mental health. Some of these elements are covered in other Heads of Loss, leading us to suggest that autonomy awards for people who were infected should be in the range of £40,000- £50,000. We noted that the 'very serious' invasion of Sir Cliff Richard's privacy by the BBC resulted in aggravated damages of £20,000, but consider this was too low to properly mark the disrespect for the autonomy in infected blood victims.

The HCV exposed autonomy award is lower as the impact was for a limited period. It is similar to the Windrush Scheme's category of 'Marked detriment such as inconvenience, annoyance, frustration and worry, where the effect on the claimant was fairly short lived (lasting up to a few weeks)' which is compensated at £10,000. We suggest that this would be appropriate for HCV exposed. We think it is appropriate to uplift the autonomy awards



for those with co-infections as they are likely to have experienced greater constraints on their choices.

Head of Loss	HCV - Acute/Expo sed	HCV/HBV - Chronic	HCV/HBV -Cirrhosis	HCV/ HBV- Decompensated cirrhosis, &/or liver cancer &/or liver transplantation	HIV
Autonomy Award	£10,000	£40,000	£40,000	£50,000	£60,000

Head of Loss	HIV & Acute HCV/HBV	HIV & Chronic HCV/HBV	HIV & Cirrhosis HCV/HBV	HIV & Decompens ated cirrhosis HCV/HBV	HIV & liver cancer &/or liver transplantation HCV/HBV	HBV & HCV- All chronic infections
Autonomy Award	£70,000	£70,000	£70,000	£70,000	£70,000	£70,000

## Care Awards

Care awards aim to compensate for the cost of care that has been received, or its value if it has been given without charge. The clinical experts have set out a typical pattern of care needs after infection in the different clinical bands. Where the wrongful infection was likely to have caused death (or is likely to do so for those still living with the infection), then it would be expected that these awards need to cover a period of end-of-life care, some months of high care, and some years of moderate care, with (for those who survive longer) periods with definite but lower care needs. These patterns are typically different for those with HIV from those with Hepatitis alone. People with decompensated cirrhosis or liver cancer will typically face greater care needs for longer periods than those with cirrhosis or chronic infections.

These care needs have been costed by experts who are experienced in commissioning and delivering care to severely injured people. They made a number of revisions to and clarifications of the suggested specification of needs prior to costing the care regimes, drawing on their experience in doing so for the purposes of legal cases as well as in the arrangement of care. No account has been taken of DWP benefits or NHS continuing care payments that might be available or have been received in the past. The focus has been on identifying care needs and quantifying the award required to meet them.



#### Estimating care needs

Every infected person's care needs will vary; in terms of the level of care they require, the length of time for which they will need it, and whether their needs steadily increase or fluctuate. In order to enable the scheme to make payments without detailed inquiry it is necessary to identify a pattern of likely care requirements that can form the basis of an award without any further evidence being required of beneficiaries once severity bandings have been established.

The profiling followed four steps.

- (1) The clinical experts were asked to describe the nature of care likely to be required by people in the different severity bandings.
- (2) The care experts were then asked to comment on whether those profiles were consistent with their experience and to cost them as they would in preparation for a legal claim.
- (3) Following discussion of the results of these first two steps, five categories of care were defined and costed; end of life, high care, moderate care, low care, and domestic support.
- (4) The clinical experts were then asked to advise on how much of their lives an infected person would typically need each of these categories of care.

This process has enabled the Expert Group to recommend a formula for an award to be calculated that would reflect what a court would be expected to award for a typical pattern of care.

#### Care Bands

The care bands are set out in this table. The first column provides a summary category. The second provides a description of care needs. The third explains the inputs of care that would be required to meet those needs and the cost of doing so on a commercial basis. These calculations are based on current national rates. We do not consider that it is proportionate to seek to adjust for regional rates as this would require detailed inquiries as to the place of residence of beneficiaries. These commercial rates are also used to calculate awards for future care as it gives beneficiaries the flexibility to arrange for care on a paid basis if they so choose.

Care Band	Care descriptor	Cost per annum (Future care)
Domestic support	Total: 6 hours per week	Total: £5,460 <u>Includes</u> :



Care Band	Care descriptor	Cost per annum (Future care)
and ad hoc care	<b>Description</b> : Support with heavier domestic tasks e.g. vacuuming, laundry, changing bed sheets and shopping = 4 hours per week.	Commercial domestic support is approx £15 per hour, varies according to region
	Support with medical appointments or essential community access when unwell. This is averaged across a week to include travel time, waiting time and any appointments = 1 hour per week. Support with household maintenance tasks e.g. gardening/DIY/decorating, this is averaged across a year = 1 hour per week.	5 hours x 52 weeks x £15 = £3900 1 hour x 52 weeks x £30 (handyman) =£1,560 weekly total = £105
Low care band	<ul> <li>Total: 16.5 hours per week (6 hours per week + 1.5 hours per day personal care)</li> <li>Description:</li> <li>Domestic support/household maintenance one additional how on the above (6 hours per week)</li> <li>PLUS</li> <li>1.5 hours personal care per day including washing, dressing and grooming. Also including household support, e.g. fetching and carrying.</li> </ul>	<b>Total:</b> £23,424.72 = Domestic/household maintenance ( $\pounds$ 5,460.00) + 1.5 hours additional personal care and household support ( $\pounds$ 17,184.72) <b>Includes:</b> <b>Full domestic support (as above):</b> £6,240 6 hours x 52 weeks x $\pounds$ 15 = $\pounds$ 4680.00 Household maintenance = 1 hour per week 1 hour x 52 weeks x $\pounds$ 30 (handyman) = $\pounds$ 1,560 <b>Additional personal care and household support:</b> 1.5 hours per day, $\pounds$ 17,184.72 per annum Monday – Friday, 7.5 hours at $\pounds$ 29.48 = $\pounds$ 221.10 Saturday – Sunday, 3 hours at $\pounds$ 35.59 = $\pounds$ 106.77 Weekly total = $\pounds$ 327.87 Public holiday 8 days x 1.5 hours at $\pounds$ 11.29 per hour (uplift)
Moderate care	Total: 34 hours per week Domestic support/household maintenance as above (6 hours per week)	Total: £51,285.92 = Domestic/household maintenance (£5,460.00) + 4 hours home care per day (£45,825.92) Includes:
	PLUS	Full domestic support (as above): £5,460
	<ul> <li>4 hours of home care per day consisting of:</li> <li>Greater support for transport to access community/hospital</li> </ul>	5 hours x 52 weeks x £15 = £3900.00 Household maintenance = 1 hour per week



Care Band	Care descriptor	Cost per annum (Future care)
	<ul> <li>appointments and engage in social activities = 7 hours per week.</li> <li>Assistance with personal care in the morning and evening = 1.25 hours per day.</li> <li>Assistance with main meal = 7 hours per week.</li> <li>Assistance with fetching and carrying = 3.5 hours per week.</li> <li>Occasional support with transfers/ stair climbing = 1.75 hours per week.</li> </ul>	1 hour x 52 weeks x £30 (handyman) =£1,560 Agency home care: 4 hours per day, £45,825.92 per annum Monday – Friday, 20 hours at £29.48 = £589.60 Saturday – Sunday, 8 hours at £35.59 = £284.72 Weekly total = £874.32 Public holiday 8 days x 4 hours at £11.29 per hour (uplift) = £361.28 Annual total = £45,825.92
High care	<ul> <li>Domestic support/household maintenance as above (6 hours per week)</li> <li>PLUS</li> <li>5 hours of home care per day consisting of: <ul> <li>Full meal cover = 10.5 hours per week.</li> <li>Full personal care = 10.5 hours per week (1 hour am, 0.5 hr pm).</li> <li>Support with bed, shower chair transfers = 0.5 hours per day.</li> <li>Assistance with medication, esp if on opioids and/or If on gastric feeds will need assistance = 1 hour per day.</li> <li>Assistance with fetching and carrying = 0.5 hour per day.</li> </ul> </li> <li>Likely to need several weeks per annum of increased care, e.g. live in care for times of worse pain or an increase in symptoms.</li> <li>At this stage, the patient would not be well enough for support to engage in leisure. Hospital transport is assumed to be managed within allowance.</li> <li>Night support of maximum 2 short calls per night.</li> </ul>	Total: £62,742.40 = Domestic/household maintenance ( $\pounds$ 5,460.00) + 5 hours home care per day ( $\pounds$ 57,282.40) Includes: Agency home care: 5 hours per day, $\pounds$ 56,830.80 Monday – Friday, 25 hours at $\pounds$ 29.48 = $\pounds$ 737.00 Saturday – Sunday, 10 hours at $\pounds$ 35.59 = $\pounds$ 355.90 Weekly total = $\pounds$ 1,092.90 Public holiday 8 days x 5 hours at $\pounds$ 11.29 per hour (uplift) = $\pounds$ 451.60 Annual total = $\pounds$ 57,282.40 Not included option for live in carer ( $\pounds$ 86,923.00 per annum)
End of Life Care	<ul><li>24 hour support.</li><li>Likely to need a waking carer for the final 6 weeks of life to manage with pain relief.</li><li>E.g. 2 x 12 hour shifts from a domiciliary care agency, with waking nights in the last 6 weeks.</li></ul>	Total: £109,835.96 = Live in carer (£86,923.00) + 2 hours home care per day (£22,912.96) Includes: Live in carer = £86,923.00 PLUS



