Cabinet Office

Minutes of the Infected Blood Inquiry Response Expert Group

May 2025

This document is a record of the minutes prepared for meetings of the Infected Blood Inquiry Response Expert Group between February 2024 and December 2024.

The Infected Blood Inquiry Response Expert Group provided expert advice to inform development of the Infected Blood Compensation Scheme. The Infected Blood Compensation Scheme was fully established in the Infected Blood Compensation Scheme Regulations 2025, which came into force on 31 March 2025. The Expert Group's terms of reference can be found here.

The minutes are a summary of the Expert Group's meetings and topics for discussion.

The Expert Group's formal advice to the Government can be found in their final report, and the addendum to their final report. These minutes should be read in conjunction with the reports. The Government's Infected Blood Compensation Scheme policy paper sets out how the Expert Group's advice has been used to inform the design of the Scheme.

Advice subject to legal privilege has not been included in these minutes [Legal professional privilege protects confidential communications between a professional legal adviser (a solicitor, barrister, or attorney) and his or her clients].

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Meeting of the Infected Blood Expert Group - *1 Feb 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy.

Attendees of the Cabinet Office

Welcome

- The Chair welcomed the Expert Group to the first meeting.
- The Cabinet Office provided detail on how the group would be publicised. It was confirmed that only the Chair's name would be published at this point.

Terms of Reference

- The Group agreed to the Terms of Reference.

Parliamentary Affairs and Legislation

- The Chair provided an update on his recent meeting with the Minister for the Cabinet Office (MCO). MCO was keen to demonstrate to Parliament and the infected blood community that progress was being made. The stages of the Victims and Prisoners Bill and Easter recess would be key moments to provide a public update.
- The Expert Group discussed policy assumptions for the scheme and stakeholder engagement. The Group noted it may be helpful to engage the Hepatitis C Trust and NHSE in stakeholder engagement for Hepatitis C. The Chair said he was collecting information about negative experiences of previous ex-gratia schemes to help consideration of pit-falls to avoid.

ACTION:- The Cabinet Office to add a standing agenda item for the Expert Group on parliamentary affairs and legislation.

- The group discussed engagement with All-Party Parliamentary Groups (APPGs). The work of the APPG on AIDS and HIV was noted. It was noted that representation from the Haemophilia Society for Hepatitis B would be helpful as there is not a big patient group of notable standing for this community.

ACTION:- Cabinet Office to invite the stakeholder engagement lead to a future meeting of the Expert Group.
ACTION:- Members of the Expert Group agreed to share contacts they have within the APPGs
Modelling assumptions

- A discussion was held on the issue of stigma (social impact): It was noted
    - Stigma is not necessarily linked to severity of disease.
    - This does not invalidate the model, but a conversation with lawyers is needed to clarify more on which heads of loss can be varied and which may be fixed according to disease; or where it is not possible to define distinctions between variations and so a flat rate is preferable in the interests of fairness and simplicity.
    - There may be a gender dimension to stigma that should be considered.
    - The group agreed that the impact of stigma on the affected is also important to consider.
    - Once eligibility criteria are confirmed, consideration needs to be given to stigma associated with Hepatitis exposure vs. infection.

Work Programme discussion

- The group noted there were two sets of questions to discuss in future meetings. The first was around timing and confidence of when contaminated blood products were out of the supply. This would be discussed at the following meeting. It was confirmed that infection as a result of transfusions, blood products and tissue transfer were the primary issue. There may be scope for people to claim infection outside of this period, but the Expert Group would need to consider how the process for assessing this could be refined.

- The group plan for severity classifications to be dealt with w/c 12 Feb.

ACTION:- Groups of questions to be circulated, and leads on areas within the EG to begin work on these questions.

- The question of evidence was discussed by the group. The key concern was around identifying evidence that could be a marker of eligibility. Previous schemes asked very intrusive questions of applicants and were criticised as a result. Identifying triggers or indicators that make it likely that a person is eligible would help to reduce the 'burden of proof' for applicants.

Learning from the England Infected Blood Support Scheme (EIBSS) Medical Assessors.

- The Expert Group noted it was important to learn from the medical assessors from EIBSS about the reasons and criteria for approving or rejecting cases. The Cabinet Office confirmed that this could be facilitated. It was agreed it would be most beneficial to review guidance from the medical assessors prior to the discussion.

ACTION:- Cabinet Office to provide guidance from the EIBSS assessors for the Expert Group prior to the next discussion

Any other business

- The Cabinet Office provided an update on progress for the recruitment of additional HIV experts for the Expert Group.

Meeting of the Infected Blood Expert Group - *8 Feb 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome and updates

- Browne Jacobson LLP was welcomed to the Expert Group.
- The Cabinet Office provided an update on the recruitment of additional HIV experts to join the group. Two individuals had been recommended to the Minister of the Cabinet Office and No. 10 for consideration.
- The group discussed the public interest following the Written Ministerial Statement announcing Professor Sir Jonathan Montgomery as chair of the Expert Group.
- The Chair provided an update from his meeting with the Deputy Leader for the House of Lords, taking the Victims and Prisoners Bill through the House of Lords, Earl Howe.
- The group discussed how to establish trust of the community in the momentum of their work. The clinical experts agreed in principle for their names to be released at the conclusion of the Group's work to help build trust with the community.
- The Cabinet Office noted that the contract with Browne Jacobson LLP had been published on contracts finder. The Cabinet Office agreed to review the position on publishing names of the other Expert Group members.

ACTION:- The Cabinet Office to update at the next meeting on publishing names of the Expert Group

Minutes of last meeting

- The group agreed that the official minutes should be a record of the topics of discussion and actions to be taken forward, rather than attributing specific points to individuals.

Discussion on questions identified in the work programme

- The group discussed secondary infections. The group noted the issue of intrusive questions in assessing applications and what was currently asked by the Infected Blood Support Schemes (IBSS).
- The Expert Group discussed cut off dates for the infections. It was noted that there are discrepancies between the cut off dates they had gathered, and the dates in the Inquiry's report. It was noted that the Inquiry provided evidence that people were infected after these dates and that different IBSS have different cut-off dates. The group discussed how applications could be assessed for those whose infections may have occurred after screening was introduced.
- The group discussed the evidence available to show someone has had a blood transfusion or blood products. The Cabinet Office asked whether the Expert Group would consider tissue transfer as a mode of infection. Clinicians requested comparison on IBSS eligibility and the recommendations of the Infected Blood Inquiry.
- The Expert Group noted there is an assumption built into the Inquiry report's recommendations that there are different severity bands for injury levels.

ACTION:- The Cabinet Office to ask IBSS what questions are used for proof of eligibility.
ACTION:- The Cabinet Office to discuss with the Expert Group Chair what data could be requested from IBSS.
ACTION:- The Cabinet Office to share the differences between existing IBSS and the Infected Blood Inquiry's report recommendations on eligibility.
ACTION:- The Expert Group to consider the workability of the bandings outlined in the Inquiry's recommendations.
ACTION:- The Chair of the Expert Group to speak to Sir Robert Francis and discuss severity bandings for the scheme.

Any other business

ACTION:- The Cabinet Office to update the work programme document to include a sheet to capture responses from Expert Group members.
ACTION:- The Expert Group to discuss timelines for work at the next meeting.

Meeting of the Infected Blood Expert Group *-15 Feb 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Minutes and actions from the previous meeting

- The Cabinet Office provided an update on publishing the names of Expert Group members following the announcement of the Chair's appointment. The Cabinet Office had maintained the position on its decision not to publish the Expert Group's names until the conclusion of the Expert Group's work. Expert Group members who had positions with other organisations and wished to inform the Chief Executive Officer or Chair in confidence about their appointment should discuss with the Cabinet Office.
- The Cabinet Office provided an update on Parliamentary activity, which was currently focused on an amendment to the Victims and Prisoners Bill.
- The Chair said he was due to meet with Sir Robert Francis on 29 February.

ACTION:- The Cabinet Office to invite a member of the Victims and Prisoners Bill team and the Infected Blood Inquiry Response stakeholder engagement team to a future Expert Group meeting.

ACTION:- The Expert Group to provide the Chair with questions for his meeting with Sir Robert Francis.

Discussion on severity levels

- There was a discussion around whether a single viral infection should be allocated a flat injury award for a HIV coinfection with hepatitis
- It was clarified that it was being suggested that HIV should be considered as a co-infection in hepatitis cases and vice versa, and that this was a different level of clinical injury award.
- The group discussed heads of loss awards:
    - Injury, social impact, and autonomy awards were likely to be at flat rates. It was understood that the Infected Blood Compensation Framework Study intended to give the affected group 50% of what the infected would receive for social impact and autonomy.
    - One potential model: initial payment for injury, social impact and autonomy awards, and then individual assessments on financial loss payments. Ministers and the community were likely to want a more developed model.
    - The severity of illness was likely to impact the care award.
    - Categorisations for the injury award provided a starting place for the care award, but likely would not affect social impact and autonomy awards.
        - One approach would be three basic categories for financial loss: Extremes which would need to be pursued via the courts, exceptional cases of particular professions, and a third category of average and easily predicted earnings for the majority of beneficiaries.
    - The group discussed stigma:
        - The distinction between external stigma vs. internal stigma was noted.
        - The questions of whether there was a disadvantage to having a flat rate award, and whether this would be satisfying to all were raised. The group thought about the community's thoughts on the idea of equity vs. complexity and personalisation.

ACTION:- The Expert Group to consider the design of a simple set of questions for potential claimants to answer in order for their award level to be determined.

Eligibility - questions for The Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO), questions for EIBSS medical assessors

- SaBTO representative to attend the next Expert Group meeting to inform work on eligibility criteria.

Any other business

- The Cabinet Office confirmed that representatives from SaBTO would attend the next meeting. They will also arrange a meeting with the England Infected Blood Support Schemes (EIBSS) medical assessors. The group agreed to extend the next meeting to one and a half hours.

ACTION:- The group to consider questions to share in advance with EIBSS medical assessors and SaBTO.

Meeting of the Infected Blood Expert Group - *22 Feb 2024 17:30 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy.

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Attendees of NHS Blood and Transplant (NHSBT)

Attendees of Advisory Committee on the Safety of Blood, Tissues, and Organs (SaBTO)

Discussion with SaBTO and NHSBT

- The group discussed the topic of cut-off dates. NHSBT confirmed that testing for the presence of Hepatitis B (HBV) had begun in 1972, which included a test for HBV antibodies alongside other testing methods. Nucleic Acid Testing (NAT) for HBV DNA was introduced in 2009. It was noted that HBV remains the most active infection in blood among the three relevant infections. For Hepatitis C (HCV), testing commenced in 1991, and the Infected Blood Inquiry ("the Inquiry") had evidence of seven cases reported post-1991. NHSBT emphasised that donor selection is as crucial as donor testing and highlighted the many changes that were made to donor selection procedures, particularly regarding HIV. NHSBT noted that cut-off dates for Scotland are likely to be earlier than those for the rest of the UK, although there would not be large disparities in the introduction of testing across different regions.
- The Expert Group inquired about how frozen blood products might impact eligibility dates for infections. It was noted that records regarding this should have been submitted to the Inquiry. The group also raised questions about occult HBV. It was noted that there have been cases in recent years. Claims related to these infections have been pursued for compensation through another route, making them less of a concern for the work of the Expert Group.
- The group concluded that the time periods should indicate when the probability of being infected by blood/blood products was greater than not being infected. It was suggested that data be collected on the number of infections within the specified period, and the possibility of plotting this data to produce a clear evidence line was discussed. NHSBT noted that the Inquiry's statistics expert group would have been provided with testing data.

ACTION:- The Cabinet Office to follow up with NHSBT regarding the relevant witness statement references for evidence NHSBT had provided the Infected Blood Inquiry. So that the Expert Group could look at the evidence on the Infected Blood Inquiry website.

- The group discussed alternative approaches to determining probable infections. It was suggested that cut-off dates could be established based on when the rate of infections declined, rather than solely on the introduction of testing. The Expert Group proposed examining clusters from batches of infections, which would imply that individuals were more likely to have contracted an infection from a product rather than through other behaviours. They asked whether it was possible to identify the specific batches used and the recipients of those products, emphasising that the guidance offered by the Expert Group to the Minister for the Cabinet Office should align with the available evidence.
- NHSBT indicated that they maintained records from donor to issue (hospital) but did not hold information on specific patients who received the products. Hospitals might still have access to individual patient data, but NHSBT would require cooperation from these hospitals to obtain comprehensive information. It was noted that under the Blood Safety and Quality Regulations (BSQR), there is a legal obligation for blood services to retain records of components for 30 years, and hospitals are similarly required to do so. However, the methods for maintaining these records are not standardised and may not be easily accessible, particularly for historical records. Hospitals may lack documentation if patients have been discharged or have passed away, complicating the tracking of donor to recipient. Although NHSBT has a non-destruction order in place due to the Infected Blood Inquiry, tracing data prior to 1995 remains challenging.

- Testing for tissue is conducted differently and is more sensitive, operating under a distinct regulatory framework. SaBTO noted that it is now a legal requirement to report transfusion-transmitted infections. Data pertaining to organs and tissues is often unreliable, with underreporting of infections occurring for various reasons. For organ transplants, testing for HBV and HCV may be carried out post-transplant, reflecting a consideration of the balance of associated risks.
- The group asked whether identifying the index case of a batch could support the assumption that if one individual was infected from a particular batch, it was likely that others had also been infected. NHSBT stated that it is generally straightforward to track down other recipients, as they remain under the care of their clinicians and hospitals for their entire lives.
- The group also discussed a scheme that intentionally uses HCV-infected organs, highlighting the critical importance of recipient knowledge and patient consent during the relevant period. SaBTO has published guidelines regarding consent, underscoring that blood and blood products are not entirely free of risk. A discussion arose regarding whether the point at which testing is introduced also signifies when the risks are better understood, thus allowing patients to be more informed when providing consent. However, there were concerns that this might result in some individuals receiving less compensation based on their consent.

ACTION:- The Cabinet Office was tasked with following up with SaBTO for further information on infections resulting from transplants and any data available.

Parliamentary update

- The Cabinet Office provided an update on the parliamentary progress of the Victims and Prisoners Bill following the insertion of an opposition amendment on infected blood.