Care Band	Care descriptor	Cost per annum (Future care)
		Home care 2 hours per day Monday – Friday, 10 hours at $\pounds 29.48 = \pounds 294.80$ Saturday – Sunday, 4 hours at $\pounds 35.59 = \pounds 142.36$ Weekly total = $\pounds 437.16$ Public holiday 8 days x 2 hours at $\pounds 11.29$ per hour (uplift) = $\pounds 180.64$ Agency home care total = $\pounds 22,912.96$
		Overall annual total = £109,835.96

Using current rates even for past care is a reasonable way to adjust for inflation. However, it is likely that care will in the past have been provided by family members or friends rather than by commercial agencies. To reflect this, the care award for past care is calculated on the basis that tax, national insurance and other costs will not have been paid. As noted by the Compensation Study paragraph 9.63 the discount of 25% that we have applied to is consistent with court practice.

Care Band	Cost per annum in relation to Past care
Domestic support and ad hoc care	Total: £4,095
Low care band	Total: £17,568.54
Moderate care	Total: £38,464.44
High care	Total: £47,056.80
End of Life Care	Total: £82,376.97

Where past care has in fact been purchased at commercial rates, then a supplementary application based on evidence of invoices and payments would ensure full reimbursement.



#### **Care Profiles**

In order to calculate awards, it is necessary to determine how much care a person is likely to need in each of these categories. The clinical experts have estimated the likely duration of each category of care while a person lives with the viruses. The periods of higher care needs may not necessarily come together, as needs may wax and wane, but we believe these are reasonable estimates of the cumulative time for which each category of care will be required over their lifetime.

The lifetime care profile for those co-infected with HIV and either HCV or HBV, is estimated to be similar to someone with HIV alone. The reason for this is that the severity of disease impact in terms of the number of life threatening illnesses over a finite period is likely to be similar.

Where a person does not live for the full period after infection that is set out in this table, then it should be assumed that they have the highest level of needs for the time that they survived. That is, the amounts due under the columns from the left should be paid as a priority over those to the right. For example, the care profile of a person with HIV infection who died 10 years after infection would constitute 0.5 years of end of life care, 1.5 years of high care, 7 years of moderate care and 1 year of low care, 10 years in total.



	Years of care required				
Infection severity band	End of life care (£109k pa)	High care requirement (£62k pa)	Moderate care requirement (£51k pa)	Low care requirement (£23k pa)	Minimal care and domestic support (£5.5k pa)
HCV Acute					
HCV/HBV Chronic					10
HCV/HBV Cirrhosis				6	10
HCV/HBV Decompensated cirrhosis, liver cancer	0.5	1.5	2	6	10
HIV, HIV & HCV Acute, HIV & HCV/HBV Chronic, HIV & HCV/HBV Cirrhosis, HIV & HCV/HBV Decompensated Cirrhosis, HIV & HCV/HBV liver cancer &/or liver transplantation	0.5	1.5	7	5	10

#### Calculations

This approach means that once the date and nature of the infection and the clinical banding is known, a formula can be used to calculate the award due for a typical pattern of care needs. This can be paid without the need for further evidence, thereby reducing delay.

Where people's care needs have exceeded the typical pattern, a supplementary route for additional payments should be available to cover the actual costs after assessment by the Infected Blood Compensation Authority. There may also be a need for adjustment for those in the supplementary health impact groups described above, depending on the evidence of care needs.

Care Awards should be paid to the estates of those infected persons who are deceased to cover the cost of care between the date of infection and death. For those living with wrongful infections a choice should be available between a lump sum to cover the anticipated costs over their expected years of life or periodical payments. Care awards can be paid directly to affected persons on the request of an infected person or their estate representative.



## **Financial Loss Awards**

Courts will award compensation for the financial losses suffered by victims as a result of the wrongful injuries through loss of earnings. This usually requires detailed individual assessments and is expensive and slow to assess. It would also disadvantage those who were not in the workforce at the time of infection who will find it difficult to prove loss of earnings. Sir Brian Langstaff and Sir Robert Francis envisaged that actual financial loss would be individually assessed. However, in order to meet the principle that the Scheme should be set up in a way that enables payments to be made quickly the Expert Group has advised that a tariff formula should be applied to calculate financial loss. This would be based on an annual earnings figure that would be paid for each of the years of working life that have been lost due to the infection, reduced for post-retirement years to be equivalent to a workplace pension. An assumption would be made about the impact of the virus on earning capacity for each of the severity bands, adjusted where advances in treatment mean that those infected more recently may have had less severe financial losses than those infected longer ago.

The financial loss formula for people who were infected would take the assumed baseline salary and multiply it by the number of years when financial loss was suffered. For those who are deceased, this would be from infection to death. For living beneficiaries who wish to take a lump sum payment, this would be from the date of infection to their "healthy" life expectancy. A lump sum supplement should be added to all annual payments of, say £12,500, to cover other items such as increased insurance costs, additional transport costs. These are likely to arise from having been infected and are not significantly altered by the impact of the infection.

People will not always have been completely excluded from work by their infections. The clinical experts have advised on the likely impacts on earning potential of each of the severity bands.

They have also advised on when new treatments will be likely to have reduced the loss of earning potential, taking into account the likelihood that the NHS will not have made them widely available immediately. This element of the advice from the Expert Group was revised to take into account feedback from the Engagement Meetings that many victims of the infected blood scandal did not in fact experience the benefits that the general population gained.

The baseline earnings assumption



Sir Robert Francis suggested that the calculation of financial loss awards should provide people who were wrongfully infected with compensation based on the assumption that they would have earned 5% more than an average salary if they had not been infected. This would be paid net of tax and national insurance.

The Expert Group has adopted this as a baseline, although it noted that there might also be a case for adopting the median without the uplift, as implied in para 9.95 of the Compensation Study: 'Where the relevant category of employment for that applicant cannot be shown, or working out a probable career path is speculative or disproportionately complex, to assess there should be a presumption that the applicant has lost income equivalent to the national median earnings.'

Adopting this baseline would provide greater compensation than a court would award to those who worked part-time hours or in insecure jobs because it assumes the same rate of remuneration during every year of working age. The Expert Group advises that this is a reasonable approach to deliver the simplicity and speed of provision that the Government wishes to see.

#### Higher earners

In the compensation study, Sir Robert Francis recommended that those who could prove actual loss of earnings at a higher level, that was caused by an inability to work due to the infection or its consequences, should be able to recover more. He recognised that this might be difficult to show and suggested that where there was no evidence, average earnings for a class of employment might be used using figures from the Office of National Statistics Annual Survey of Hours and Earnings (SRF 9.95). The Expert Group advises against this complication of the Scheme, noting that it could be said to disadvantage groups in irregular employment or out of paid employment. It advises that compensation for actual loss of earnings should be available via a supplementary route but that the core route should retain the single earnings rate. We note that an individualised assessment would need to take into account years when earnings were below the average (plus 5%) as well as those years when earnings were greater.

#### Assessing the impact of illness

The Expert Group recommends a formula based on this approach that also takes into account that the impact on a person's ability to work will vary over time. There will be stages in a person's life where they cannot work at all because of their infection. At other times, possibly for a long period, their ability to do work will be impaired. The clinical experts have estimated the degree of impairment, taking into account that this would have



sometimes been greater prior to improvements in available treatment than it would be in the present day.

#### Financial loss for people infected with Hepatitis

The prevailing narrative around liver disease amongst experts is that it is largely asymptomatic and that individuals living with various forms of liver disease do not experience symptoms until the advanced stages; usually when cirrhosis develops. There is increasing recognition, however, that this is rather a simplistic point of view. Increasing numbers of studies that have investigated the impact in particular of HCV infection in people living with the virus have demonstrated that there is impairment in quality of life compared to healthy individuals. This especially manifests as fatigue as well as a phenomenon called 'brain fog'. These symptoms are often not related to the degree of liver scarring. Based on this, it is indeed probable that individuals infected with HCV may well have experienced difficulties in employment both in terms of their ability to persist at jobs and to take on more demanding work. There is some evidence that curing individuals of HCV infection can reverse many but not all of these symptoms. This is why there is recognition in the table above of financial loss even for the more 'mild' stages of HCV infection with a higher percentage being awarded to those who lived with the virus prior to the widespread availability of modern directly acting antiviral therapy. The onset of cirrhosis is undeniably associated with further impairments in the quality of life in persons living with HCV and this is recognised in the uplift to the financial loss award once individuals progress to this stage. Once decompensated cirrhosis occurs or individuals are diagnosed with Hepatocellular carcinoma or undergo transplantation, then it is safe to assume that their ability to work will be severely impaired and that financial loss will be 100%.

Although the data for persons living with HBV is much less mature, preliminary studies have identified impairment in the quality of life regardless of the stage of liver disease. In light of this, the categories of financial loss are equivalent to those with HCV. For those infected with HBV who die in the acute phase of their infection, there will be a short period of financial loss and it is proposed that a flat rate of £17,500 is used for people in this category.

The ability of claimants to work may have been strongly influenced by the time frame in which infections started and therefore the treatments available to patients. A person who acquired an infection in the 2000s is likely to have a different outcome and options to manage impact on working ability compared to an individual who acquired an infection in the 1970s. The assumptions about the reductions of earning capacity that are made in calculating financial loss should be adjusted accordingly.

Hepatitis C: Effective curative treatment for HCV was widely available from 2016 onwards - these directly acting antiviral agents (DAAs) had minimal side effects (by enlarge) and were



very efficacious even enabling a subset of patients with decompensated cirrhosis to improve back to compensated disease.

*Hepatitis B*: Effective treatment for HBV was widely introduced circa 2008 with the wider availability of Entecavir and Tenofovir. Prior to that, weaker antivirals were widely used (e.g. Lamivudine) from circa 1998 but were associated with the development of resistance making treatments ineffective.

These adjustments should not be applied from the age of 55, given how difficult it is to re-enter the workforce after a period of absence. This point was made strongly in the engagement meetings. The tables below set this out by reference to the date of birth of those who would have reached the age of 55 before the treatment advances became widely available. We hope this strikes an appropriate balance of fairness while remaining simple to administer.



#### Table 1: Hepatitis B- For those born before 1953

Milestones for the introduction of major treatments	Chronic	Cirrhosis	Decompensated cirrhosis, liver cancer
Financial loss	£11,863 (40%)	£23,726 (80%)	£29,657 (100%)

#### Table 2: Hepatitis B- For those born after 1953

Milestones for the introduction of major treatments	Financial Loss Award Based on Disease Progression				
	Chronic	Cirrhosis (assumed 6 years)	Decompensated cirrhosis, liver cancer (assumed 4 years)		
Effective management from 2009	£5,931 (20%)	£17,794 (60%)	£29,657 (100%)		
Infection pre effective treatment (2008 and earlier)	£11,863 (40%)	£23,726 (80%)	£29,657		

#### Table 3: Hepatitis C- For those born before 1961

	Financial Loss Award Based on Disease Progression			
introduction of major treatments	Chronic	Cirrhosis (assumed 6 years)	Decompensated cirrhosis, liver cancer (assumed 4 years)	
Financial loss	£11,863 (40%)	£23,726 (80%)	£29,657 (100%)	



#### Table 4: Hepatitis C-For those born after 1961

Milestones for the introduction of major treatments	Financial Loss Award Based on Disease Progression			
	Chronic	Cirrhosis (assumed 6 years)	Decompensated cirrhosis, liver cancer (assumed 4 years)	
Effective management from 2017	£5,931 (20%)	£17,794 (60%)	£29,657 (100%)	
Infection pre effective treatment (2016 and earlier)	£11,863 (40%)	£23,726 (80%)	£29,657 (100%)	

#### Table 5: Hepatitis co-infection- for those born before 1961

Milestones for the introduction of major treatments	Financial Loss Award Based on Disease Progression			
	Chronic	Cirrhosis (assumed 6 years)	Decompensated cirrhosis, liver cancer (assumed 4 years)	
Financial loss	£11,863 (40%)	£23,726 (80%)	£29,657 (100%)	

#### Table 6: Hepatitis co-infection- for those born after 1961

Milestones for the	Financial Loss Award Based on Disease Progression			
introduction of major treatments	Chronic	Cirrhosis (assumed 6 years)	Decompensated cirrhosis, liver cancer (assumed 4 years)	
Effective management from 2017	£5,931 (20%)	£17,794 (60%)	£29,657 (100%)	
Infection pre	£11,863 (40%)	£23,726 (80%)	£29,657 (100%)	



effective		
treatment (2016		
and earlier)		

*Supplemental route:* Whilst the categories above are designed to enable rapid processing of individual claims, it is recognised that there will be some individuals whose ability to work is fully hampered due to the fatigue they experienced. There is also clear evidence that some individuals experienced HCV or HBV-associated stigma and discrimination in the workplace. In such cases, individuals will be able to apply higher levels of financial award via the supplementary track to bring their financial loss compensation inline with their actual financial loss.

#### Financial Loss for people infected with HIV

HIV is a lifelong infection and the majority of those infected will have experienced progression to advanced symptomatic HIV disease including AIDS conditions and have died as a consequence of their infection.

Early antiretroviral therapies were of low efficacy and were associated with frequent and multiple adverse side effects, further limiting the capacity to work. Even when newer more tolerable treatments became available, exposure to the earlier drugs often resulted in long term sequelae such as painful peripheral neuropathies, lipodystrophy, chronic diarrhoea, pancreatic, liver and bone co-morbidities.

The life-shortening and life-damaging impact of an HIV diagnosis meant that people no longer had the educational, training and work opportunities that someone of their age might reasonably expect. There is also clear evidence of HIV associated stigma and discrimination in the workplace that further compromised the ability of people with HIV to fulfil their working ambitions and potential.

Although effective combination antiretroviral therapy became available in 1998 and will have had an immediate impact on improving survival and reduced risk of disease progression, the majority of those surviving will have continued to experience side effects from medications and symptoms from long term sequelae of severe immunodeficiency impacting on their quality of life and work capacity. It was not till the mid to late 2000s that more tolerable antiretroviral treatments with lower risk of side effects became more routinely available. Even on effective ART, ageing with HIV infection is associated with increased risk of multiple non-AIDS co-morbidities and increased frailty compared to the general population, further affecting their ability to work.

The majority of those infected will have experienced significant psychological ill health including chronic depression and anxiety and adjustment disorders impacting on ability to work and financial planning.



Because all those with HIV will have been impacted by their infection in a way that compromised their working lives, a 100% financial award is appropriate. It may be that the ability to work was compromised prior to diagnosis and treatment and this is reflected by assuming impairment rather than inability to work during the period between infection and diagnosis.

Persons co-infected with HIV and HCV/HBV infections experience a faster progression to severe liver disease when compared to those people with viral hepatitis mono-infection. Even after the availability of effective combination ART for HIV infection, those co-infected with HCV continued to experience a higher mortality from liver disease through the 2000s. There was a higher risk of treatment failure with the earlier HCV treatments in HIV co-infected patients. In addition, their access to potentially life saving liver transplants was curtailed. The direct consequences of HIV across the entire course of infection on physical and mental health compromised people's ability to work. For people with co-infections the impact would have been even greater.

Milestones for the	% of full financial award received (approx £29,657 per annum from infection)				
introduction of major treatments	HIV	HIV & HCV/HBV - Acute	HIV & HCV/HBV - Chronic	HIV & HCV/HBV - Cirrhosis	HIV & HCV/HBV - Decompensated cirrhosis
Following diagnosis	100%	100%	100%	100%	100%
Point of infection to diagnosis	50%	62.5%	62.5%	75%	75%

#### HIV and Co-infection of HIV and Hepatitis C or Hepatitis B financial loss award

#### Enhanced impact

Whilst the categories above are designed to enable rapid processing of individual claims, it is recognised that there will be some individuals whose ability to work is fully hampered due to the fatigue they experienced. There is also clear evidence that some individuals experienced HCV or HBV-associated stigma and discrimination in the workplace. In such cases, individuals will be able to apply for higher levels of financial award via the supplementary track to bring their financial loss compensation inline with their actual financial loss.



There may also be a need for adjustment for those in the supplementary health impact groups described above. This is not applicable for people diagnosed as infected with HIV as it is already assumed that they would lose all their earning capacity.