Advice to the Minister for the Cabinet Office

ACTION:- The Expert Group Chair to produce a summary of the work the Expert Group has undertaken so far to present to the Minister of Cabinet Office (MCO)

ACTION:- The Expert Group to share questions for the Chair's meeting with MCO

Any other business

- The group clarified a point on HIV and HCV co-infections arising from the 15 February meeting.

Meeting of the Infected Blood Expert Group - *29 Feb 2024 17:30 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Feedback from Sir Robert Francis meeting (29/02)

- The Chair confirmed that Sir Robert Francis was content with the work done by the group. He indicated that he was satisfied with the group using the cut-off dates in either the Infected Blood Inquiry's Compensation Framework Report ("the Compensation Report") or the final Infected Blood Inquiry Report ("the Report"). He was also agreeable to the group exploring alternative dates if evidence for this existed. The Expert Group suggested using the dates in the report while developing a rationale for circumstances in which cases outside of these dates could be accepted onto the scheme. Sir Robert Francis emphasised the importance of designing the scheme with a focus on the core cases.
  Bandings:
- Sir Robert Francis agreed with the suggestion that the severity banding should not impact the amount someone received under the social impact award. The Chair raised the relationship between social impact awards for the infected and affected. The Compensation Report indicated that the affected might receive half of what the infected receive. The social impact award's annual multiplier, as mentioned in the Report, was discussed, and the Chair felt it might be counter-productive. Sir Robert Francis was content with the suggestion that there should be one flat rate payment to recognise the social impact.
- There was a discussion regarding eligibility for affected individuals outside of the family and where to draw the boundary. It was suggested that non-family carers might need to be considered outside of the Scheme. The group discussed the potential evidence of injury that these individuals could bring, noting that it might not be easily quantifiable or evidenced. One possible solution from the Report proposed that the starting point should be the sum of money that should be paid in respect of an infected individual, which would then form a pot for affected people to share. This would create a boundary on the group of people recognised. While this approach could deliver some money quickly, if the sum were to be shared among a number of affected individuals, operational issues could arise, as payments could not be made until information on the numbers of the affected had been gathered. This could result in time spent on bespoke assessments. Sir Robert Francis thought that the Scheme should operate with an algorithmic approach rather than a panel-based assessment for the majority of individuals.
- The Chair and Sir Robert Francis also discussed the issue of the group working with the infected and affected communities, as well as the issue of individuals receiving payments and tax exemptions.

Group discussion on infection severity bandings

- The group agrees that both Hepatitis B (HBV) and Hepatitis C (HCV) caused liver cirrhosis should be under one banding, in order to simplify the bandings.
- Bandings to be used primarily for the injury award, and as a starting point for the care award.
- An update on current modelling is provided:
  - The issue is raised on how categories drawn from the England Infected Blood Support Scheme can be matched to the bandings being formed by the group.
  - For HCV, it is thought that mild and moderate are to be simplified into a single category, and for the severe category or categories, there will be a difference between decompensated cirrhosis and liver cancer.
  - It is confirmed that HIV positive individuals will be considered as one band.
  - The issue of potential banding within co-infection cases is raised.

Advice to Ministers

- The Chair confirmed that he would provide the Minister for the Cabinet Office with an interim update on the Expert Groups work. Initial conclusions of the work were to be set out in mid-March.

Update from Browne Jacobson LLP

- It was confirmed that Browne Jacobson had received interest from social care experts who could provide input to quantify the care awards.

Any other business

- It was confirmed that NHS Business Services Authority (NHSBSA) guidance would be circulated to the group. Group members were asked to provide a list of questions for NHSBSA medical assessors.

Meeting of the Infected Blood Expert Group - *7 Mar 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome

- An update was provided on the impact of the Autumn Budget 2024 on the work of the Cabinet Office policy team and the Expert Group.

Review of Infection Severity Tables (Descriptions and Proportions of Infected per Banding)

An update on the modelling was given:

- It was noted that the proportion across the new Hepatitis C bandings will differ for living and deceased infected individuals, with a larger proportion of deceased individuals in the more severe bandings.
- It was noted that those with Hepatitis C will have been provided curative treatment, halting the progression of their disease. A small proportion (approximately 2%) of those who have received curative treatment may go on to develop liver cancer.
- The group discussed co-infections and the four bandings proposed for individuals with co-infections.
- It was noted that individuals with co-infections have a significantly different experience compared to those with singular infections, and that this experience should be recognised in its own right within the scheme.

Affected Persons Injury Impact Award and Autonomy Awards

- It was discussed whether the approach used in the Windrush Compensation Scheme may be appropriate for use in the Infected Blood Compensation Scheme, as an example of autonomy awards aimed to recognise the collective wrong done to the community. The Autonomy award was intended to serve as a marker for how individuals had been treated, acknowledging that infected blood had a significant and negative impact on their lives.
- It was suggested that the same figure used in the Windrush Compensation Scheme Impact on Life award could be utilised, scaled appropriately for affected claimants.
- The topic of how much compensation should have been allocated to those in the exposed (acute) severity banding was raised, noting that the impact on these individuals would have been relatively minimal compared to those chronically infected. It was also discussed that the autonomy impact for family members of an exposed (acute severity band) individual would have been very low.
- The group deliberated whether this difference should be captured in the autonomy award or in one of the other heads of loss. It was agreed that the affected autonomy award should be at approximately half the rate of Level 5 Windrush Impact on Life awards and directed to those identified as affected most significantly impacted as set out in the reports, such as bereaved partners, parents, and siblings.
- There was agreement to proceed on the assumption that current devolved support schemes would be absorbed by the proposed new compensation scheme, noting this will be a decision for Ministers.

Update from Browne Jacobson LLP

- It was confirmed that care experts were being contacted to advise on the Care award. More information would be provided to the group in due course.

Any other business

- Confirmation was given that a meeting between the group and NHSBSA assessors was being finalised.

Meeting of the Infected Blood Expert Group - discussion with EIBSS medical assessors - *12 Mar 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (chair), Dr Ahmed Elsharkawy, Professor Graham Foster

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

EIBSS medical assessors

Application Patterns and Evidence

- It was noted that there were grades of evidence, and it was rare to obtain original blood transfusion documentation or documentation from haematologists and virologists.
- The issue of incentivising medical professionals was raised, confirming that many people did not have a constant relationship with medical professionals from whom they could request evidence.
- It was suggested that a skilled medical assessment of applications would have been preferable to a list of procedures reviewed by a non-clinical assessor, given the wide variety of circumstances experienced by applicants.
- The current burden of proof on the applicant was discussed as problematic, as they likely did not possess the medical knowledge necessary to present their case effectively and often faced challenges in building their cases independently. Commonly, applicants did not receive medical assistance and may not have included evidence such as virology results or death certificates with their applications. The appeal panel had experienced some success in reviewing additional evidence that applicants obtained from electronic records, but individuals were often unclear on how to retrieve these records.
- The suggestion to grant assessors access to individual data was discussed.
- The experience of the vaccine damage payments scheme was noted, where the responsibility had been placed on the NHSBSA to find the necessary records, leading to numerous complaints due to delays. There was an extra charge for assessors to access records, which typically extended the length of cases.
- Blood transfusion laboratory records existed separately from patient records and might have been available even when patient records were not, although applicants were often unaware of this fact.
- A recommendation was made to the Inquiry that the compensation scheme accept “statements of truth” in support of applications, although concerns regarding the risk of fraud associated with this approach were noted.
- It was mentioned that appeals in Scotland can be heard in person, which might be beneficial for determining an individual’s acceptance into the scheme.
- The value of personal statements, in conjunction with other evidence, for helping assessors determine a case was acknowledged.

- The infected community expressed a preference for long-term support payments rather than a one-off payment. This is particularly relevant given that some infected individuals were quite young, necessitating consideration of the budget for long-term payments. There were also requests for assistance with ongoing palliative care.
- The challenge of balancing recognition payments with long-term care payments was raised.
- Instances were noted where individuals had been questioned by the Department of Work and Pensions or queried regarding Financial Conduct Authority regulations after receiving the initial £100,000 interim payment, indicating a need for advice on how to handle this payment.
- It was suggested that using nursing staff to access records and retrieve evidence might provide a solution, as the relationship between nurses and patients was seen as an untapped resource.
- Although mode of acquisition of virus forms had been filled out by nurses, the obligation of nurses to support the patient and maintain a positive clinical relationship posed potential issues.

- Many applications had been declined due to evidence of behaviour indicating an alternative transmission route, despite individuals also having received a transfusion. It was noted that it was not uncommon for individuals to have multiple potential causes of infection.
- A two-stage assessing route was proposed: first, evidence submission, followed by a statement of truth if evidence cannot be provided. However, it was noted that this might lead to intrusiveness.
- Consideration was given to potential reapplications from individuals who had previously been declined under current support schemes and whether the compensation scheme should have access to previous application data. Data protection issues needed to be addressed.
- Secondary infected individuals typically presented more straightforward cases, as they were only considered once the primary infected individual was accepted.
- Evidence requirements focus on family relationships, childbirth, sexual relationships, and drug use within partnerships. Genotype viral information could aid in confirmation.
- EIBSS recommended that personal statements be included as part of the original application, as they were often requested by assessors due to the scarcity of medical records and had proven more essential than initially thought. While subjective, personal statements were viewed as effective.
- Guidance to individuals on required documents, such as GP notes and transfusion documents, would be beneficial.
- EIBSS expressed that personal statements were less useful for stage 2 evaluations, as solid medical evidence was required to demonstrate that someone had cirrhosis or met other set criteria.
- While genotypes were helpful for secondary infections, they were not considered essential.
- The minutes from the EIBSS Focus Group were noted as a useful resource.

Policy Issues

- On the issue of payment amounts, EIBSS suggested annual inflationary changes to amounts to the Department of Health and Social Care based on the Consumer Price Index, which were invariably approved. It was noted that since bereaved partner annual payments were introduced, there were cases where affected individuals received higher payments compared to infected individuals.
- Current payment structures did not adequately reflect the varying effects of Hepatitis C on different patients, such as the disproportionate impact on those with haemophilia.
- All bereavement payments were uniform and do not account for varying familial relationships, for example, a distant grandchild claiming as a representative of the estate compared to a bereaved spouse.

ACTION:- A follow-up meeting would be arranged with the EIBSS operational manager.

Meeting of the Infected Blood Expert Group - *14 Mar 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy.

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Browne Jacobsen LLP Presented

Advice subject to legal privilege has been removed from this minute.

Any other business

- Cabinet Office confirmed an upcoming meeting with the chair and Minister for the Cabinet Office on 18 March.
- Cabinet Office confirmed a decision on the appointment of further HIV clinical experts was expected early the following week.

ACTION:- The meeting scheduled for 21 March needed to be rearranged.

Meeting between the Expert Group and the NHS Business Services Authority (NHSBSA) *15 Mar 2024 12:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy

Attendees of the Cabinet Office

Attendees of NHSBSA (EIBSS)

Application approach and eligibility criteria of IBSS

- The Expert Group felt an evidence based route should be taken to assessing claims and discussed considerations of potential fraud risks. Approaches to evidence for being eligible for the Infected Blood Support Schemes (IBSS) were discussed, including the concept of a 'statement of truth'.
- At the time of meeting there was no data-sharing between the devolved nations' schemes, so there was a risk of beneficiaries being registered with more than one scheme. Particularly as Scotland accepted people who were resident in Scotland as well as those infected in Scotland. It was noted that following the announcement of interim payments there was a significant increase in applications with many not having sufficient evidence to be accepted onto IBSS. Those who were declined often appealed this decision.
- It was noted that Sir Brian Langstaff had stated that beneficiaries who were accepted by the Alliance House Organisations (AHO) or IBSS should go through to the new compensation scheme without having to be reapproved.
- The experience and knowledge of the IBSS medical assessors and the benefit they could bring to any compensation scheme was noted.
- It was suggested that current IBSS beneficiaries were considered as a cohort in their own right, particularly due to the trust they built with the support schemes. For the affected cohort, there needed to be an index infected person case to whom affected applicants could be linked. It was noted that the challenge would be with bereaved affected individuals where the deceased individual was not registered under a scheme. It was proposed that the arm's-length body needed to have a mechanism to track family trees.
- It was confirmed that the records from AHO schemes existed. These were paper records managed by Skipton Fund who were administered by a solicitor's firm, Russell Cooke. There were challenges in digitising these but it was being considered. It was noted that there might be work required to ensure all files are in order before they were digitised. It was noted that the NHSBSA do not hold data on when an individual was infected, solely whether they were assessed to be eligible.
- It was confirmed that in NHSBSA focus groups, individuals had not suggested any particular figures for compensation. It was suggested that beneficiaries of the proposed compensation scheme should be given a choice between receiving lump sum payments, or instalments to provide long term support, as the NHSBSA focus group heard a variety of positions on this. It was proposed that for all beneficiaries under the new scheme they were likely to receive a lump sum payment but for living individuals it was noted that long-term support was desired by many in the community.
- In terms of ease of user experience with the scheme it should be considered that financial advice should be provided due to the amounts of money that individuals could receive.

Meeting of the Infected Blood Expert Group - *21 Mar 2024 15:30 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy.

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update on MCO Meeting

- The group discussed the need to consider how to effectively present details of the group's advice to Ministers so they were able to outline the scheme to colleagues and the public.
- It was highlighted that rationales must be fully developed in the event of divergence from the Inquiry's recommendations.

ACTION:- The group to discuss how advice should be best structured for Ministers

- Ministers expressed interest in the core Track A supplemented by a Track B approach which recognised that some cases would require more individual adjustment to awards.
- Ministers had indicated a preference to avoid discretionary awards to help ensure it is clear how the scheme will function in practice and operationally administer awards.