Condition category(1)	Infection	Impact on financial award (2)
1) Severe visual impairment	HIV	HIV: No adjustment applicable as financial loss 100% under core route.
2) Neurological disorders which result in long term severe physical/mobility disability	HIV Hepatitis C	HIV: No adjustment applicable as financial loss 100% under core route. Hepatitis: Financial loss to 100% from diagnosis of the condition regardless of liver disease stage if person can show that they have been unable to work.
3) Neurological disorders which result in long term severe neurocognitive impairment	HIV Hepatitis B Hepatitis C	<ul> <li><u>HIV:</u> No adjustment applicable as financial loss 100% under core route.</li> <li><u>Hepatitis</u></li> <li>Hepatitis B/C Decompensated cirrhosis: financial loss already 100% for longer than 4 years</li> </ul>
4) Severe psychiatric disorder	HIV Hepatitis B Hepatitis C	HIV: No adjustment applicable as financial loss 100% under core route. <u>Hepatitis</u> : financial loss based on psychiatric assessment
5) Other Hepatitis C associated extra hepatic disorders resulting in long term severe disability.	Hepatitis C Hepatitis B	<u>Hepatitis C</u> Financial loss: Match to cirrhosis band.
6) End stage kidney disease requiring renal replacement	HIV Hepatitis B Hepatitis C	<u>HIV:</u> No adjustment applicable as financial loss 100% under core route. <u>Hepatitis</u>



	Duration of dialysis treatment: 100% financial loss.
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#### Lifetime impacts

Many people who have been wrongfully infected will have the length of their working life reduced and this is a loss that must be compensated. The Expert Group proposes that for those who are deceased, awards should include compensation for earnings lost until retirement age based on average annual earnings plus 5% and for financial loss between their retirement and their death at half that rate (as would be typical for defined benefit retirement schemes). Compensation for financial losses up to the date of death would be paid to the estate of the deceased. Where there are dependants of the deceased, they should receive further compensation related to lost earnings between death and the date when the death of the deceased might have been expected in the absence of the wrongful infection. This should be paid directly to the dependants. For those living with wrongful infections a choice should be available between a lump sum to cover the anticipated financial loss during the remaining expected years of life or periodical payments.

## Awards for People with Acute Hepatitis B/Hepatitis C Infection

Not all hepatitis infections become chronic. For Hepatitis C, this means that the impact will last for a shorter period during which earning capacity will have been impaired, with limited care needs and a lesser likelihood of experiencing stigma and other impacts as many of those around the infected person will be unaware that they had been infected. Most of those who suffer an acute Hepatitis B infection that clears without becoming chronic will experience limited effects and some may not even be aware that they had been infected. Sir Brian Langstaff recommended that the scheme should not compensate them. However, a small number of those infected with Hepatitis B die during the acute phase of infection. Sir Brian recognised that they require compensation. The injury, social impact and autonomy awards for these people should match those of the most badly affected HCV and HBV beneficiaries. Care awards reflect the likely intense needs at the end of life. Financial loss is a flat rate calculated on the basis of six months loss of earnings.



Category of Award	Hepatitis C (Acute)	Hepatitis B Acute where the infection resulted in a fatality in the acute period
Injury award	£10,000	£180,000
Social Impact award	£5,000	£50,000
Autonomy award	£10,000	£50,000
Care award	£500	£41,188.49*
Financial Loss award	£12,500	£17,500
Total	£38,000	£338,688.49

\*This figure is to reflect end of life care required for the deceased infected person, discounted by 25% to reflect past care costs.

# Awards for people affected by the wrongful infections of others

Sir Brian Langstaff was clear that awards to people who were affected by the infections of those close to them should be made on the basis that they are entitled to compensation in their own right. The Expert Group considers that this means that the awards should primarily reflect the relationship between the person affected and the person infected rather than which virus or viruses were involved.

#### Injury awards for those affected

We recommend that injury awards should reflect the quantum of damages that would be ordered by courts in respect of psychological damage, distress, anxiety and emotional upset that are likely to have been caused. The Expert Group noted a number of potential comparators for social impact awards, including Judicial College Guidelines on "the indignity, mental suffering, humiliation, distress, or anger caused" for victims in abuse cases (suggested typically to lead to awards ranging £15,000-£25,000).



No specific or additional evidence of such impacts should be required beyond establishing the relationship of the person who is affected to the infected person. The scale for injury awards should vary according to the closeness of the relationship, with the largest awards for partners, reducing for parents who have lost children, then children who have lost parents, with others getting a lower rate.

The Expert Group notes that for most people an acute HCV infection was without enduring consequences (that is it was not in the 'chronic' severity band) and was often not identified at the time. This means that there would have been very limited impact on those around the person who was acutely infected. It therefore recommends that no awards should be payable to those affected by a person who was acutely but not chronically infected. The Expert Group recognises that some people have developed significant post-viral symptoms following infection and such individuals and their partners may choose to present evidence of impact to the Infected Blood Compensation Authority and seek a further supplementary award.

For immediate family members, where the law provides for loss of society or bereavement awards, then this should lead to an increase in injury awards in cases where the infection was likely to have contributed to an early death (cirrhosis, decompensated cirrhosis, liver cancer and HIV).

Bearing these points in mind, the Expert Group initially approached the quantification of injury awards for affected persons by considering values drawn from the middle Vento bands (awards drawn from a court case to reflect injury to feelings) as suggested by Sir Brian Langstaff on pp 44-5 of the Second Interim Report. We took the upper end of the band for partners and the lower end for others. A 20% discount was then applied for overlap between Vento awards with reference values used to set autonomy and social impact awards. We then added a psychological injury award at a flat rate of £10,000 and also a bereavement award in circumstances where it is likely that the virus had or could cause death.

As a cross-check, we then looked at the different approaches under the Fatal Accidents Acts in England, Wales and Northern Ireland and compared them to the Scottish provision for loss of society. In cases where there was or could be a bereavement, we noted that our proposals were for significantly higher awards than under the Fatal Accidents Acts but less generous than the Scottish law would provide. We therefore adjusted the amounts upwards to the mid-point of the estimates that we had been given from Scottish Law firms as likely outcomes in proceedings there.

Our advice at the end of this process is set out in the tables below.



## Injury Awards for affected of HCV/HBV Cirrhosis, HCV/HBV Decompensated cirrhosis, HIV mono-infected and all Co-infected

Heads of Loss	Partner	Parent (loss of a child)	Child (loss of a parent)	Other affected group
Injury Award	£86,000	£65,400	£40,400	£22,000



#### Injury Awards for affected of HCV/HBV chronic

Heads of Loss	Partner	Parent or Child	Other affected group
Injury Award	£34,000	£20,000	£20,000

This approach may lead to the scheme paying more compensation when there are more affected persons in relation to a deceased infected persons. In cases of larger families this will provide greater compensation than would be payable under the Fatal Accidents Acts in England, Wales and Northern Ireland, where awards are shared. We believe this is fairer and closer to the intention of the Second Interim Report than would be achieved by a closer mimicking of that legislation.

#### Social Impact awards for those affected

The Expert Group recommends that there should be a flat rate of social impact award as all those close to people who are infected will have been affected by societal stigma without variation by virus, disease condition or relationship. We have understood the social impact award to reflect the stigma experienced as a result of external pressures. It would therefore be the fact of connection as perceived by outsiders rather than the closeness of that connection that would generate attention. For that reason, once people are within the scope of the 'affected' category, then we believe it makes sense to give them the flat rate of social impact award.

As Sir Robert Francis noted, awards under this head should be proportionate to those made to people who were infected as it would be inappropriate for those affected to receive more than they did. The recommendation is that the Social Impact award for affected persons should therefore be proportionate to the award for persons with chronic infections, bearing in mind that there may be a number of persons 'affected' in relation to a single infected person. These awards are not shared within the family as would be the case under the fatal Accidents legislation. It would be inappropriate for them to cumulatively be awarded more than the infected person but this is possible as each affected person receives an award in their own right. We suggest the figure of £8k as the lowest rate for infected persons recommended in the Compensation Study, discounted by 20% to reflect some overlap with the Vento awards, which had already been factored into injury awards.



Heads of Loss	Partner	Parent	Child	Other affected group
Social Impact Award	£8,000	£8,000	£8,000	£8,000

#### Autonomy Awards for those affected

It is suggested that autonomy awards for those affected by another's wrongful infection broadly reflect court awards for the intrusion into privacy. These awards should be made to the partners, parents and children of the infected person. For partners, we advise that a comparator of judicial awards for very serious intrusions is adopted. For parents and children, it is advised that the benchmark should be the mid-point of awards that have been made as aggravated damages in privacy cases. This leads to the following figures.

Heads of Loss	Partner	Parent	Child	Other affected group
Autonomy Award	£16,000	£6,600	£6,600	£0

#### Care Awards for those affected

The Expert Group advises that care costs are part of the awards to infected persons rather than those who are affected. These costs are related to the services required by the person who is infected. They are calculated by reference to their needs. They should normally be paid directly to them (or if they have died to their estates). It will be for the infected person or those administering the estate of the deceased to choose how to divide the funds between those who provided the care in order to provide fair recompense. It would not be appropriate for the compensation scheme to take away the control from the infected person. There would therefore not be separate care awards for those who are affected by the wrongful infection of others. Rather, the costs incurred by them, and which Sir Brian Langstaff recognises must be met by the compensation scheme, would be reflected in the care awards for the persons who are infected. The Compensation Authority could be asked by beneficiaries to pay awards directly to others on their behalf.



#### Financial Loss for dependants

Under Fatal Accident Acts dependants are able to claim a variety of dependency awards (although of varying amounts). These cover both the loss of the financial earning power of the deceased and loss of services. In litigation cases all dependants should come forward as one claim within 3 years of the death so apportionment could be agreed with a known cohort of dependants/affected. Should the compensation scheme wish to pay the affected dependants of people who are deceased directly there would be a need to understand the size of the group of people who are dependent affected claimants. If this approach were adopted, it would therefore probably require that a deadline is set for all those who are affected to come forward before financial loss awards to the deceased person could be paid out.

Financial loss awards should be paid to dependents of an eligible deceased person in order to compensate for the support that they will have lost due to the death. These should reflect the deceased's lost earnings between the actual and expected date of death, discounted by 25% to recognise that some of those earnings would have been spent by the deceased person on their own account. This would apply during the dependency and be derived from the formula explained above. As noted above, compensation for financial losses up to the date of death would have been paid to the estate.

Where an infected person is deceased, past financial loss from the point of infection to death is paid to the estates of the deceased person. Financial loss from the point of death to the estimated healthy life expectancy age of the deceased is paid to the affected dependents<sup>1</sup> registered with the Scheme. Healthy life expectancy is determined using the Office for National Statistics Expectations of Life tables and where necessary the Ogden Tables.<sup>2</sup>

To enable bereaved affected dependants to receive Financial Loss awards independent of when other affected persons apply for compensation, the Scheme proposes a tariff-based approach to assess the financial loss of dependants. The Scheme proposal assigns fixed proportions of financial loss to affected individuals considered most likely to have a dependency, i.e. partners and children under the age of 18 at the time of the infected person's death. Partners or children under the age of 18 at the time of the infected person's death would not need to provide evidence of a dependency on the infected person.

Starting from the net median UK earnings + 5% described above, we propose the Scheme assigns proportions of financial loss to bereaved affected persons. We propose the scheme first deducts 25% to reflect the expenditure that the infected person is assumed to have spent on themselves. Proportions of the remaining financial loss would then be assigned to

<sup>&</sup>lt;sup>1</sup> Dependant as defined in the Fatal Accidents Act 1976

<sup>&</sup>lt;sup>2</sup>https://www.gov.uk/government/publications/ogden-tables-actuarial-compensation-tables-for-injury-an d-death



bereaved affected persons. The proportions assigned are 75% for a partner and 25% for a child. A child who has lost both parents to infected blood related infections can claim both a child's and partner's tariff rate i.e. 100%.

Proposed tariff rates for Financial Loss awards to bereaved affected persons, dependent on circumstances are therefore as follows:

- Partner of an infected person at time of death: £16,682 per annum.
- Child under 18 at the time of the infected person's death: £5,561 per annum, until the age of 18.
- Child under 18 who has lost both parents to infected blood related infections: £22,243 per annum, until the age of 18.

Other bereaved affected persons (e.g. parents or children over the age of 18 with a disability) may be eligible to receive Financial Loss awards but they would be required to provide evidence of dependency on the infected person at the time of death. This would be done via the Supplementary Route.

## Beneficiaries with multiple claims

Where a recipient has multiple loved ones who have been infected, multiple injury awards will be made to reflect the scale of their loss. A single Autonomy award and Social Impact award will be made. The issuing of Financial Loss and Care awards will depend on individual circumstances. Where a person is eligible as both an infected and an affected person, the person will receive all awards due to an infected person, as well as (an) additional Injury award(s) as an affected person. A single Autonomy award and Social Impact award will be made. The issuing of Financial Loss and Care awards will depend on individual circumstances.

Heads of Loss	Award availability applicants with multiple affected awards	Award availability to applicant who are both infected and affected
Injury Award	Additional injury awards available.	Additional affected award available beyond infected award. Multiple awards available per the number of associated infected loved ones.
Social Impact	One off award per affected	No additional award beyond infected



Award	applicant	award.
Autonomy Award	One off award per affected applicant.	No additional award beyond infected award.
Financial loss Award	Dependant on whether future financial losses have been paid to the infected.	Dependant on whether future financial losses have been paid to the infected.
Care Award	Only available on the request of the infected person.	Only available on the request of the infected person.



## Clarifications of eligibility criteria

Sir Brian Langstaff set out the eligibility categories for the new compensation scheme. The Expert Group has advised on clarifications required to ensure that in practice the scheme will operate in accordance with the principles that have been set out above.

### Eligibility for people wrongfully infected by contaminated blood or other products.

All those registered with current or previous support schemes will be eligible. Some further information may be requested to enable the calculation of their compensation but not to assess whether or not they are eligible. The Expert Group has identified relevant clinical parameters that should be recorded in medical records that show disease progression. It has also identified imaging and biopsy results that can be used to assess severity banding.

For those persons infected but not previously accepted on to a scheme, evidence of infection and receipt of a contaminated product will be needed (akin to what has been required for acceptance on to the current Infected Blood Schemes). This will include all those eligible because of HBV infection as that has not previously been covered by the Support Schemes.

In determining eligibility for new applicants, the Expert Group acknowledges there is a balance between the need to provide supportive medical evidence, that may be difficult to obtain or be considered intrusive, and the need to have sufficient information to be able to assess and exclude claims from applicants who acquired their infection by other means. In addition to clinical confirmation of infection and the applicant's personal narrative (or in the case of an application on behalf of a deceased individual the applicant narrative), the Expert Group sets out below types of supportive evidence that could be considered in determining eligibility. The quality, extent and detail of this evidence would need to be assessed by the Infected Blood Compensation Authority vetting processes.

The Expert Group has identified relevant clinical markers of infection that ought to be documented in and accessible from medical records. The Expert Group recommends that mention of HIV, HCV and HBV on a death certificate should suffice as evidence of infection (although its absence would not be taken to exclude it). Further clarification and examples might emerge as the compensation scheme becomes operational. Where there is an absence of clear medical records of receipt of a contaminated product, the Expert Group recommends that the likelihood of receipt of a blood product could be inferred, for example from major surgical procedures, even if it is not specifically recorded in notes. The Expert



Group confirms the finding of Sir Brian Langstaff that there should be no rigid cut-off that precludes claims in relation to receipt of products after any specific dates. However, this may make the causal link between their receipt and the infection unlikely and requires further inquiry.

#### **Direct Infections**

This category includes those who have been directly infected:

- with HIV through the use of NHS-supplied blood, blood products and/or tissue;
- with an acute or chronic case of Hepatitis C through the use of NHS-supplied blood, blood products and/or tissue;
- with a chronic case (more than 6 months) of Hepatitis B through the use of NHS-supplied blood, blood products and/or tissue;
- with an acute case (less than 6 months) of Hepatitis B through the use of NHS-supplied blood, blood products and/or tissue <u>and</u> died as a result of the Hepatitis B infection during the acute period.

Eligibility category	Description of entry application	Evidence
Established infected individuals	People registered on a current UK infected blood support scheme or predecessor Alliance House Organisation Scheme would automatically be considered eligible for compensation. There may be requirements for further evidence for infection severity assessment.	Current support scheme registration details.
Infections pre introduction of effective screening	People with infections who received one or more blood transfusions or blood products known to be capable of transmitting one or more of the relevant pathogens before effective screening for infection/contamination was introduced. This group would be asked to provide minimal evidence to prove infection cause (evidence of infection and relevant treatment). The dates recommended for this are:	<ul> <li>Essential (provided by all new applicants) <ol> <li>Personal narrative</li> </ol> </li> <li>Documentary evidence of a positive blood test for a blood borne virus (e.g a laboratory report showing HCV antibody +ve and/or HBsAg positive and/or HIV positive), plus details of any previous negative tests and dates.</li> </ul>



i. HIV infection - before November 1985.

ii. Hepatitis C infection - before September 1991.

iii. Hepatitis B infection - before December 1972.

# Additional (suggested examples of supporting evidence)

- Evidence from medical records that blood or a blood product had been administered at a time when contamination was likely
- 2. Evidence from **medical records** of a procedure likely to have resulted in administration of blood or blood product at a time when contamination was likely.

3. Statement(s) signed by a registered medical professional that they have seen evidence of either: a) administration of blood or blood products at a time when contamination was likely and or b) a procedure highly likely to have led to a transfusion of blood or blood products that took place during the period of 'high risk' e.g. a discharge summary detailing an operation that, in the opinion of the medical professional would have been likely to have resulted in a blood transfusion.

3. Statement(s) signed by a registered medical professional that following an assessment and review of available information, they judge the administration of blood or blood products to be the most likely route of infection. The medical professional should be someone who has been responsible for aspects of the applicant's medical care for at least 1-2 years and knows the applicant well.