Stakeholder Outreach Programme

The group discussed the community's reception to the news of the Minister for Cabinet Office (MCO) outreach programme:

- A short narrative explaining the current work on the compensation scheme was being created to help reassure community members on progress of the work.
- The Expert Group advised the Cabinet Office may wish to engage with the British Liver Trust, as such organisations frequently connected with the infected and affected communities.
- The group advised that approaching umbrella community groups could help reach a broader segment of the community, particularly concerning representation for patients with Hepatitis B.
- The group advised that the purpose of the ministerial meetings with stakeholders must be clearly articulated to the invited infected and affected individuals. The framing of the meeting and the balance of discussion were crucial to manage expectations.
- The group noted an interest in testing eligibility criteria during these meetings. The group were invited to raise topics MCO may wish to discuss at outreach meetings. The group noted MCO may be asked about the identity of the Judge chairing the scheme and the timelines for payments.
- The group noted that the issue of casefinding might be raised at engagement events, and it would be beneficial to have a prepared statement from NHS England, particularly in regards to Hepatitis C. The group noted that the interaction between current Infected Blood Support Schemes (IBSS) and the compensation was likely to be raised.
- Considerations regarding venues for community outreach were discussed, emphasising that selected locations should not have past connections to contaminated blood products or their usage.

ACTION:- The Stakeholder team would meet with the relevant Expert Group members to further develop their engagement plans, particularly with individuals in the HIV community.

- It was suggested that the Expert Group may meet with the Minister to explore issues raised following engagement.

Any other business

- The group discussed modelling for the care award, focusing particularly on the number of years of care to attach to each severity band.

ACTION:- The group to continue discussions regarding assumptions of years for the care award to inform indicative modelling

Meeting of the Infected Blood Expert Group - *28 Mar 2024 17:00 GMT*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster.

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update from Meeting with Horizon compensation scheme and Lessons Learned

- It was noted that the meeting with representatives of the Horizon compensation scheme confirmed that, broadly, the group's work aligns with precedence.
- The group discussed the value of records from legacy schemes in assisting an arm's-length body to deliver compensation where an infected person had died or for affected persons.
- It was suggested that the Hepatitis C Trust may be able to provide advice on data sources regarding the prevalence of Hepatitis C in the UK and the number of individuals who might be unknowingly infected. It was noted that it was unlikely there were a significant number of cases involving unknown infections of Hepatitis C and HIV.

Update on Advice to PM, Latest Work, and New Experts

- It was confirmed that the advice was currently with the Prime Minister, and that policy officials were awaiting further questions after which further instructions will follow.
- It was confirmed that additional meetings would be scheduled to discuss particular issues.

ACTION:- The group was to be provided with outstanding questions and issues for their consideration over the Easter period.

Any other business

- It was confirmed that the meeting scheduled for 4 April was to be cancelled.

Meeting of the Infected Blood Expert Group - *11 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr Ian Williams, Professor Alexander McNeil, Professor Jane Anderson, Dr David Asboe

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome and Introductions

- It was confirmed that social care experts were in the process of being onboarded.
- No requests had been received for further information from the expert group following the submission of advice to Number 10. The group discussed publication of the Expert Group membership.

Infected Awards

(i) Single Acute or Exposed HCV Infection

ACTION:- The financial loss award for those with acute or exposed Hepatitis C (HCV) infections would be adjusted.

(ii) Single Chronic Cases of Hepatitis C(HCV) /Hepatitis B (HBV) /HIV

- The issue of the award compared to those with liver cirrhosis and other life-threatening illnesses was raised.
- The group discussed the various effects of social impact for these diseases and how this could be quantified fairly.
- It was noted that since the focus for this award was on non-clinical factors, severity was broadly equivalent despite differing experiences. It was confirmed that all individuals claiming for HIV infection would be categorised as 'severe'.
- This differs from the bandings for HCV and HBV, and it was important that the rationale for this distinction is well-constructed. It was argued that the payment difference for injury awards between liver cirrhosis and decompensated liver under HCV/HBV should be higher.
- The development of decompensated disease from cirrhosis needed to be considered as having a significantly greater negative impact, warranting a clearer distinction.
- It was noted that there should be a step from decompensated liver disease to HIV infection.
- The current working assumptions for HIV/Hepatitis co-infections were that the HIV co-infection was the primary infection, with uplifts based on the level of HCV/HBV infection (e.g., acute, cirrhosis, decompensated disease, etc.).
- The group agreed that for co-infected individuals, the social impact and autonomy award should be increased from the single infection rates.

Care Awards

- It was noted that there was no 'low' level of care for patients with decompensated cirrhosis.
- The entire patient journey had been accounted for, indicating that patients were likely to have received low and moderate levels of care prior to developing decompensated cirrhosis.
- It was noted that moderate care for chronic HBV/HCV infection was an unnecessary banding.
- It was noted that there would be a supplementary route for those who could provide evidence of higher costs for care requirements.

Meeting of the Infected Blood Expert Group - *12 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams, Professor Jane Anderson

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Infected awards

- It was noted that a managed chronic disease might never advance to more serious stages, which might impact the care award for Hepatitis C (HCV) and Hepatitis B (HBV). For individuals with HIV infection, their levels of care were not on a continuum, and they might require severe care at different points during their infection.
- The group discussed care profiles for individuals with co-infections.
- Individuals with HIV would have care requirements for co-morbidities in addition to the direct impact of the disease.
- Individuals with decompensated liver disease or liver cirrhosis were likely to have needed low levels of care, and this needs to be captured.
- Two primary models for capturing the care award were discussed:
    - a) a fixed and continuous model of increasing levels of care;
    - b) variable care models, where, over a period of time, an individual would require a specific level of care for a percentage of the time.
- It was acknowledged that these models were not exclusive to each other.

Financial Loss award

- It was proposed that all financial loss payments would be given to the infected individuals, with the working assumption that payments might be divided to be paid to estates or as dependency awards to individuals linked to the primary infected individual.
- The assumption for the calculation of the financial loss award would be based on earlier modelling. A decision was to be made regarding the financial loss award for individuals who were infected as minors.
- The issue of pensions was raised, focusing on how this could be accounted for with regard to individuals infected at pension age and those infected during working age.
- It was discussed that severity bandings for financial loss awards might not be useful, and extreme cases could be addressed through, for example, an extension of working years lost.

ACTION:- Ogden tables to be considered with regards to the design of the Financial Loss award

Supplemental awards for the Infected

- It was confirmed that there were some treatments for which individuals would receive a supplemental award due to the difficult nature of receiving this treatment. These supplementary awards applied to a proportion of the population and would be additional to their flat rate injury award.
- It was noted that supplemental awards for individuals with decompensated liver disease and cirrhotic individuals should not exceed the injury rate for HIV, indicating that the HIV flat rate award might need to be uplifted.
- The group considered the possibility of dropping the supplementary awards in future due to the complexities of accurately reflecting individuals' experiences.
- Revisiting the injury award flat rates across all diseases was viewed as potentially more functional for the overall compensation scheme.

ACTION:- A review of the supplementary awards would be undertaken.

ACTION:- Rationales for the figures would be reviewed and strengthened.

Meeting of the Infected Blood Expert Group - *16 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Dr David Asboe, Dr Ian Williams, Professor Jane Anderson

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Affected awards

- The Cabinet Office confirmed that the affected awards were not linked to the severity bandings but were instead linked to the experience of the affected person in their own right.
- It was conceivable that a partner of someone severely impacted would have suffered more than those with a partner with a milder form of the disease, but it was stressed that the focus was on the impact on the affected person themselves.
- It was agreed that not compensating those in a relationship with an infected individual with acute illness was reasonable. It was difficult to see where they would have been significantly impacted as a result of an acute Hepatitis infection. It was noted that it was conceivable that an affected person of an individual with a more severe infection would be more likely to suffer psychological harm. There was a concern raised around the possibility of double counting between affected awards and bereavement/estate payments, especially for care.
- Sir Brian Langstaff recommended that the heads of loss were the same for the infected and affected. It was confirmed that the group was working to that framework. The group discussed one possible approach - starting with the bereavement awards and then calculating an equivalent for affected awards where the infected person was still living. The group discussed how to compensate individuals who had been affected and infected.
- The group discussed how to compensate those who had lost both parents and whether someone could only receive one award as an affected person. The group discussed how cases with more than one infected individual should be managed.
- One approach considered was that the eligibility criteria confirmed someone would receive compensation and then there would be a separate part of the assessment to cover multiple awards in relation to multiple infected persons. It was noted that the group would need to consider each award and how it was to be assessed, for example, some could be per individual affected and some could be per case they are associated with. It was confirmed that infected and affected would also apply to siblings.
- The group agreed that awards for the affected should not be linked to the infected person's severity of illness.
- The group considered whether a distinction needed to be drawn between a parent of a child infected in childhood and a parent of a child infected in adulthood.
- The group discussed whether there was a need for a more bespoke process for more complicated infected and affected families. For example to put a cap on the amount that could be awarded to an individual without being referred to a panel.
- The group agreed to a flat rate for affected individuals regardless of the person's relationship to the infected person and the severity banding of the infected individual. The group agreed there was equity in simplicity, it would be difficult to design a scheme to account for all circumstances. The group agreed to a HCV flat rate and reflected in the bereavement award and compensation for the impact of watching a loved one die from the disease. The group agreed to a flat rate for psychological impact with a supplementary award for greater impact.
- The working assumption was that there would be no mechanism to go back for affected, but it was expected that there would be an option for deterioration for infected people. This also pointed to a flat rate for the affected. There was a need to avoid “residual problems” for the affected that would require the arm’s-length body to remain open. The challenge what how bereavement and psychological injury award should be dealt with. Does this always require proof of injury or should this be applied to everyone. The conclusion of the psychological award was that either it would be included in the injury award or it would be in the supplementary award which would require further evidence.

Social Impact award

- The Sir Robert Francis report recommended that the social impact award for an affected individual will be a maximum of 50% of the social impact award for an infected person. The group reduced this benchmark by 20% as some aspects would be covered in other heads of loss. The group agreed that a flat rate approach was appropriate.

Autonomy award

- Sir Robert Francis's report suggested equating this to aggregated damages. The group discussed whether an affected and infected partner should receive a different award. The group discussed the impact of not having children. The Sir Robert Francis report recommended differentiating awards for this, but applying this would require intrusive questions. Conclusion is that a variety of circumstances needed to be considered within the core awards.

ACTION:- The Cabinet Office to draw up a table for the infected, affected and the affected of multiple infected persons with the proposed amount per individual and amount per case of infection.

Bereavement award

- The group discussed types of bereavement. Definitions proposed included "those in the position of a parent" which would include individuals such as grandparents who took on a parenting role.

General conclusions

- The group agreed on a flat rate for the injury award, social impact award and the autonomy award. The group agreed that a level of evidence would be required for a psychological impact award. The group agreed that for the bereavement award they required more advice with relation to Scot's law and the litigation risk.

ACTION:- For the infected, affected and the affected of multiple infected persons the Cabinet Office would draw up a table of a proposed amount per individual and the amount per case of infection.

- The next step would be to test the package against some archetypal cases to sense check. The plan for Thursday would be to discuss the slide pack with the aim of ministers seeing the pack the following week.
- It was expected that the VAP Bill amendment would be tabled and published on 17 April, along with the Terms of Reference and possibly EG names.

Meeting of the Infected Blood Expert Group - *18 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr Ian Williams, Dr David Asboe, Professor Alexander McNeil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update on the Victim and Prisoners Bill

- The Cabinet Office provided an update on the Victim and Prisoners Bill which would provide a legal framework to establish; a delivery body, the scheme and pay interim payments to estates of the deceased people (registered with existing or former support schemes including Alliance House organisations) who were infected with contaminated blood or blood products and who have not yet been recognised. The arm's-length body (ALB) would be a non-departmental public body. All ALB's required a sponsor department and it was usual for the Chair of any ALB to be appointed by the Secretary of State.

Expert Group interim advice for Ministers

- The Chair presented the interim advice from the Expert Group which would be provided to ministers. The group provided feedback which would accompany advice from Cabinet Office officials for ministers.

Financial Loss Award

- The group discussed varying financial loss dependent upon infection severity and availability of treatment. The group felt that this might not be proportionate for those with HIV. The group agreed that for HCV more discussion was required.

Meeting of the Infected Blood Expert Group - *19 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr Ian Williams, Dr David Asboe

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Reflections on draft slides for Ministers

- Reflecting on the difference between HIV and Hepatitis C, and the level of impact on financial loss for those who have been infected for a long-time or since childhood this may not be reflected in the current framework.

ACTION:- To be reflected in the supplemental process, utilising existing evidence e.g. Special Category Mechanism status under EIBSS where possible

- The group agreed there was a need to keep clear messages in slides about the Expert Group trying to implement both Sir Robert Francis and Sir Brian Langstaff's reports.

ACTION:- Group to review proposals against the recommendations as part of the sense check, being clear where there are variations and the reasons for this

- The group noted ministers will want to understand where there are variations from the recommendations

Financial Loss

- There was a further discussion held on the suggestion to vary financial loss percentages dependent upon the date of infection:
- For HCV the group discussed whether there were clear transition points which resulted in significantly reduced impact on someone's ability to work. For those that were diagnosed prior to 2014 meant exposure to treatments like interferon. When new DAA drugs were first introduced they were prioritised by the level of severity but they were not widely available on the NHS for all patients who wanted them until 2017. Children could only be treated from the age of 3. Anyone infected post-2015 would have access to curative treatment within 3 years and would have significantly reduced impact. The group concluded there should be two bandings. One was pre-introduction of DAA (effective treatment) and one was post-effective treatment. Having a clear reduction post-treatment would also future proof the scheme given there was a small ongoing risk of HCV infection.

ACTION:- Clinicians to provide feedback on the Cabinet Office presentation

- Introducing percentage variance to reflect disease progression (similar to care award) was discussed:
- Average profile -
    - Those with decompensated cirrhosis - 4 year, 6 years cirrhosis, remainder at lower percentage level
    - Cirrhosis - 6 years cirrhosis, remainder at lower percentage level
- This formula could be used for both living and deceased.
- The rationale for HIV and co-infected was that they could not have worked. For HCV the assumption was that some work would have been possible and therefore financial loss would be applied at different levels across different years.
- For HIV, the group noted that effective therapy was first recommended in 1998. This impacted on survival and disease progression but those came with side-effects which did impact on people's ability to work. The lower impact only really applied to the last ten years post-introduce of protease inhibitors.
- The group thought that having a step-change in the framework would have limited impact given the cohort and the impact on their ability of work-related conditions which developed prior to the availability of protease inhibitors. Having been out of the workforce was also likely to have had an

impact on their ability to work to their full potential. This represented a financial loss even though some people would have the ability to undertake some work post-antiviral therapies their earning capacity was likely to have been impacted. Either due to only being able to work part time or having career gaps which would impact on their career progression.
- The group agreed that co-infections should be at 100% in line with those with a HIV infection.