		<b>Physical evidence</b> (e.g. an operation scar) of such a procedure. Evidence of childbirth would not alone automatically lead to confirmation of eligibility.
Infections after the introduction of effective screening	People infected who received one or more blood transfusions or blood products known to be capable of transmitting one or more of the relevant pathogens after effective screening for infection/contamination was introduced. The burden of proof would increase for people infected after effective screening for infection/contamination was introduced including need for a medical certification of causal assessment.	<ul> <li>Essential (provided by all new applicants)</li> <li>1. Personal narrative</li> <li>2. Documentary evidence of a positive blood test for a blood borne virus (e.g a laboratory report showing HCV antibody positive and/or HBsAg positive and/or HBsAg positive and/or HIV positive). Plus details of any previous negative tests and dates.</li> </ul>
		<ul> <li>Additional (suggested examples of supporting evidence)</li> <li>1. Evidence from medical records that blood or a blood product had been administered at a time when contamination was</li> </ul>
		<ul> <li>possible</li> <li>2. Evidence from medical records of a procedure likely to have resulted in administration of blood or blood products at a time when contamination was possible.</li> </ul>
		3. Statement(s) signed by a registered medical professional that they have seen evidence of either a) administration of blood or blood products at a time when contamination was possible and



a procedure highly likely to led to a transfusion of d or blood products e.g. a harge summary detailing an ation that, in the opinion of nedical professional would been likely to have resulted blood transfusion. ement(s) signed by a ical professional that wing an assessment and w of available information, judge the administration of d or blood products to be nost likely route of infection. medical professional should been who has been onsible for aspects of the cant''s routine medical care t least 1-2 years and knows applicant well.
rtificate- cause of death ce HIV, HCV or HBV and / condition associated with an AIDS defining condition once of either does not ication. tary evidence of a <b>positive</b> <b>or a blood borne virus</b> (e.g report showing HCV e and/or HBsAg positive bositive). Plus details of any gative tests and dates <b>it narrative</b> from <b>medical records</b> that
report e and/o ositive gative f <b>nt narr</b> a



	administered at a time when contamination was likely 5.Evidence from medical records of a procedure likely to have resulted in administration of blood or blood products at a time when contamination was likely.
	6. Statement signed by a registered medical professional that they have seen evidence of: a) administration of blood or blood products at a time when contamination was likely and or b) a procedure highly likely to have led to a transfusion of blood or blood products that took place during the period of 'high risk' e.g. a discharge summary detailing an operation that, in the opinion of the medical professional would have been likely to have resulted in a blood transfusion.

#### Indirect Infections

A person who is or was indirectly infected when there has been

- transmission of infection from a person who is or was directly infected (e.g. a person infected by their partner); or
- transmission of infection, in defined circumstances, from another person who was infected by someone who was directly infected (e.g. a child infected by their mother who was infected by her partner).

This will not be easy to assess and the clinical experts have provided the following summary of the available evidence.

**HIV**: Mother to child (vertical) transmission of HIV can happen during pregnancy, during childbirth and through breast milk. Most mother to child infections happen during delivery and through breast feeding. Without anti-retroviral treatment and intervention between 25 and 30% of babies born to women living with HIV will acquire HIV. The risk of transmission is related to the mother's viral load - the higher the viral load the greater the risk. With effective treatment for the mother, appropriate interventions during delivery and with replacement feeding the likelihood of transmission is less than 1%.



**HCV**: Mother to child transmission of HCV occurs in 4-6% of viraemic mothers. The timing of transmission is not clear and may be either in utero or during delivery. Mother to child transmission post delivery is very rare and breast feeding and close maternal contact are not recognised risk factors, albeit occasional transmission events by, for example, bleeding nipples may occur. Co-infection with HIV increases the risk of materno-fetal transmission, particularly in the context of high HIV viral loads. Children born to HCV infected mothers should be tested for infection during the first few months when antibodies to the virus will be present (passive transfer from the mother) but only infected children will have detectable HCV RNA. A repeat test at 12-18 months of age is recommended when maternal antibodies will have disappeared in the non-infected and at this time point a positive antibody and RNA test is confirmation of infection. Treatment with current agents is not approved for children under the age of 3 and therefore the family must wait until the child is at least 3 years old before therapy can be given. Previous treatments, interferon and ribavirin, were usually only given to older children, typically over the age of 10, although practice varied. Fathers are not believed to infect their children.

**HBV**: Mother to child transmission (MTCT) is thought to be the most common route of HBV infection worldwide. The risks of transmission mainly depend on the levels of virus (HBV DNA) in the mother. The administration of hepatitis B immunoglobulin (HBIG) at birth in high risk pregnancies as well as timely birth dose vaccination and completion of the full HBV vaccination regimen significantly reduces MTCT.

In addition, antiviral therapy is recommended in the third trimester for all high risk mothers (HBV DNA >200,000 IU/ml) and has been shown to significantly reduce MTCT risk. In the absence of any preventative measures, the risk of transmission of HBV to the infants born to HBe antigen positive mothers is believed to be as high as 70-90%. With preventative measures the risks of an e antigen positive mother transmitting HBV to her child is reduced to 8-30%. Testing of infants for Hepatitis B surface antigen (HBsAg) and HBV DNA is only accurate after 6 months of birth as transient positivity in these tests can occur at the time of birth but do not necessarily indicate the establishment of chronic infection. It is important to note that routine antenatal testing for hepatitis B was introduced in the UK in 2000 and so since that date the chances of vertical transmission of HBV for children born in the UK has been significantly mitigated. The various Public Health bodies in the UK provide enhanced surveillance of maternal testing of HBV as well as preventative measures taken for confirmed cases to reduce transmission.

**HBV transmission** - household transmission is possible, but this is rare. Needlestick injury transmission is very rare, mainly due to at risk individuals being vaccinated against HBV.

HBV is considered a highly infectious virus, thus national and international guidelines recommend vaccination of household contacts to minimise the risk of HBV transmission. The main risk of transmission would be to children (under the age of 4 years), where HBV



infection is more likely to result in a chronic infection. Exposure to older children, young adults and adults would most likely result in an acute self limiting HBV infection.

#### Establishing eligibility as an 'affected' person

Persons who are 'affected' become eligible under Sir Brian's recommendations because of their connection with a person who was eligible for compensation due to their wrongful infection. The Expert Group has recommended definitions of partner, parent, child, sibling to reflect the range of family relationships as well as formal legal status.

It suggests that where eligibility is based on having provided care the threshold should be the same as that used for the 'low' banding of provision that is used to calculate the care awards made to persons who are infected. This marks a difference between occasional support and regular care. The Expert Group has not been able to identify ways to make workable the category of affected individuals who were 'so close that it could reasonably be expected that their mental or physical health would be seriously affected by the consequences of the disease, and who have suffered emotionally, mentally and/or physically as a result'. The summary of our advice on eligibility criteria for affected persons is as follows.

Who is eligible	Eligibility definition
<b>Partner</b> of eligible infected person	Spouses, civil partners and long term cohabitees (for at least one year) of living or deceased eligible infected persons following infection. "Cohabiting partner" means any person who:
	a. Is or was living with the infected person in the same household; and
	b. Has or had been living with the infected person in the same household for at least a continuous period of one year
	c. was living during the whole of that period as the wife or husband or civil partner of the deceased
	Partners who separated from the eligible infected person prior to infection are not eligible for compensation.
Parents of eligible infected person	In addition to biological and adoptive parents, a person is or was "in the position of a parent" to the infected person if they cared for and provided accommodation in their own home (or the home of their
	spouse, partner or cohabitee), to an infected person under the age of



Who is eligible	Eligibility definition
	<ul><li>18, other than for payment (in money or in kind, and whether a salary, allowance or any other form of payment) in circumstances in which the provision of care and accommodation continued or was expected to continue for a period of at least 1 year.</li><li>Potential to include parents of older infected children where the infected</li></ul>
	child is unmarried or lives without a co-habiting partner.
Child of eligible infected person	In additional biological and adopted children, a person is or was "in the position of a child" to the infected person, while under the age of 18, if they were cared for and provided with accommodation by an infected person in their own home (or in the home of the spouse, civil partner or cohabitee of the infected person), in circumstances in which the provision of care and accommodation continued or was expected to continue for a period of at least 1 year.
<b>Sibling</b> of eligible infected person	Siblings (biological or adopted) and step siblings who lived in the same household as the infected person for a period of at least 2 years after the onset of the infection while under the age of 18, as a family with an eligible infected person.
<b>Carer</b> of eligible infected person	A person is or was a carer to the infected person if they are a person who, without reward or remuneration, has provided the infected person with personal care or support greater than that which they would have been reasonably expected to provide to the infected person but for the infection and its consequences. Such carers will be eligible for compensation in their own right where the provision of care averaged at least 16.5 hours of care per week over a time period of at least 6 months.
Extended family or friend of eligible infected person	Sir Robert Francis's Compensation Study report defines as "Members of the family, or friends of an eligible infected person, whose relationship with them was so close that it could reasonably be expected that their mental or physical health would be seriously affected by the consequences of the disease, and who has in fact suffered a mental or physical injury as a result". The Expert Group has not been able to determine a way to make this practicable under the principles established for its work.