Entry categories - infected beneficiaries

ACTION:- The clinicians agreed to review the evidence requirements for claimants for the four different entry categories for someone who was infected. Particularly to suggest scenarios for the structured assessment that might be used to assess an individual who might come forward claiming an infection post-screening.

Applications by affected

- The group felt that the affected must demonstrate their relationship to an eligible infected person either from;
    - The infected person applying to the scheme themselves;
    - The infected person registered with either an Infected Blood Support Scheme or an Alliance House Organisation;
    - By bringing forward evidence of the infection status and the cause of a deceased person. The arm's-length body may need to use its powers to assist with information gathering
- The group felt that payment could only be released in respect of the compensation award 'in the shoes of' the infected person to estate representatives. The limitation would be that the arm's-length body would not be able to go against the wishes of an infected person to disclose their medical information. This would need to be looked at in more detail with regards to data protection and confidentiality.

Applicants who are both infected and affected, or affected by relationship to multiple infected persons

- The Cabinet Office presented the rationale to the Expert Group.

ACTION:- The group agreed to reflect their thoughts. It was also agreed to be sense checked against case studies

ACTION:- Cabinet Office agreed to consider different scenarios for the Expert Group depending on if the infected person was living or deceased.

ACTION:- Expert Group to discuss the use of the Ogden tables to inform life expectancy

Psychological damage

- The group noted that the injury award for affected already included recognition for pain, loss and suffering. They discussed whether there was a case for a separate psychological damage award or whether this should be part of the injury award and therefore applicable to all applicants.
- The group considered the Inquiries recommendations which included a recommendation of an award for psychological injury as well as for anxiety and stress, social impact and autonomy. . The conclusion was that psychological injury was to be incorporated into the injury award in the interest of simplicity and in recognition of the difficulty that applicants may experience in evidencing such an injury.

Next steps

- The Cabinet Office updated the group on financial loss for the affected. The Expert Group agreed to review and provide further thoughts.
- A workshop would be held the following week.

Meeting of the Infected Blood Expert Group - Care award workshop - *19 Apr 2024 11:00 BST*

Attendees of Expert Group: Professor Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ian Williams, Dr Ahmed Elsharkawy, Dr David Asboe, Professor Alexander McNeil, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees from health and care expert witness agencies

Attendees of the Cabinet Office

- The CO presented to the social care experts on the approach to the care awards.
- There were two proposals for a tariff based, standardised formula that could be applied to a care award. The first were care requirements for each severity banding profiles across a lifetime and the second was a percentage approach. The Expert Group felt that based on the Compensation Framework Study, which recommended compensation being timely, the first option was more practical.
- It was felt by the group that £46,000 was reasonable for past care based on calculations done by Bush & Co who looked at long-term conditions. The Social Care Experts felt that this could be considered low when considering end-of-life care (final 6 months to one year). It could be expected that very complex symptoms for this period would be difficult to manage, therefore 24 hour care would be required for this period. £40,000 would be expected for end of life care for a moderate condition but £60,000-£70,000 would be more appropriate for complex cases.

ACTION:- Consider adding an 'end of life' category for one year

- The Social Care Experts provided example costings from other cases, for example an annual live-in carer would be around £88,500 per annum and 24 hour care which provided domiciliary and nursing care would be around £67,000 per annum.
- Care was usually commissioned on the basis of weekly care, for example £46,000 was £886 per week which would be an average for the past.
- Moderate and low care costings would include activities such as gardening, DIY, shopping, heavy-housework. People living with HIV before anti-retrovirals would suffer from night-sweats and diarrhoea so would have needed extra laundry and cleaning, alongside additional help with household tasks.

ACTION:- Social Care Experts to confirm the basis for the costings of low level.

- Care costs would need to consider where infected had resulted in an individual needing additional help themselves. Where they had not been able to provide support to others (for example childcare) this would be considered under financial loss. From the Compensation Framework Study the assumption was that the focus for the care award was more related to personal care. The Social Care Experts felt it was difficult to comment on the estimates as it was difficult to know at this stage what was being included, but it was important to ensure that the supplementary process was right.

- The current assumptions for costings were based on gratuitous care were:
  -Low care: 2 hours per day discounted by 25% (as tax and national insurance were not paid)
  -Moderate care: 5 hours per day discounted by 25%
  Severe care: 12 hours per day discounted by 25%
- The key difference between gratuitous care and commercial care costs was significant. Applying a standard rate based upon today's rates off-sets some of the uncertainties.
- One approach would be to have different rates for past care (gratuitous) and future care (based on commercial rates). The Social Care experts recommended that future care was based upon commercial care being required.
- Care experts needed to have some assumptions about what a person can and can't do at each stage of care, for example shopping, cooking, personal care. The Social Care Experts suggested the following:

- Very low care: 5 hours per week (e.g. help with shopping, heavy lifting)
- Low care: 2 hours per day
- Moderate care: 5 hours per day
- Severe care: more information was needed from clinicians on the likely impact on an individual's ability to do daily tasks

ACTION:- Cabinet Office to share Infected Blood Inquiry report on HIV with the Social Care Experts

ACTION:- Social Care Experts to provide the Care Act definitions of low, moderate and high care.

ACTION:- Social Care Experts to provide a view on what care might include and cost for Personal Care, Domestic Care and a full care package for a person with soft-touch, low, moderate and high care needs.

Meeting of the Infected Blood Expert Group - Social Care Workshop - *24 Apr 2024 14:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair)

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Social Care Experts

Care Band Descriptions

- The draft descriptions for care bands were reviewed and updated based on the discussions held during the meeting.
- These descriptions would serve as a framework for calculating a reasonable “normal case” scenario, while acknowledging that individual needs might vary (e.g. some individuals might require more assistance with shopping and less with cleaning).

Rates

- It was noted that there might be regional variations in care rates; however, these were generally marginal for care services, while domestic support rates might vary more significantly.
- Care experts had derived the figures from national rates reflecting fees charged by reputable agencies that provided both care and nursing support.

Domestic Support Needs

- For individuals requiring full assistance with domestic support, it was noted that typically 5 hours of support would be required, in addition to 1 hour per week for attendance at health appointments (e.g., hospital, GP, physiotherapy).

High Care vs Low Care

- The primary distinction between high care and low care is the number of hours allocated.
- High care does not encompass live-in or overnight care, which may be necessary for some individuals. The choice between live-in care and overnight (waking) care will depend on specific care needs and the individual's home accommodation.
- The cost difference between waking and sleeping live-in care is approximately £9 per hour.

End of Life Care

- An action item was noted to update the documentation to reflect cost estimates based on 2 shifts of 12 hours providing 24-hour care. An example costing table will be provided in due course.

Profile of Care

- Occupational therapy experts were unable to provide guidance on care profiles as they typically do not follow the entire trajectory of a patient's condition, advising only when care needs are greater.
- The rationale behind the profile of the care table was explained to the group.
- The nursing viewpoint for liver cancer was provided, with proposed figures of 0.5 years for end-of-life care, 1 year for high care, 4 years for moderate care, and 4 years for low care, with minimal care for the remainder of the infection period.
- The logic for this was that fixed figures for end of life care are 0.5 years and high care at 1 year. Clinicians are expected to provide advice on the balance of medium, low, and very low care based on disease profiles.

Regional Variation for Domestic Care

- To simplify calculations, it was agreed that a national average rate should be applied for domestic care.

Next Steps

- The relevant individuals will send example tables for calculating 24-hour care.
- Further advice will be sent to Ministers this week, with additional input from care experts anticipated once Ministerial feedback is received.

Meeting of the Infected Blood Expert Group - *25 Apr 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr Ian Williams, Professor Jane Anderson, Dr David Asboe

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Care awards

- There was an update provided on the discussion with care experts regarding the clinical bandings for severity. They provided a more refined description for the levels of care needed for each of the severity bands.
- The group discussed the minimum care years for those with Hepatitis C and HIV.
- The chair set out that the outstanding decisions were profiling levels of care throughout the patient journey. End of life care was added at the top end and an ad-hoc care level was added at the lower end. The chair said that the task for the meeting was to test the profile of care for each severity banding. Care experts had confidence in advising on high care and end of life care, which the clinicians would now review.
- The group felt that, for Hepatitis C, the lowest band of care would vary depending on people's experiences. However 8-10 years would reflect additional needs, for example increased fatigue as someone aged. Fatigue syndrome had greater recognition in Hepatitis C than Hepatitis B, but the clinicians did not consider there to be a clear rationale for the difference of treatment between the two infections.
- Decompensated cirrhosis typically lasted for four years and therefore the Expert Group felt that care should be split as 0.5 for end of life, 1.5 years for high, 2 years for moderate care, 6 years for low care and 10 years for minimal care. It was agreed that cirrhosis should have 6 years for low care and 10 years for minimal care.
- An end of life payment should not apply where someone died suddenly, for example from a heart attack, rather than from a condition such as decompensated cirrhosis or liver cancer that would be likely to lead to a period of end of life care.
- For HIV, the expert group discussed the rationale for the profile, which totalled 23.5 years of care. Support with domestic care would have been common for this group. The rationale for one year of high care was that this would be required for severe ill-health linked to an AIDS-related condition, or other severe co-morbidities. The group therefore agreed they should receive 8 years of high care and 5 years at low care.
- Considering an average pathway, the group advised that someone would develop AIDS somewhere between 8 to 10 years after their infection, with mixed amounts of minimal to low care. For high care, someone who survived to receive effective anti-virals would have progressed in their disease and had greater care requirements. The group agreed to amend the amount of years of high care from 1.5, to equal 2 with end of life care. Once someone got to a level of care with either serious AIDS or decompensated cirrhosis these were comparable and therefore should be matched.
- The group agreed that co-infection should not change the number of years for the care profile as there is only a fixed period of terminal illness. The group noted that the burden of co-infection is covered in other heads of loss.
- The group felt it was difficult for the table to reflect the circumstances of both those who died quickly and those who survived for a long time, which could result in overcompensation for those who had a short illness.
- There was a discussion about the difference in care costs for those with hepatitis and those with HIV and the group wanted to ensure there was a clear rationale communicated to the community.
- The group also suggested the need to consider that those who had lost their sight or were wheelchair bound would have higher care needs, this should be named as a trigger for entry into the supplementary route.

HIV financial loss

- The group discussed the rationale for those with HIV receiving financial loss at the top rate. The group acknowledged that there might be some who were infected younger or secondary infected that might have been able to work. Numbers in this cohort would be small and therefore the group felt it was disproportionate to seek to identify them in order to distinguish them from the majority of those victims with HIV. It was noted that the cohort prior to 1985 would have been infected prior to effective therapy and would all have seen an impact in their ability to work.

Psychiatric injury for the affected

- The group wanted to recognise that all would have had some psychiatric impact and therefore agreed to increasing the injury award by £10,000. For cases of diagnosed psychiatric conditions, the cost of treatment should be sought through another part of the scheme (where this hadn't been funded elsewhere). The group agreed with taking a flat rate approach, and felt this was proportionate within the overall context. A flat rate approach was a less intrusive option.

Eligibility

- The group noted that where someone's death certificate mentions HIV and/or Hepatitis there would also need to be an assessment of the cause of infection. It also needed to be clear in the eligibility criteria that an illness not being mentioned on a death certificate would not rule out someone's ability to claim, additional information would need to be provided, for example from medical records.
- The group asked about medical causal assessment where the cause of infection needed to be established. They noted the need for medical evidence to establish causes of infection outside of the window when this should be presumed and that it was possible to suggest factors that could be taken into account when assessing this. . This was an area where ministers needed to take a view on the appetite for fraud risk and how to balance this with the Inquiry's recommendations on evidential requirements.

ACTION:- Expert Group to provide comments on current proposals

Bereavement Award

- The group discussed whether the bereavement award should be limited to those who died with decompensated or liver cancer. Diagnosis of cirrhosis might affect someone's ability to receive other treatment, so this could contribute to their death, even if it was not the case of death. For HIV it would always expect that it was a contributing factor if a person died from a long-term condition. Therefore the group agreed that the bereavement award should not be dependent upon the cause of death.

Financial Loss - Life Expectancy

- The group discussed whether net earnings for financial loss should continue until life expectancy or to retirement age. The median +5% for the period to retirement was agreed. The outstanding question was whether the group should consider a median pension for post-retirement. The alternative would be based on an in-work amount, for example 50% of the median salary as a post-retirement rate. The proposal for ministers would be median salary to retirement, with further consideration to be given regarding a post-retirement rate.

Meeting of the Infected Blood Expert Group - *2 May 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Professor Alexander McNeil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcomes and Introductions

- A summary was provided regarding meetings held that week with the Minister for the Cabinet Office (MCO) and with Sir Robert Francis, noting contentment with the work conducted by the Expert Group . Discussion focused on likely next steps for the Expert Group, including the finalisation of an interim report for publication.
- A discussion was held regarding the continuation of the Expert Group post-20 May, acknowledging that no formal decision had yet been made.
- An overview of MCO engagement with community representatives was provided.

Future Advice to Cabinet Office

- The Expert Group discussed two key questions arising from the advice provided:

  Q1: Window for registration
  - The group discussed the length time applicants should have to bring a claim for compensation. The group agreed this should link to diagnosis and that 6 years was appropriate from the point of diagnosis.
  - The group discussed how active case finding could be undertaken by the arm's-length body to ensure the community was aware that the scheme would exist. It was noted that awareness of the scheme would be promoted with health bodies, GPs, and those administering tests.
  - The group noted Hepatitis cases are still being identified related to infected blood so there was a need for a process to ensure those diagnosed in the future could still claim.

  Injury award
  - The group discussed whether the injury award should vary across infections for the affected. There was a consensus that the injury award should not vary between infections, although distinctions might be appropriate between severity bands, particularly chronic and acute cases.

Scenarios Discussion

- The Expert Group discussed sense checking case studies for compensation against the scheme proposal. The group expressed interest in considering scenarios involving multiple beneficiaries.

- Additional scenarios would be circulated to the group, with the aim of testing the proposed scheme to ensure the proposal functions as intended.
- Scenarios should include a test involving a beneficiary of the current Infected Blood Support Schemes (IBSS) and someone on the new scheme to assess the top-up payment designed to ensure that infected beneficiaries on an existing IBSS were not worse off under the new scheme.

Any other business

ACTION:- The Cabinet Office committed to commission the expert group for further thoughts on the injury award and impacted individuals ahead of further discussions.

ACTION:- Updated scenarios would be prepared, including those relevant to an IBSS and multiple beneficiaries.

Meeting of the Infected Blood Expert Group - *9 May 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Professor Alexander McNeil, Dr David Asboe, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Policy Update

- The Cabinet Office provided an update regarding ministerial feedback on current proposals. A substantive Government response was expected to be published on 20 May.
- The following areas were identified as requiring further advice:
    - Eligibility criteria for affected individuals and the timelines regarding the start of infection
    - Injury and bereavement awards for the affected individuals
    - Community validation

Forward Look of the Expert Group

- It was noted that the Expert Group was likely to remain active in some capacity to advise the Government on potential outputs from the community validation process.
- An update was provided regarding the forthcoming output from the Expert Group, which would be made public. It was expected that this would be a report which would be presented by the Chair of the Expert Group, informed by advice provided by the full Expert Group. Concerns were raised regarding the responsibility falling solely on the Chair. Further discussions were required to clarify the content and timing of the report in relation to a potential announcement on the Compensation Scheme.
- An outline was given concerning the future work of the Expert Group, including a timetable which aligned with work drafting of the regulations. It was acknowledged that the drafting process would likely prompt further questions that would need to be addressed with the Expert Group.

ACTION:- Clinicians to determine the optimal point for when care needs would arise, considering the rationale for defining when those needs would commence (point of diagnosis versus point of infection). The consensus was that the date of infection was a sensible starting point for care awards.

Next Steps

- A note would be circulated following tomorrow's conversation regarding the output of the expert group and the anticipated report format.

Meeting of the Infected Blood Expert Group - *13 Jun 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr David Asboe, Professor Alexander McNeil, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update on regulation timelines and community engagement

- The Cabinet Office provided an update on timelines for the Infected Blood Regulations, including confirmation that the Infected Blood Compensation Authority was now a legal entity. They noted that the three-month statutory deadline to make regulations to establish the compensation scheme began on 24 May. Consequently, the Government was required to make these regulations by 24 August.
- The Cabinet Office updated the group on Sir Robert Francis' community engagement.

Recruitment of IBCA medical assessors

- The Cabinet Office provided an update on IBCA and confirmed that the first board meeting had taken place.

Hepatitis B: (i) review of how cases of Hepatitis B which resulted in death in the acute period should be handled by the Scheme (ii) Additional areas of focus required for Hepatitis B

- The Cabinet Office outlined the rationale for compensation regarding certain categories of Hepatitis B, including those who died from acute infections. A discussion ensued concerning the likelihood of such specific cases occurring and whether it would be more appropriate to establish bespoke settlements for unique instances. It was confirmed that evidence of these cases was present in the Infected Blood Inquiry's final report.
- The group agreed with the rationale for the inclusion of affected people linked to those who died of an acute Hepatitis B infection.
- The group noted that some acute Hepatitis B infections might have resulted in a liver transplant, though these were not widely available in the 1970s. The group agreed to align the eligibility criteria to Inquiry's recommendations which was acute Hepatitis B infections which resulted in death in the acute period.
- The Cabinet Office asked the group to share guidance to support the assessment of people with Hepatitis B.

Any other business

- The Cabinet Office set out next steps for this work and committed to bring information from the engagement events to discuss with this group. The Chair would attend Sir Robert Francis' engagement meetings.
- The group discussed the impact of the report on haemophilia clinicians and how the impact could be mitigated.

Meeting of the Infected Blood Expert Group - *4 Jul 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update on timelines

- The Cabinet Office provided an update on timelines following the United Kingdom General Election.

Supplementary Route

- The Expert Group discussed the health triggers which would make someone eligible for the supplementary route. There was agreement that conditions should be focused on levels of care required rather than individual diagnosis, otherwise the list of conditions would become unwieldy. This included severe psychiatric disorders which could lead to long term functional impacts. It was agreed there needed to be a read across to all conditions. The group discussed chronic encephalopathy. It was agreed that CDK replacement therapy would be removed because it was covered by domestic support.
- The group discussed how IBCA could be satisfied that there was a link between the infection and the related condition. For example it would be reasonable to expect a clinician supporting the infected person to provide a supporting statement, although there were ambiguities around age-related complications such as diseases more common in those with HIV.
- There was a discussion around the prevalence of certain conditions. The group agreed numbers were expected to be small, for example chronic refractory hepatic encephalopathy was around 1-2%.
- The group discussed whether there should be two supplementary routes and whether there should be a supplementary route for the injury award. The group agreed that reopening this would be complicated in the time frames available.
- The group discussed eligibility of those currently with Special Category Mechanism (SCM). The Chair suggested that the working assumption should be that those with SCM would be passported so they did not need new evidence. The rest of the route would be the small number of people that have not already come forward to the schemes.

Expert Group Report

- The Chair gave an update on the expert group's report. Sir Robert Francis recommended that the report was published by the end of July and it should be a full report. The aim is to explain what the group has done and why. There should be consideration about who the report is for.

Meeting of the Infected Blood Expert Group - *10 Jul 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery, Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Dr Ian Williams, Professor Graham Foster

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome

The group was updated by Cabinet Office on policy development progress from the last week and discussed the agenda for the meeting.

Decompensation and Life Expectancy

- The Expert Group discussed the possibility of treating encephalopathy as a separate condition. The Expert Group noted that a specific class of individuals might have encephalopathy as their sole feature of decompensation, impacting life expectancy.
- Concerns were raised about factoring in the impact of encephalopathy given that it indicated decompensated status. It was suggested that patients with decompensated cirrhosis should focus on the 4-year duration relevant to those who had died, although for living patients, duration could shift. Agreement was reached that, at this juncture, one would transition to a full rate of financial loss.
- Clarification was sought regarding the level of care required for decompensation and encephalopathy. It was agreed to extend the low care band for the duration of encephalopathy. The expert group discussed that low care costs would apply continuously until higher care needs arise.

Renal Impairment

- The Expert Group highlighted that renal impairment could occur without a vascular component, with implications for care and financial loss being dependent on dialysis needs. For patients undergoing dialysis, complete financial support, along with some home help and domestic support, would be necessary. It was clarified that this also applied to renal dialysis patients with HIV, necessitating enhanced domestic support and low care requirements.
- The Expert Group confirmed the necessity for renal failure to be properly categorised. Discussion ensued about the level of care required for end-stage renal replacement, particularly for Hepatitis B and Hepatitis C cases, with a consensus not to specify causation by the virus due to the lack of biopsy in many cases.

Special Category Mechanisms (SCM) Clarifications

- The Expert Group noted the varied severity and outcome of conditions which complicated categorisation. It was suggested that individuals with exacerbated autoimmune disorders would receive low care automatically; however, those with demonstrated enhanced care needs would be subject to bespoke assessments.
- A preference for the current supplementary route was expressed, whilst addressing that new entrants to the scheme would likely be rare. It was clarified that individuals that were receiving SCM currently would passport to this framework rather than have to demonstrate eligibility, whilst new participants would be subject to specific eligibility criteria, aligned with the financial loss associated with cirrhosis.
- Clarification was given that individuals with encephalopathy would receive financial loss at the full rate.
- There was a discussion on psychiatric disorders and the Expert Group agreed that there was a need for significant evidence for classification.

Severe Neurological Disorders

- The Expert Group discussed that low care classification for severe neurological disorders may be inadequate, particularly for those receiving NHS continuing care.
- It was noted that severe psychiatric conditions should warrant 100% financial loss; however, significant evidence of diagnosis through psychiatric assessment would be required. Evidence indicating the inability to work must come from a psychiatric evaluation, rather than primary care.
- Long-term care considerations for cognitive issues were highlighted, and the possibility of a name change to clarify severe cognitive impairment was discussed in relation to its significant impact on care needs.

ACTION:- Further discussions on the categorisation of conditions and care levels were due to be scheduled.

ACTION:- Continued assessment of financial loss definitions would be considered to refine eligibility criteria.

Meeting of the Infected Blood Expert Group - *11 Jul 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams, Professor Alexander McNeil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Supplementary route

- The Chair thanked the group for their work over the past week on the supplementary route.
- The Group was asked for examples around what conditions are relevant for neurological disorders. For HIV cerebral toxoplasmosis resulting in a severed stroke would be relevant.
- The Group thought there would need to be examples for the thresholds for severe psychiatric disorders. Inpatient care is a very high threshold and there are potential problems. Three months treatment is standard for mild or moderate psychological harm but the counterproposal would be to increase it to six months for consistency. The group asked whether the issue of prognosis would need to be considered.

ACTION:- The Chair to seek advice from Professor Sir Simon Wessely on whether the use of ICD categories might be a way forward for the category of severe psychiatric disorders

Ministerial portfolios and submission deadlines

- The Cabinet Office provided an update on new ministers and likely timelines for decisions.
- It was expected that the Minister for the Cabinet Office would make a statement to Parliament ahead of summer recess.

Final report

- The Chair shared a draft structure for the Expert Group report and requested feedback. The group concluded that the fact that this is a UK-wide scheme should be mentioned, including the inquiry's recommendation on that point.

Meeting of the Infected Blood Expert Group - *25 Jul 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams, Professor Graham Foster

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update

- The Cabinet Office updated on the latest developments regarding regulations, including advice received from Sir Robert Francis and the statement from the Minister of the Cabinet Office to the House of Commons to be made 26 July 2024. Cabinet Office committed to sharing the statement following the announcement. Furthermore, it was stated that the expectation was for the Expert Group report to be published concurrently with Sir Robert Francis's report and the Government's statement prior to 24 August.
- The Cabinet Office detailed that there are plans for two sets of Infected Blood regulations. The first set, to be published on 24 August, would establish the scheme and set core awards for those infected. The second set of regulations would address the supplementary route and awards for those affected.
- Members of the Expert Group were requested to inform the Cabinet Office of their availability during the summer period to facilitate planning and coordination for upcoming meetings and activities.

Expert Group Report

- The group provided feedback on a draft of the Expert Group report.

Meeting of the Infected Blood Expert Group - *1 Aug 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (chair), Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome and Update

- The Expert Group discussed that the SRF report will be published on 8 August. Publication of the EG Report and Government response was expected by 16 August.
- The plan is to issue the policy explainer in the week commencing 19 August and to produce additional community-facing materials using non-policy language shortly thereafter.

Acute Hepatitis B and Care Award Considerations

- Questions were raised regarding the Hep B acute flat rates for heads of loss in relation to the care award, designed to account for care by working back from the point of death.
- The Expert Group deliberated whether to maintain the amended 12-month period for the care award at six months of end-of-life care or to cover the entire duration.
- It was clarified that infected people receive a flat rate for injury and end-of-life awards to clarify entitlements for recipients.
- Concerns were expressed that a lack of definition could lead to criticism if issues arise in the coming months, noting that if a death occurs outside the six-month window, it would no longer be classified as acute. The Expert Group agreed that the definition of acute Hepatitis B should remain at six months and considered the creation of a flat tariff for the care award.
- Further discussion addressed financial loss, with an explanation that it would transition into dependency payments based on healthy life expectancy.
- A question was raised about the procedural steps for acute Hepatitis B patients receiving a transplant, prompting an investigation into the route for transplant consideration. The Expert Group confirmed that this aspect is covered.

Discussion on the Report

- It was agreed that the shortened moral case section provides a stronger presentation. The specific attention to research failures was supported but it was agreed that extensive work would be needed to define the scope of the additional autonomy award. Concerns were highlighted regarding the historical context of research ethics and practices in teaching hospitals. There was acknowledgement of the insufficient information on this topic for a definitive view.
- The Expert Group noted that while some consent forms were signed, the historical records limit current understanding. The Expert Group acknowledged a lack of expertise and information on this matter and speculated about potential legal challenges.
- A question was raised regarding whether, given the moral case that has been made, a scheme could be designed to accommodate the inherent complexities. Concerns were expressed that any actions taken in this regard might be rushed, as it represents a different era, and applying broad brush strokes could fail to address the underlying issues adequately.
- It was concluded that any advice needed to sit within SRF’s recommendation and that expanding on this topic falls outside the scope of the Expert Group's work.

Supplementary Route and Award Tables

- Discussion focused on the best layout for supplementary award tables, suggesting care descriptors could be eliminated, allowing groupings to be expanded.
- A specific definition of visual impairment from the RSB was noted.

Injury Award Details

- The Expert Group sought to balance detail and clarity in the information presented, taking into account insights from the engagement and SRF.
- It was suggested that an annex for certain tables may be beneficial, including a table that separates coinfections.

Direct Infections and Patient Narratives

- The necessity for patient narratives was debated, with a suggestion to alter the requirement to allow for an "OR" instead of "AND" outside the relevant window when causation was presumed.
- The discussion included the importance of a declaration from living patients, and emphasised the strength required of medical statements.

Definitions for Biological or Adoptive Parents

- The definition alignment with regulations was highlighted, noting further investigation may be needed.

Meeting of the Infected Blood Expert Group - *8 Aug 2024 17:00 BST*

Attendees of the Expert Group: Professor Jane Anderson, Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Dr Ian Williams, Professor Graham Foster

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Government Update

- The Cabinet Office provided an update on upcoming communications, changes to the Scheme design following the engagement, including around support scheme payments and the change in government.