# Conclusion

The Expert Group believes that these recommendations will enable the Infected Blood Compensation Authority to calculate the awards to which people would be entitled under Sir Brian Langstaff's recommendations promptly and without disproportionate requests for complex or inaccessible evidence. Our initial advice had to be provided to the Government without the opportunity to hear directly from those harmed by the contaminated blood scandal. There has been a limited opportunity for us to understand their thoughts on the advice that we offered and the Government's decisions on the proposed Scheme. We have revised a number of our suggestions in the light of the feedback received through the Engagement Events that Sir Robert Francis KC has convened in his capacity as Interim Chair of the Infected Blood Compensation Authority. It will be for the Government to finalise the details of the Scheme and for Parliament to approve it. The Infected Blood Compensation Authority will then take on the vital task of making the payments that victims are entitled to. We hope that some measure of justice will then be achieved, albeit far too late.



# Annex 1: Infected Blood Inquiry Response Expert Group Terms of Reference

### (Membership Updated 17 June 2024)

#### Background

- In 2017, the UK government launched an independent 'Infected Blood Inquiry' (www.infectedbloodinquiry.org.uk) to "examine the circumstances in which men, women and children treated by National Health Services in the United Kingdom were given infected blood and infected blood products in particular since 1970" under the Inquiries Act 2005. This is the largest public inquiry ever carried out in the UK.
- The inquiry is ongoing and is expected to publish its final report on 20 May 2024. To date, there have been two interim reports published. On 29 July 2022, the Chair of the inquiry, Sir Brian Langstaff, published his first interim report on the subject of interim compensation for victims of infected blood. On 17 August 2022, the Government announced that interim payments of £100,000 would be made to infected and bereaved partner beneficiaries of the current infected blood support schemes. These payments were made by October 2022. The government has also accepted the moral case for compensation.
- On 5 April 2023, <u>Sir Brian Langstaff's second interim report</u> was published outlining the Chair's final word on compensation and recommending that work begin immediately to develop a compensation system.
- The Government is currently considering all recommendations made by Sir Brian Langstaff, alongside the 2022 Compensation Framework Study and recommendations made by Sir Robert Francis. <u>Compensation and redress for the</u> <u>victims of infected blood: recommendations for a framework - GOV.UK</u> (www.gov.uk)
- The Cabinet Office (CO) is the sponsor department for the Infected Blood Inquiry and is leading on the Government's response. The CO has been working with other government departments, including the Department of Health and Social Care, HM Treasury, Department for Work and Pensions and Ministry Of Justice [not exhaustive], to consider the recommendations and Government's response.





#### Role and Purpose of the Expert Group

- The Infected Blood Expert Group will provide expert advice (legal and clinical) to the HMG, working with officials to help develop a potential infected blood compensation framework. Advice provided by group members will be based on their area of expertise.
- This includes but is not limited to:
  - Reviewing existing work undertaken by officials on policy and cost analysis;
  - Advising and supporting Government in defining eligible infections and severities;
  - Providing advice and support to Government on potential compensation tariffs for the eligible infected and affected beneficiaries based on infection severities, within the principles agreed by Government;
  - Advising and supporting Government to develop a potential compensation framework within the principles agreed by Government;
- Members of the group are expected to work collaboratively with the Chair, other group members, CO and other cross-government officials and the Minister for the Cabinet Office.
- In addition, the Expert Group is expected to respond to any ad-hoc issues that the CO may require expert advice on during the development of the compensation framework, which might be required at short notice.
- The Expert Group will consider a variety of evidence available to it to formulate its advice. 'Evidence', includes, but is not limited to:
  - The expertise of each group member and any evidence provided to the members (e.g. independent research / findings on infection severities and care requirements, case law on Personal Injury damages);
  - Evidence and modelling provided by CO and/or other government departments or agencies;
  - Evidence and feedback gathered from any separate targeted consultation with infected and affected focus groups;
  - Evidence submitted to and made public by the Inquiry.
- For the avoidance of doubt, 'evidence', as listed above, cannot be provided by the Expert Group inviting a person (or group of people) who is not ordinarily a member of the Expert Group to attend a meeting to provide such evidence.

#### Membership

• The Expert Group will have representation from legal and clinical experts. The full list of expert members can be found at Annex A.



- Direct Ministerial appointed members will be remunerated for their time (to be agreed with each member separately) and reasonable travel and subsistence which will be paid in line with the CO expenses policy.
- For commercially contracted members of the group, costs will be in accordance with the CCS Framework terms and conditions or as agreed in the contract at the time of appointment.

#### The Chair

- The Chair will also be directly appointed by the Minister for the Cabinet Office (MCO).
- The Chair and Expert Group members will nominate a deputy who would act as the Chair in their absence. The deputy Chair will chair meetings and represent the Expert Group in Government led meetings as required.
- Alongside the duties outlined in the Letter of Engagement, the Chair is required to perform the following functions:
  - Harness the full expertise of the Expert Group;
  - Represent the views of the Expert Group;
  - Act impartially and ensure the independence of the Expert Group;
  - Ensure the Expert Group's advice stays within the scope agreed by Cabinet Office;
  - Act as a liaison or 'point person' between the secretariat (Annex B) and the Expert Group;
  - Undertake the role of the Chair in addition to the role of Expert Group members, working with CO and reporting directly to the MCO.

#### **Conflict of Interest and confidentiality**

- Members will have signed a declaration form to alert the secretariat to potential conflicts of interest or concerns.
- All terms under the Letter of Engagement, particularly on confidentiality and use of official information at paragraphs 24-25 are applicable. Members will agree to honour confidentiality in terms of all information and advice provided by the MCO, CO and other government departments. The work of the Expert Group is to be treated with the strictest confidence, and the sensitivity of the discussion and individual members' views must be respected.
- This confidentiality applies to all discussions, papers and/or evidence provided by the MCO, CO and all other government departments, to the Expert Group, to



facilitate the group's role. These papers must not be shared with anyone who is not a member of the Expert Group without consent from the Chair and CO.

- Expert Group members must not discuss or disseminate, in the public domain, any discussion or decision made by the group, CO, MCO and other government departments before, during and after work is completed on the infected blood inquiry.
- Expert Group members conduct in office should be at all times in accordance with the Nolan Report Recommendations, 'The Seven Principles of Public Life' which are attached as Annex C, and such relevant provisions of the <u>Code of</u> <u>Conduct for Board Members of public bodies</u> as could reasonably be applied to the appointment.

#### Governance and secretariat

- The Expert Group will be sponsored by the CO, who will provide a secretariat function for the group. Only the appointed Chair of the Expert Group, members, CO officials and Minister of the Cabinet Office can request a meeting of the Expert Group and commission work as appropriate.
- The Chair of the Expert Group will provide advice to CO and other government departments as appropriate, who will advise their respective Ministers. However, on occasion the Expert Group may be requested to advise Ministers directly and attend other CO led meetings and, in such instances, advance notice and prior agreement with individuals will be sought as applicable.
- The secretariat will ensure timely meeting notifications and dissemination of meeting papers and minutes.

#### **Timing and Meetings**

- The duration of the Expert Group is expected to be time limited, anticipated up to 3 months, with the possibility to extend for a further 6 months. If the Expert Group is extended, agreement from each member will be sought in advance.
- The Chair and Expert Group members will meet weekly on Thursdays for 1 hour or as required to progress work.
- The Expert Group will meet virtually (e.g. Microsoft Teams / Google meet).
   However, face to face meetings will be considered and if agreed, these will be held outside of the government estate, paid for by the CO.
- The quorum for a meeting of the Expert Group shall be two-thirds of members present. At least the Technical Chair or deputy Chair must be present before a meeting can commence.



#### Transparency

- To facilitate transparency in this process, the government may publish on gov.uk:
  - Details of the Panel's Terms of Reference;
  - Membership of the Panel, (as agreed in the first instance the name of the Chair will be published); and
  - Meeting minutes so far as appropriate to disseminate into the public domain.

# Annex A: Membership of the Infected Blood Inquiry Response Expert Group

The Infected Blood Inquiry Response Expert Group is composed of legal and clinical experts, assisted by care specialists and an actuarial expert.

#### Chair: Professor Sir Jonathan Montgomery

Sir Jonathan is an experienced healthcare law scholar who has played a leading role in UK public bioethics for many years, having previously chaired the Human Genetics Commission (2009-2012), the Nuffield Council on Bioethics (2012-2017) and the Health Research Authority (2012-2019). Sir Jonathan is currently the Chair of the Oxford University Hospitals NHS Foundation Trust and Professor of Healthcare Law at University College London. Sir Jonathan received a knighthood in 2019 for his services to bioethics and Healthcare Law.