Outstanding decisions on draft final report

- The group discussed the outstanding sections of the draft report around evidentiary requirements, including the higher evidential requirements for those that apply with infection dates outside the cut-off dates stated in the regulations. One option could be to request patient narrative from a medical professional.
- A patient narrative should accompany a statement by the applicant regarding truth and accuracy. Rather than saying and/or there should be additional information about what the individual could provide to support their narrative from a medical professional, not a healthcare professional, however the group noted that for Hepatitis C is it difficult to decipher whether the blood transfusion is the cause, unless they received a negative test prior to the blood transfusion. This would put a lot of pressure on the consultant.
- The group discussed screening dates and the bar needing to be high for those coming to the Infected Blood Compensation Authority (IBCA). People applying outside of the cut off dates in the regulations would be required to provide more documentation. It could be helpful for the panel to report on the number of patients infected from other sources and check that against sources such as the UKHSA data on frequency for liver cancer. If a larger number are outside that window, the panel might need to reconsider the decisions they are making. There was a concern about equity and stigma. Gay men and drug users might be disadvantaged. There will be people with other risk factors who still did receive infections through infected blood. The group agreed that before this was added into eligibility the group would want to raise concerns about not being too intrusive but also ensuring those that have a real claim are eligible. IBCA will have to take into account different types of evidence.
- The group discussed Sir Robert Francis' recommendation around research misconduct and noted that information on studies and centres identified in the Infected Blood Inquiry Report would inform further consideration.

Meeting of the Infected Blood Expert Group - *15 Aug 2024 17:00 BST*

Attendees of the Expert Group: Dr Ahmed Elsharkawy, Dr David Asboe, Dr Ian Williams, Professor Graham Foster

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Government update

- Cabinet Office provided an update on recent meetings between the Minister for the Cabinet Office and stakeholders.
- The group discussed the government response to Sir Robert Francis' recommendations around evidence requirements for applicants and unethical research awards. The group also discussed how IBCA could ensure those applying were eligible. There was a discussion about IBCA's legal and medical boards and how to communicate technical points to IBCA.
- The Cabinet Office thanked the group for their work on the case studies for the gov.uk explainer, which were due to be published next week.

Meeting of the Infected Blood Expert Group - *19 Sept 2024 17:00 BST*

Attendees of the Expert Group: Professor Jane Anderson, Dr Ahmed Elsharkawy, Dr David Asboe, Dr Ian Williams, Professor Graham Foster, Professor Alexander McNeil, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Government update

- The Cabinet Office provided an update on the establishment of IBCA and timelines for the second set of Infected Blood regulations.

Return to Scheme - Health Impacts

- The Expert Group discussed options for when an infected person should be eligible to return to the scheme. It was noted that for Hepatitis C and Hepatitis B, disease progression is unlikely to occur as a consequence of the infection. Around 2-5% will get liver cancer and it is known that the risk remains for the first seven years post-effective treatment. People are likely to re-present with cirrhosis due to other risk factors. If someone is not presenting now, the likelihood of developing it in the future is very small. It was agreed there were analogies with HIV too and a small proportion of people who drop out of care re-present later. The group agreed that the driver in terms of returning to the scheme would primarily be liver cancer on the back of viral driven liver disease, but if repressed/cured it is likely to be other issues driving the cirrhosis.
- One option to consider would be progression within a time limit after effective treatment, however there would be limitations with the clinical evidence as it has not been long enough since treatment has been introduced for those with Hepatitis C. Data on liver cancer shows that the risk is still high after seven years of effective treatment. It might be that ten years is when the viral impact begins to reduce.
- The group agreed that other areas of the Scheme built in assumptions about the impact of an infection and the approach to returning to the Scheme should be in keeping with those. There needs to be an opportunity for individuals to return to the scheme if the core route does not cover their situation.
- For HIV, the group noted that the original banding factored in the co-morbidity potential, and that there is no progression in banding and in determining the care profile, giving the example that if someone with HIV had a heart attack that had been factored into the core route award.
- Another issue might be, for example, someone falling out of care due to their mental state for example which means they have not been able to take their treatment.
- However there is a possibility that those with HIV may need to return due to a supplementary condition. Examples discussed were that people with HIV have a higher risk of stroke, dementia, renal failure, vascular disease. There is potential for someone who presented (for example) with a severe stroke and who develops disability problems to need to return to the care banding. It was expected that this would be a small amount of people.
- The group discussed those with a severe psychiatric impact and the levels of care required. Those who have developed another condition might, as a result, develop a severe psychiatric impact. For example if someone had a vascular stroke they might develop vascular dementia which would mean a higher care profile than the profile developed under the core award.

Hepatitis Delta

- The Expert Group raised a query from the Hepatitis C Trust about people with Hepatitis B and Hepatitis Delta. Whilst the Infected Blood Inquiry did not mention Hepatitis Delta, the Group asked whether someone with two viruses would be co-infected. It was agreed that Hepatitis B and Hepatitis Delta were so closely linked they could be included as a single virus. Hepatitis D is an accelerant to Hepatitis B and so all costs are dealt with through Hepatitis B. It would be reasonable to regard Hepatitis B and Hepatitis Delta as a single impact, but the group agreed it might be worth being explicit about this.

Meeting of the Infected Blood Expert Group - Evidence Led Supplementary Route Workshop - *20 Sept 2024 17:00 BST*

Attendees of the Expert Group: Dr Ian Williams, Professor Alexander McNeil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

- The Cabinet Office provided an introduction to the evidence led supplementary route and introduced two options for consideration.
- The Expert Group thought it would be useful to go through worked examples.
- One piece of evidence someone could produce was their enrolment in a defined benefits scheme with a certain accrual rate. These calculations could be fairly simple.
- In terms of considering comorbidities the Group noted this may be difficult, including when it came to haemophilia. Getting medical evidence to distinguish this would be difficult. The impact of haemophilia was also not discussed when looking at life expectancy. It was noted that the scheme should be consistent with itself on how it considers co-morbidities.
- The group noted that there are different scenarios of applicant to the Scheme, noting that living infected people's access to evidence would be much greater than for those making a claim on behalf of a deceased infected person who died a number of years ago.
- The group noted that in terms of stigma of the illness, there were very few sick notes/fitness to work notes that would mention 'HIV' explicitly. This could mean that the reason for them requiring long-term sickness absence might not be documented. The group said 'chronic viral infection' was frequently used instead, and advised that overall the scheme could not rely on what is put on a sick note. They noted that, for similar reasons, secondary infections may be relayed on a death certificate, and any additional relevant information would be relayed to the coroner separately.
- The Cabinet Office explained the proposed application process to the supplementary route and invited the group to comment on two potential options, either ASHE tables to benchmark median salaries against professions, or to consider a percentile match to contemporary values. The group thought that the fact that there was no way of recognising career progression in the percentile matching option made option one preferable. The group thought that a career average salary might be the most equitable approach to take, if ASHE tables allowed for it. They noted that if it was possible to have salaries by age for different kinds of jobs it would be straightforward to create a set of multipliers indexed by age and career. A hypothetical example was raised - teacher to headteacher (across different career categories but a possible progression someone could expect to see in their career) and the group advised discounting speculation about progression. They noted that age-related progression could be built in.
- The Cabinet Office noted that the difficulty with ASHE is there are many splits within the data, for example by gender, progression, overtime, standard wage, and the professions listed are quite general. By the time these were brought together they noted there would be very wide confidence intervals. They noted that ASHE tables themselves provided remarks on data quality, including that some estimates are 'unreliable for practical purposes'.
- The group said that, in an approach based on use of Ogden tables, it was normal to take into account career profession, the examples given look at how they have applied multiplicands for progression. Ogden tables rely on employment experts. The group felt some progression was needed to be included in this system. The group thought that some subsidiary data analysis could help the group arrive at some ballpark multipliers.
- The group noted that pensions still needed to be discussed but thought it would be possible to apply the multiplier to ASHE. ASHE was being used to locate historical salaries in today's values. Percentile was being used to do the same thing. Pensions could follow the majority of figures in the examples but not the final percentage calculations. Ogden has two worked examples of going about pensions. One was based on contributions and one was based on a final salary. Sticking closely to one or the other, if the option was taken to use final salary that would become more expensive.

ACTION:- the group agreed to consider pensions at a future point

Meeting of the Infected Blood Expert Group - Finance Supplementary Route Workshop - *24 Sept 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Dr Ian Williams, Professor Alexander McNeil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

- The Cabinet Office provided a summary of the previous week's workshop, outlining its aim, which included the key principles of the financial supplementary route and the three questions presented to the group: how the scheme should factor in career progression, how this route equated past earnings to present day values, and calculations for assessing pensions. The Chair noted it would be useful to know how many people would be covered by the core route's financial loss assumptions of average earnings plus 5%, and how this information should be communicated to clarify who might be eligible for a supplementary award.
- The Cabinet Office guided the group through two options for calculating financial loss under the supplementary route; either the Annual Survey of Hours and Earnings (ASHE) table profession matching or percentile matching past earnings for value in 2023.
- The Expert Group expressed concerns about using gender as a variable in the ASHE tables, given historical instances of gender inequality in pay. They inquired how far back the ASHE tables extended. It was noted that there were two aspects to consider: career progression and pay inflation. The group was concerned that utilising ASHE by the median salary alongside the progression uplift might lead to double counting. They recognised that difficulties could arise for individuals who moved between categories, such as transitioning to a management role, which would shift someone into a different category. While the group felt this option might not always provide a reliable match, it could serve as a basis for developing an approach. The group felt that the progression multiplier could mitigate this issue, although noted it may complicate the Scheme. They discussed the potential for an alternative route whereby an individual could propose up to three relevant occupations, concluding that this could yield a reasonable match based on the categories within ASHE.
- The group queried how far back the Office for National Statistics went to determine the percentile match under option 2. It was agreed that applicants should provide the correct evidence, rather than IBCA attempting to source it themselves. This approach would allow for establishing a set of thresholds, ensuring that individuals at a certain age would need to have received a specific annual salary to qualify for a supplementary award. The group also considered it reasonable within the context of this tariff-based scheme to impose a cap on the annual salary amount and suggested that a lump sum could be offered in addition to recognise this. Under this option, anyone in the top 10% of earners would likely need to consider a court case to receive full consideration of their earnings while the supplementary route would apply to those earning in the top 10-25%.

ACTION:- The group agreed to further investigate the lump sum option; otherwise, percentile matching was preferred.

- The Cabinet Office then presented the group with the next stage of the approach: the progression multiplier. The group agreed that this multiplier should not be split by gender (for reasons noted earlier in the meeting) and concluded that a percentile driver multiplier would be preferable to a median driver multiplier. While the group appreciated the simplicity of this approach, they acknowledged that it would not be suitable for individuals experiencing rapid career advancements. Additionally, it was noted that there was currently no mechanism in place to capture bonus payments. The group also discussed the implications for individuals with Hepatitis C who experienced chronic fatigue. The Cabinet Office confirmed that a progression multiplier would consider what someone was earning before the onset of chronic fatigue and apply the progression, rather than implementing caps or percentile matching.

ACTION:- The group agreed to adopt non-gendered progression percentile driver multipliers.

- The Cabinet Office then guided the group through stage four: phasing. They asked whether it would be necessary for applicants to provide evidence for the entire infection period, as there might be instances of individuals working more than the core scheme anticipated. The Expert Group believed that this would depend on the individual's career and societal context. Historically, employers often did not accept part-time work, and there are professions where fatigue cannot be accommodated. The Cabinet Office confirmed that the scheme would not assume that individuals were working fewer days; rather, any work completed should be averaged out.
- The Cabinet Office further queried what should happen to individuals who had a reduced capacity to work and subsequently returned to work. The Expert Group felt that the approach to evidence should be somewhat flexible, allowing for the benefit of the doubt, such as providing approximate dates and any evidence demonstrating payment received. They noted that high earners might typically cease their career to receive statutory sick pay and may not return with reduced hours, making such occurrences uncommon. When evidence existed, it was suggested that the focus should be on pay figures rather than the number of working days or capacity. Ideally, evidence could be provided through tax returns, but the availability of such documentation remained uncertain.

ACTION:- The group agreed that they did not wish to enforce phasing.

- The Cabinet Office then presented the group with the pension calculation. The Expert Group identified the primary issue as the disparity in amounts. They noted that an attractive private sector pension scheme might offer around 8-15%, which is three times the amount suggested by the Cabinet Office. Whereas, the NHS Pension has an employer contribution rate of 12-13% for higher earners. The Expert Group inquired whether individuals should be required to provide evidence of the benefits they received as part of their employment, such as health benefits. They also asked if there would be consideration of the state pension, as some individuals may not contribute to their pension until later in life.
- The group expressed concerns that this route could be perceived as significantly more generous than the reality of circumstances for many potential applicants, necessitating evidence provision. However, they recognised the need to balance this against the complexity that such evidence-gathering would create, while also being mindful that pensions are individualised. Additional questions arose regarding how this would apply to self-employed individuals, noting that some may not receive employer contributions, while others might need to allocate their earnings towards pensions. The scheme does not apply any deductions to account for money placed into a pension pot, so it was important to ensure there would be no duplication of payments. This viewpoint supports the notion that individuals who believe they are owed more in relation to their pension should provide specific evidence.
- The Cabinet Office queried what evidence would be necessary. The Expert Group suggested that living infected individuals who contribute to a pension may also receive payouts from that pension, indicating a need for documentation to provide insight into the pension that could assist with calculations. They acknowledged that these calculations are not straightforward, even with the evidence presented. The group was concerned that creating a system requiring every individual to submit their own evidence would be complex. They agreed that there should be a proposal to align the approach with the core route.
- The Expert Group proposed that salaries should be uprated by 3% to match automatic pension enrolment. The group agreed that it would be reasonable to establish a minimum recognition going forward. They felt this could be justified and potentially linked to automatic enrolment requirements, which have only been introduced recently and are already considered quite generous. An alternative option discussed was the possibility of not considering a provision for pensions at all.
- Next, the Cabinet Office inquired about an appropriate level for a cap on the award. The Expert Group expressed that both the 90th and 95th percentiles seemed fair; however, they noted that setting the cap below the 90th percentile would be challenging to justify. The group agreed that the cap should apply to the total award, rather than just to this specific portion of it.

ACTION:- The Expert Group to consider both the 90% and 95% options and circulate these for further views.