#### **Clinical experts**

#### Professor Jane Anderson CBE

Consultant physician in HIV Medicine at Homerton Healthcare NHS Foundation Trust. Professor Anderson has been involved in the clinical care of people with HIV since the beginning of the epidemic. Professor Anderson is a past Chair of the British HIV Association. Professor Anderson received a CBE in 2015 for services to HIV Medicine and Sexual Health Research.

#### Dr David Asboe

Consultant and past Clinical Director (2014-2022) of HIV Medicine and Sexual Health, Chelsea and Westminster Hospital, London. Past Chair of the British HIV Association (2013-2016) and past Chair (2019-2022) of the NHS England Clinical Reference Group. Dr Asboe's specialist clinical and research interests are antiretroviral resistance and treatment, sexual health of people living with HIV, and HIV and ageing.

#### Dr Ahmed Elsharkawy

Consultant Transplant Hepatologist at University Hospitals Birmingham with experience in Hepatitis C, Hepatitis B and Hepatitis D and extensive knowledge of liver fibrosis. Dr Elsharkawy is an honorary senior lecturer at the University of Birmingham and a Fellow of



the Royal College of Physicians of London and past Chairman of the British Viral Hepatitis Group. He is the Treasurer of the British Association for the Study of the Liver and a member of the governing board of the European Association for the Study of the Liver.

#### Professor Graham Foster

Professor of Hepatology at Queen Mary University of London and a consultant at Barts Health Trust. Professor Foster has a long-standing interest in the management of chronic viral hepatitis and is a past President of British Association for the Study of The Liver and was previously the NHS England Clinical Lead for Hepatitis C.

#### Professor Patrick Kennedy

Professor of Translational Hepatology at Queen Mary University of London with extensive experience in viral liver disease. Professor Kennedy is an expert advisor for the World Health Organisation, the European Association for the Study of the Liver and he provides expert opinion for the United Kingdom Advisory Panel on blood-borne viruses. Professor Kennedy is the current chair of the British Viral Hepatitis Group and former Lead for the British Association for the Study of the Liver Hepatitis B special interest group.

#### Dr Ian Williams

Former senior clinical academic in the Centre for Clinical Research in Infection and Sexual health, Institute for Global Health at University College London and past honorary consultant physician at Central North West London NHS Trust and University College London Hospitals NHS Trust. Dr Williams has extensive clinical and research experience in HIV medicine since 1987. Dr Williams is a past chair of the British HIV Association and chair of the clinical reference group for HIV for NHS England from 2015 to 2019.

#### Legal experts

Legal advice was provided by Browne Jacobson LLP

#### **Care experts**

The Expert Group received advice from health and care expert witness agencies including:

Apex Health Associates Lisa Barnes & Associates Ltd

#### Actuarial specialist.

#### Professor Alexander McNeil

Professor of Actuarial Science at the University of York since September 2016. Educated at Imperial College London and Cambridge University, he was formerly Assistant Professor in the Department of Mathematics at ETH Zurich and Maxwell Professor of Mathematics in the Department of Actuarial Mathematics and Statistics at Heriot-Watt University. He founded and led the Scottish Financial Risk Academy between 2010 and 2016.





## Annex B: Cabinet Office contacts

Name & responsibility Contact details Health Policy Team Lead REDACTED Expert Group Secretariat Support REDACTED

## Annex C: The Seven Principles of Public Life

Holders of public office should take decisions solely in terms of the public interest. They should not do so in order to gain financial or other material benefits for themselves, their family, or their friends.

Selflessness Holders of public office should act solely in terms of the public interest.

**Integrity** Holders of public office should not place themselves under any financial or other obligation to outside individuals or organisations that might influence them in their performance of their official duties.

**Objectivity** In carrying out public business, including making public appointments, awarding contracts, or recommending individuals for rewards and benefits, holders of public office should make choices on merit.

**Accountability** Holders of public office are accountable for their decisions and actions to the public and must submit themselves to whatever scrutiny is appropriate to their office.

**Openness** Holders of public office should be as open as possible about all the decisions and actions that they take. They should give reasons for their decisions and restrict information only when the wider public interest clearly demands.

**Honesty** Holders of public office have a duty to declare any private interests relating to their public duties and to take steps to resolve any conflicts arising in a way that protects the public interests.

**Leadership** Holders of public office should promote and support these principles by leadership and example.



These principles apply to all aspects of public life. The Committee has set them out for the benefit of all who serve the public in any way. <u>Committee on Standards in Public Life.</u>



# Annex 2: Special Category Criteria used in the Support Schemes

#### Scotland

Category	Criteria
Advanced HCV payments	Chronic Hepatitis C infection and Cirrhosis, Primary liver cancer, B-cell non-Hodgkin's lymphoma, or transplant/waiting list, Renal Disease due to Membranoproliferative Glomerulonephritis (MPGN
Chronic HCV severely affected	Summarised: unable to work full-time due to physical or mental health impact, had to leave better paid job, breakdown of relationship due to mental health problems, mental health problems make it difficult to leave home or socialise
	Linked to examples of physical conditions: type 2 or 3 mixed cryoglobulinaemia, sporadic porphyria cutanea tarda causing photo-sensitivity and blistering, or immune thrombocytopenic purpura with anti-platelet antibodies. in addition, autoimmune diseases, such as coombes positive haemolytic anaemia, idiopathic fibrosing alveolitis of the lung or rheumatoid arthritis, may sometimes be caused or worsened by interferon treatment.
Chronic HCV moderately affected	Some mental health problems due to your HCV or stigma caused by having HCV, but this does not now significantly affect your ability to work, leave your home or manage day to day activities, such as shopping and household maintenance.
	E. You do not have a relationship or children because you had HCV, or felt unable to apply for a promotion at work as a result of your HCV, where there was a good chance that you would have secured the promotion.



#### Northern Ireland

Category	Criteria
HCV stage 1 (enhanced payment)	Need to confirm that due to the impact of HCV and / or its treatment you: A. have autoimmune disease due to or worsened by interferon treatment for hepatitis C (HCV), for example:
	A1 Coombes positive haemolytic anaemia; A2 Idiopathic fibrosing alveolitis of the lung; A3 Rheumatoid arthritis.
	B. have sporadic porphyria cutanea tarda causing photo sensitivity with blistering.
	C. have immune thrombocytopenic purpura.
	D. have type 2 or 3 mixed cryoglobulinaemia which is accompanied by:
	D1 Cerebral Vasculitis; D2 Dermal Vasculitis; D3 Peripheral neuropathy with neuropathic pain.
	E. You are suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to HCV infection as a result of infected blood/ blood products, which affect your ability to perform daily tasks.
	You will need to describe in section 2 what symptoms or conditions you suffer from, when these began and how these symptoms impact on your daily life by preventing you from carrying out normal day to day activities. If you are not sure how your daily life is affected, the information below is included to help you.
	<ul> <li>You may be eligible to receive the HCV stage 1 (enhanced) payment under criterion E if due to the impact of HCV and / or its treatment:</li> <li>You are unable to work or have had to reduce your working hours or change your working pattern due to the impact of physical or mental health problems.</li> <li>You had to leave a better job, role or career due to physical or mental health problems.</li> <li>Your mental health problems have directly resulted in the breakdown of your mental health problems and this is still having airrificent effect.</li> </ul>
	<ul> <li>marriage or other long-term relationship and this is still having significant effect on your life.</li> <li>Your mental health problems frequently make it very difficult for you to leave your home or socialise with other people.</li> <li>You are unable to carry out day to day activities e.g. shopping, cooking,</li> </ul>
	gardening or cleaning.



#### Wales

Category	Criteria
HCV Stage 2	Cirrhosis of the liver, Primary liver cancer, B cell non-Hodgkin's Lymphoma, received/waiting list for a liver transplant.
HCV Stage 1 + enhanced support	Mental health issues or post-traumatic stress who feel these issues are related to their infection from contaminated blood or blood products; and the symptoms are affecting their ability to carry out day to day activities can apply, application form is narrative only.

## England

Category	Criteria
SCM	Evidence needs to show that you have:
	An autoimmune disease which was due to, or worsened by, interferon treatment. This includes coombes positive haemolytic anaemia, idiopathic fibrosing alveolitis of the lung and rheumatoid arthritis; sporadic porphyria cutanea tarda (causing photosensitivity with blistering); immune thrombocytopenic purpura, if autoimmune with antiplatelet antibodies; type 2 or 3 mixed cryoglobulinaemia, if accompanied by cerebral vasculitis, dermal vasculitis or peripheral neuropathy with neuropathic pain; been affected in performing your daily duties due to the infection or the treatment.