Meeting of the Infected Blood Expert Group - *27 Sept 2024 17:00 BST*

Attendees of the Expert Group: Dr Ian Williams, Professor Graham Foster, Dr Ahmed Elsharkawy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Forecast Modelling

- The Cabinet Office summarised the costing model used to support Scheme design, including the expected number of deceased estates. The overall goal established for the meeting was to get a better understanding of the cohort claiming for financial loss through the supplementary route - and anticipated costs.
- The Expert Group felt the proportion of infected blood donors were also likely to be overestimated by the model, and expected that the lower end of the estimate was more likely to be the top estimate.
- In terms of numbers, the Expert Group noted that the Haemophilia Society had some well described cohort studies. The average age of infection in the Haemophilia cohort was 24. For those not related to haemophilia there was a much smaller number.

ACTION:- The Expert Group agreed to share HIV coinfected haemophilia patients' data studies with Cabinet Office

- The Expert Group noted that the death rate for those with HIV and the coinfected cohort was much greater than for those with Hepatitis C monoinfection.
- The average untreated survival time for someone infected in 1979 would be between 8-10 years, although the younger the age of infection, the higher proportion would have died with coinfection as opposed to Hepatitis C monoinfection.
- The Expert Group questioned why the HIV figures in the model were low, the Haemophiliac Society had a cohort of 2,500 people known to be infected by blood products. Of that 2,500 cohort, the Expert Group questioned the amount of estates expected to claim.
- The Hepatitis C figures were suspected to be lower than demonstrated in the model. The issue here was that the more blood transfusions a person received, the more likely they would have been to contract Hepatitis C. The group noted it was challenging to get accurate Hepatitis C figures, but agreed it would be sensible to go with a lower median. For HIV, the Expert Group thought it would be an underestimate. In terms of bleeding disorders, there were 1,250 infected, about 80% had died, leaving around 200 people from this cohort alive. Towards end of life, there tended to be a higher level of medical care required. Younger people tended to have received blood transfusions for less life-threatening issues, so it was harder to know about survivorship.
- The Expert Group asked whether there was information from other data sources, such as from the Irish compensation scheme.

Survivorship Figures

- The Expert Group felt that survivorship figures could be derived by looking at published cohort studies from haemophiliac centres. Survival curves would be useful to assess. This data was published until the early 2000s. Non-progression for HIV was related to age, i.e. if someone is infected at a younger age, progression of HIV is slower than for older age groups. The greatest impact on survival was antiviral therapy.
- There was much less data on recipients of blood transfusions. It was thought to be more helpful to separate out the haemophiliac cohort as this would be much more accurate. The group felt that the central survival for young people seemed low.
- The group noted that this data was based on age range, however when looking at survival, it was better to look at lung cancer, especially for younger people because once you were past your early 20s, it was highly unlikely someone would receive a blood transfusion for cancer related reasons. After the age of 50 it was highly unlikely a person would receive a blood transfusion due to cancer. An intermediate range would be between ages 20-50.

Evidence-Led Supplementary Route

- The following questions were asked by the Cabinet Office:
    1. How should we take historic care costs and compare them against the core route?
    2. How do we compare paid for care with care packages under the core route?
    3. Do we set caps within the supplementary route?
    4. How can we distinguish between care requirements for other comorbidities?
- The Expert Group asked whether there were similar tables to financial loss, which compares average earnings (ASHE), for an hourly rate for a carer in the past compared to now.
- Gratuitous care would be the hardest for people to evidence.
- Another consideration in relation to care was starting from the view of knowing people had a need with a value. If they did not receive the care assumed under the core route they suffered more because they weren't receiving that care.
- The Expert Group also discussed the importance of protecting against fraud by ensuring a cut-off period for when commercial costs had been paid by the individual, whilst allowing for estates with care requirements from the past, particularly on end of life care, to be reimbursed at full commercial cost.
- Experts agreed that the care model under the core award already captures a wide range of circumstances. It was expected that the cost of future care for those living with an illness was unpredictable. The Expert Group questioned which circumstances require additional care. HIV received high quality support, and the Hepatitis C cohort had already catered in expected issues under the core award. The group thought therefore that all the Scheme could do is offer the care award without the gratuitous care discount.
- The Expert Group suggested exceptions to this, and questioned in terms of return to scheme and health impact, whether that automatically put someone into a higher care category.
- The Expert Group noted that the equality aspect was that the people most likely to have the most expensive packages were those who had substantial assets to pay, otherwise family and friends provide care. The Scheme already catered for family and friends who provided care through the enhanced financial award and there was a policy question as to whether the Scheme should reimburse someone if they had the privilege to pay for an involved care package. The Expert Group further noted it would be difficult for someone to prove a lifetime of care above what has been set in the core route because the Scheme was already provided for substantial sums in the care award under the core route.

ACTION:- Cabinet Office to consider recent correspondence to assess feedback from the community on the care award.

Meeting of the Infected Blood Expert Group - *3 Oct 2024 17:00 BST*

Attendees of Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Professor Patrick Kennedy, Doctor Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome

- It was agreed that the group would discuss issues related to unethical research awards in the following week, alongside ongoing discussions within the Department of Health and Social Care about broader future response to research governance.
- A key focus for this meeting was to refine and clarify definitions for the regulations where needed for legal drafting purposes.
- It was noted that the IBCA had appointed their Non-Executive Directors. The information would be circulated once officially published.

Definitions for Regulations for Health Impact Route

- A discussion was introduced by the Cabinet Office regarding the transition of the health impact route into regulations. They noted the need to refine certain definitions to draft appropriately detailed regulations and enable IBCA to fulfil its functions as according to the VAP act. To support the discussion, the Expert Group asked clarifying questions regarding the level of discretion that IBCA would hold in assessments. The Expert Group suggested utilising existing definitions, such as those related to psychiatric disorders in the Disabilities Act. It was acknowledged that certain conditions, like hepatic encephalopathy from infectious diseases, were rare, and any lists of relevant conditions in the regulations should include those that the Expert Group had identified.
- The challenge of defining criteria for functional disability was discussed, with suggestions made to the Cabinet Office to consider seeking specialist input. Evidence for cognitive impairments, for example, would require documentation from memory clinics or neuropsychometric tests, ensuring the use of appropriate grading systems.
- The topic of causation was addressed, with the requirement that evidence must include correspondence from specialists indicating HIV as a likely cause of the assessed conditions. The importance of precise language surrounding concepts such as cause and association was reiterated.
- Using conditions as defined by the International Classification of Diseases was also suggested. It was noted that using standardised definitions was beneficial and could include categories that encompass HIV-related infections, tumours, or comorbidities associated with ageing.

Next Steps

- The Cabinet Office confirmed a request for additional input from the group would be circulated tomorrow, and members were encouraged to collaborate on this before the next meeting.

Meeting of the Infected Blood Expert Group - *10 Oct 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Dr Ahmed Elsharkawy, Dr Ian Williams, Professor Graham Foster, Professor Alexander McNeil, Professor Patrick Kennedy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update

- The Chair thanked the group for their work on the evidence-led and health impact supplementary routes. He noted there would need to be a narrative on the supplementary route around the explanation of the advice the Expert Group is providing.
- The Cabinet Office provided an update on the Written Ministerial Statement laid on that day relating to the Non-Executive Directors appointed to IBCA. There was also an update on Parliamentary dates for debates.

Unethical Research Awards

- The Cabinet Office introduced this item and the option to set the eligibility pathways for infected people to meet the criteria and receive the Unethical Research uplift to the autonomy award. The Chair said that the aim would be to keep this straightforward and simple for applicants, broadly focused on what Sir Brian Langstaff commented on in the Infected Blood Inquiry report, for example the research culture at Treloar's College.
- The Expert Group discussed whether the scope should be wider than only those who received blood products. There was a discussion on the importance of speaking to the community about the scope of this award. The group acknowledged that no records were likely to be available and for that reason the best approach would be to name certain time limited research projects and named research centres. This option would ensure very few people would miss out on the uplift. Concerns were raised around whether this would allow anyone to argue that their data was used in retrospective studies.
- The Group voiced concerns around the impact this could have on current research There was a discussion about whether there would need to be a separate pathway for non-haemophiliacs to show whether they were part of unethical research, it was noted that the Infected Blood Inquiry report focused on haemophiliacs when discussing unethical research.

Meeting of the Infected Blood Expert Group - *17 Oct 2024 17:00 BST*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Graham Foster, Professor Patrick Kennedy, Professor Alexander McNeil, Dr David Asboe, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update on the House of Lords Debate on the Infected Blood Inquiry

- The Cabinet Office provided an update on the Lord's debate which took place on Monday 14 October and the two debates the following week for the Infected Blood regulations. There was also an update on the first cohort of people that were due to apply for compensation through IBCA and interim compensation payments to estates due to open later in the month.

Health Impact Route eligibility criteria

- The Cabinet Office thanked the group for their work on the eligibility criteria for the health impact route. The group discussed whether the discretionary element attached to some of the health conditions should be removed. The group thought the significant contributing factor was that the infection was a causal mechanism for the health impact. The group said it should be phrased as evidence of one of these conditions after the onset of infection.
- For those with HIV that developed a haemorrhagic stroke the group thought it was important to qualify that it had caused serious physical disability and that someone with a minor stroke with no long-term disability would not qualify. They noted the need to demonstrate severe physical or neurodisability in order to qualify, and noted the need to demonstrate a needs assessment that the condition was of sufficient severity as to require additional care. The group thought it was important to list eligible conditions as well as a description of the severity of the disability to improve the specificity that this was a HIV-related condition.
- The group discussed the conditions already covered under the core route and how that interacted with the conditions in the supplementary route. The group agreed to review the list of conditions and consider those that were not sufficiently likely to be causally connected. For those that were removed this should be explained in the narrative. The group discussed whether any conditions currently in the list needed to be added or removed from the list.

Health Impact Route Special Category Mechanism (SCM) award

- The Cabinet Office introduced this item and asked to test the rationale for how the award would be applied to particular people and how the tariffs should be adjusted, for example nature and duration of care needs. The group thought it would be important to ensure that those with HBV had equivalent consideration to those who had HCV, especially where the core route did not capture the impact of SCM and they did not automatically qualify as they had not been eligible for previous support schemes. The group felt that Hepatitis B complications could be characterised via a small list, up until the point treatment was introduced because most complications normalised fairly quickly. Most conditions would likely be lifelong but candidates applying would be rare. The number of people who had interferon who had Hepatitis B was small.
- For Hepatitis C the group noted it would be important to know if the duration would lead to a bigger award than the Infected Blood Support Schemes payments; if it does not their needs would be met by the IBSS payments continuing. For Hepatitis B the group felt it was important to understand the duration and if the amount was much less than the IBSS payments then this would be an anomaly. It was felt that the logic of the scheme as designed should not be distorted to respond to the decision to continue with Support Scheme payments. The Expert Group agreed that advice should try and quantify the approach for increased care needs that were likely there.

ACTION:- The Expert Group agreed to consider amounts for an increased care award for those on IBSS and to those newly presented to the scheme, to ensure they are catered for in the Scheme.

Meeting of the Infected Blood Expert Group - *31 Oct 2024 17:00 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Graham Foster, Professor Patrick Kennedy, Dr David Asboe, Dr Ian Williams, Professor Jane Anderson, Dr Ahmed Elsharkawy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Update

- The Cabinet Office provided a progress update on drafting the second set of Infected Blood regulations.

Special Category Mechanism (SCM)

- The Expert Group agreed that those with Hepatitis applying for the health impact supplementary route due to SCM should have a tariff adjustment close to those who had cirrhosis.
- For those that were deceased the Expert Group suggested an additional 10 years of domestic support and care would be an appropriate adjustment. It was noted that taking historical diagnosis would expand the numbers that are eligible. This also meant that for the living the Infected Blood Compensation Authority would need to be pragmatic to ensure there was not a higher burden of proof on the living.

Health Impact Supplementary Route: Severe Psychiatric Disorders

- The Expert Group discussed the severe psychiatric disorders which should be in scope for eligibility to the supplementary route. They noted that it would be hard to separate clinical manifestations of different disorders. They agreed that there would need to be a significant change after infection to ensure there was a reasonable confidence that it was due to the impact of the infection. It was noted that a certain level of poor mental health was already considered under the core award.
- The group discussed how to change financial loss and care as a result of those diagnoses. One proposal suggested by the group was that a consultant psychiatrist reviewed the person and there was regular or inpatient treatment and that this could be an appropriate threshold.

Expert Group Report

- The Chair provided an update on the work of the addendum expert group report, including the structure and the approach for unethical research awards.
- The Chair provided an update on the evidence-led route as ministers had agreed to impose a cap which would be the 90th percentile.

Meeting of the Infected Blood Expert Group - *7 Nov 2024 17:00 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Jane Anderson, Professor Patrick Kennedy, Dr David Asboe, Professor Alexander McNeil, Dr Ian Williams

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Cabinet Office Update

- The Cabinet Office provided an update on the Infected Blood Compensation Authority's progress.

Modelling of the health impact supplementary route

- The meeting commenced with an update on the modelling for the health impact supplementary route. Discussions centred around establishing the range for the HIV cohort to calculate the proportion anticipated to go down the health impact group.
- There was acknowledgment that providing precise figures is challenging, and it was advised that these should not be cumulative across different groups. It was suggested that approximately a maximum of 10-20% of those with HIV would likely go through the health impact supplementary route overall, with numbers anticipated to be much smaller. A distinction was emphasised between the number of individuals making a claim and those making a successful claim.
- The group noted that current data indicates that 1,200 individuals were infected with HIV in total, with 200 still living. This does not impact on costs for financial loss as the core route already assumes 100% financial loss, and the group noted that the core route also provides a generous care profile. The focus should therefore be on those who could justify an increased care profile, such as individuals with visual impairments or various 'defining' illnesses who survived sufficiently long to benefit from treatments that became available in the late 1990s.
- The assessment was that the proportion of individuals requiring additional care is likely small, around 10%. This percentage is reserved for those who can demonstrate a need for more care beyond their present profile, as exemplified by historical groups surviving severe illnesses like AIDS during the late 1990s—these groups were very small, and considerations related to their impact on disability must be ensured.
- Among approximately 300-400 individuals reviewed for visual blindness, only two met criteria, illustrating the minimal number affected; renal impairment is more prevalent, especially among Black African communities, posing different challenges than visual impairment. Additionally, only a small number live with long-term neurocognitive impairments. Thus, setting an overarching estimate at 10% seems appropriate.
- The group considered whether individuals, such as those who survived and then progressed to end-stage renal failure, could justify higher demands for care and noted that while they constitute a small number, the expenses involved could be substantial.
- It was clarified that the infected blood community is not necessarily identical to the one currently observed and consideration needs to be given to the historic context too. Claims can be made from the estates of individuals who have died, meaning they do not need to have lived with the condition for an extended time to file a claim. This group was disproportionately affected by conditions that historically affected life expectancy, and thus considerations are toward the upper range of previously discussed projections.
- The current core care profile already accounts generously for those who would have died, and estates can claim, though contemporary complexities arise with individuals currently living through age-related conditions, such as strokes, which represent additional challenges within these analyses.

Evidence-led supplementary route

- Cabinet Office provided an update on the evidence-led financial loss award, initiating a discussion about establishing 'twin salary' points at both the time of infection and the point where work was reduced.

- The concept considered the progressive nature of impairment, potentially impacting an individual's career throughout the period of infection to the point where they reduce work. The application of a progression multiplier to the salary at the point where work was reduced acknowledges this. There is a progression which applies the salary at two points.
- There was mention of cases where individuals worked while infected and reduced work only once symptoms, such as those of Hepatitis, manifested after a dormant period. For example, someone might work for 15 years before infection symptoms begin to impact their capacity.
- Concerns were raised about using a midpoint in salary calculations, as some individuals may have progressed in their careers and reached higher earnings levels during the intervening period than a midpoint would suggest. Conversely, a person might have experienced a salary drop after infection, which would not reflect the true impact if a reduction over time is averaged out. This may be simpler and be better achieved by identifying specific salary points to avoid disparities between evidence and calculations.
- Discussion included identifying ways to calculate salaries for individuals who were infected for many years with no impact if they are asymptomatic for a time, while also acknowledging that the impact on work might occur immediately.
- A query was raised about whether centiles or deciles are being used, with an understanding that ASHE data operates in deciles, indicating the need to interpolate between to match salaries. Given this context, using deciles was agreed to make more sense as a midpoint.
- A provision was proposed which allows for flexibility, taking either the salary at the point of infection or the reduction, giving the benefit of the doubt where evidence shows earnings higher than predicted. This approach was confirmed to work for taking the higher salary either at the point of infection or reduction.
- The approach needs to consider instances where jobs are lost unrelated to infection, with the highest salary considered helping mitigate risk.
- It was suggested that if the group was content with using the higher salary, it may not be necessary to specify points, but rather select a relevant salary within the infection to reduction period. Evidential challenges could arise if a payslip falls between these points, particularly over a span like 15 years.
- Constraints in regulations around defining terms were acknowledged, with consideration that a salary might be set within 18 months of specific points, based on those points.
- A payslip that sits between either time point can provide evidence from which reasonable inferences may be drawn, assuming similar conditions at those points.
- There are limitations to investigating things like dividends and shares; therefore, annual salaries form the basis of this. A payslip acts as shorthand for various evidence forms, with tax records ideal for gathering complete information.

- The discussion focused on determining the appropriate rate to use for the years between initial infection and reduction in work capacity. There is a preference for taking a midpoint between these two points, but consideration was given to whether it might be more rational to apply the calculation forward from the point of reduction.
- Concerns were raised about the effectiveness of sorting evidence at two points in time and whether there might be an objection to using a midpoint. If the higher salary is used to apply the progression multiplier, questions surfaced about the validity of using a midpoint.
- There was a discussion of when there would be a need for evidence of actual salaries and addressing scenarios where evidence is provided across multiple stages between infection and reduction. This is where using a midpoint can help draft an inference.
- The matter of asking individuals to provide earnings annually after reducing work capacity was examined, with thoughts on how to lessen the evidential burden during this period.
- Concerns were acknowledged regarding the types of evidence individuals might possess and the duration for which wage information and bank statements are typically retained. Broad evidence, such as letters stating a new salary, may provide useful information, but efforts should be made to simplify this process.
- The rationale for needing to identify which salary to apply the progression multiplier was discussed, recognising that individuals continued working during this time.
- Compensation through the core route was noted, with supplementary awards aiming to address the amount beyond the core route.

- It was agreed that utilising the salary at the reduced work capacity makes sense for calculations, as higher working potential between infection and reduction periods is already compensated. Differences with the core award need to be computed.
- There was a concern that by requesting evidence, individuals might default to presenting the highest salary from the point of infection onwards, impacting core award calculations.
- When considering centile matching at reduced rates, it was noted as important to ascertain earnings immediately before work capacity reduction, given existing core route provisions help frame the range in between.
- Options for working out the salary during the period between infection and reduction include using a midpoint or requesting annual figures.
- It was highlighted that there is potential for overcompensation, especially among higher earners, as many would likely have earned more during the intervening period. Starting with the assumption that deductions must be made because they classify themselves as high earners, the burden of producing earnings evidence was discussed as a way to conduct year-by-year calculations.
- For those entering the scheme asserting high earnings, there is an option to deduct amounts from financial loss prior to that date, negating the necessity for detailed earnings information in that period.

- There was a discussion about potentially overcomplicating this proposal.
- Concerns were expressed about people potentially selecting their highest-earning year, proposing a rolling average or a three-year average could account for variations and provide an equitable basis.
- Determining how to account for reduced capacity in earnings was recommended through a three-year average, facilitating the matching of salaries to multiplier applications.
- Suggestions included providing one to three salary certificates for the years preceding reduced work, allowing flexibility and accommodating potential documentation issues.
- The inclusion of bonus and overtime payments in salary calculations was debated, particularly how fatigue might affect such earnings, especially for lower earners.
- Earnings by commission were suggested to be treated similarly to bonuses, ensuring corresponding ASHE tables are used to match percentile calculations.
- It was noted that bonuses can be included alongside commission payments under PAYE, and further examination into methodology was advised to consider whether incentive tables should merge these elements.
- This requires raw numbers for accurate percentiles matching.
- It was important to ensure bonuses do not inflate someone's percentile disproportionately, and a clear understanding of what constitutes salary was crucial.

- Reflection was encouraged on considerations within tariff-based scheme constraints, focusing on what should be included or excluded from standard income calculations.
- An action was agreed for further consideration of the methodology and constraints within a tariff-based scheme.
- There is a question regarding how to assess earnings after an individual's capacity to work is reduced, particularly if they have changed professions. The intent is to draft a full proposal and follow up with further discussions next week.
- To address the evidential burden, an alternative approach for missing evidence periods could involve reverting to the core route award for a given year or averaging the years surrounding a missing piece. While there is an opportunity to provide evidence, it is not an absolute requirement.
- A rolling three-year basis for determining earnings was suggested to accommodate variations in evidence availability.
- In cases lacking evidence, returning to the core route as a reasonable starting point is proposed. This principle emphasises not providing compensation without tangible evidence, as reductions in earnings are already built into the core scheme.
- The evidence-led approach does not carry over assumptions from the core route. It was therefore noted that the Infected Blood Compensation Authority (IBCA) will need to explore how to bridge information gaps to ensure fairness in outstanding claims.

- The group noted that the estimates of haemophilia cases in the SEG report might be overly generous, suggesting figures between 1,200 and 1,500.
- Reference was made to data from an epidemiological report by Robin Lancaster. Data from a Haemophiliac database illustrates roughly 1,250 cases up to 1986/87. Post-screening numbers might be small, with about one hundred affected via blood transfusions. Estimates stood at around 1,250, sourced from epidemiological data and the Haemophiliac database.
- Discussion raised the idea from the SEG report it was noted that the initial count of 1,250 cases was divided into two sections: those with HIV and bleeding disorders, and a second group with HCV and bleeding disorders, totalling up to 5,000. When combined, this results in a total of approximately 6,250 in the register. This suggests that the 1,250 count does not solely represent those infected with HIV, but also includes a cohort infected with HCV.
- Additionally, it was highlighted that within the HIV cohort, there were individuals coinfected with HCV, leading to a smaller subset infected only with HIV. The report indicated that the larger numbers accounted for either sole infections with HIV or Hepatitis. The SEG report attempted to confirm possible cases within the 5,000 number. Overlapping these figures with the HIV data produced the combined totals, although there was speculation that the category for possible cases may not have fully materialised as anticipated.
- It was noted that Hepatitis C diagnoses have historically been delayed compared to HIV. While HIV was diagnosed and screened by 1986/87, confirmation of Hepatitis C did not occur until around 1991/92. Consequently, there is a possibility that many individuals were not screened for Hepatitis C during this interim period. However, it is presumed that haemophilia centres would have implemented screening protocols as soon as Hepatitis C antibody tests became available, as patients receiving care at these centres would have been subject to regular screening procedures
- The group deliberated on future products required to communicate these findings and clarifications to the community effectively.

Meeting of the Infected Blood Expert Group - *12 Nov 2024 12:00 GMT*

Attendees of the Expert Group: Professor Jonathan Montgomery, Professor Alexander Mcneil

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Ready Reckoner

- The Cabinet Office introduced the latest proposals for the evidence-led financial loss route. The Expert Group asked the Cabinet Office about how the tool would work after someone had retired. The Chair noted that there would be a more detailed opportunity to consider someone who decreases the amount they work and how a ready reckoner would work. The group noted that the key factors for this tool would be age, salary reduction and percentile. Progression multipliers were designed to account for career progression, they were particularly helpful to those infected at a younger age to better understand how careers would have progressed if it were not for their infection. The idea was to account for those infected who felt the effects of that infection at a young age. The key focus would be what percentile and at what age. The group noted that what happens after the reduction in earning could be complicated and highly individual. But the percentile before, and the age of the person, should be the focus. On someone's pension this looks at mimicking the kind of calculations used for lost employer pension contributions in the Ogden tables. The tool applies 6.1% to today's equivalent salary so it was thought the increase in the value was built in. This would of course be less than defined benefits-style pension which would be likely to be more generous. The group noted the core route financial loss award already builds in a very significant pension provision.

Questions on process

- The Cabinet Office looked at the evidence that IBCA could consider for the evidence-led financial loss route. The group discussed whether someone could provide evidence from the previous 12 months' salary but given the option if that was lower than the ones before, then to provide the average of the three previous years.

Earnings following reduction to work - evidence

- The group noted the importance of guarding against fraud when considering evidence requirements. They enquired about whether if someone presented what they had available to them as evidence, whether IBCA would be able to draw inferences from that evidence. The question would be to ask an applicant to produce evidence of earnings in each year, but whether IBCA can create a set of principles of what to do in the absence of that evidence. They noted that where evidence was difficult to find, applicants should approach HMRC for evidence of earnings at an earlier stage. The group thought someone could get all previous year assessments. The group agreed that the discussion would need to go further than fraud when it was discussed with HMRC as it should be an opportunity for the applicant to check whether they should go down the evidence-led route on the basis of their circumstances.
- The group discussed the progression multiplier and how salaries would change under time. The group felt it comes close enough to what was looked at previously that it is workable, there were concerns about which would be more appropriate for the regulations. The group agreed to consider accounting for progression and return for a further discussion.
- The group discussed how this should be explained, ensuring consistency in approach.

Alternative discount factors

- The core route asks for current salaries to prevent the need to ask questions around inflation. The group felt it would be best not to disrupt this principle if it could be avoided. The group noted that the pension calculation was very different which made the core route attractive. At the beginning the group made the assumption that if someone worked in the public sector they might have a defined benefit but if private then it might be a defined contribution. Historically that might

have been true but since 2000 that was not the case. High earners might say compared to the core they would have had a better pension. The Chair noted that in these cases they always have the option to go to court.

ACTION:- Cabinet Office to arrange a call with ONS ASHE table team

ACTION:- Expert Group to review pension pot interest calculator

Meeting of the Infected Blood Expert Group - *21 Nov 2024 17:00 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Graham Foster, Professor Patrick Kennedy, Professor Alexander McNeil, Dr David Asboe, Dr Ian Williams, Professor Jane Anderson, Dr Ahmed Elsharkawy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome and Update

- The Chair updated the group on his meeting with the Minister for the Cabinet Office.
- The Cabinet Office provided a progress update on the regulations.

Follow-Up Discussion on Health Impacts Supplementary Route

- The Cabinet Office updated on the work undertaken on the conditions for psychiatric disorders, including a recent conversation with the Department of Health and Social Care, which resulted in further refinement of the condition list. A proposal was shared with the group, focusing on which conditions might increase the likelihood of someone requiring psychiatric care due to infected blood.
- It was noted that there was a distinction between a causal relationship and a pre-existing disorder that worsened due to the infection. A point was raised that there might not be compelling reports linking Hepatitis to schizophrenia without the use of Interferon.
- The current status of International Classification of Diseases (ICD)-11 was noted as not yet implemented, it was mentioned that an earlier version (ICD-9) was more limited in scope.

ACTION:- The Cabinet Office to discuss the list further with DHSC

- Concerns were raised regarding retrospective evaluations of what caused psychiatric disorders. The importance of distinguishing between conditions that caused or exacerbated issues was highlighted.
- The need for quantification in the proposed regulations was emphasised., It was discussed that whilst costs associated with HIV might be covered, longer domestic or low care costs might not be included.
- It was noted that this award might primarily relate to Interferon treatment, along with a noted higher prevalence of Hepatitis C among inpatient mental health patients without substance abuse issues.

Background Assumptions

- The group discussed whether to reassess background assumptions regarding the ability to work or non-medical care costs, and how to identify the subset of mental health disorders that might change that.
- It was concluded that there were very few diseases that would invoke disorders, and it was suggested that no further tweaks are necessary. If an individual required a high level of care for psychiatric disorders, that should be sufficient to demonstrate a cause and effect. The only uncertainty mentioned was regarding chronic fatigue.
- A query was raised regarding the meaning of "sustained" care and the relationship between being under active care and long-term disability. It was noted that interferon-induced psychosis was a clear example that needed further understanding regarding changes to earning and care cost assumptions.

Care Cost Considerations

- Discussion turned to identifying how alterations in care cost profiles, particularly for HIV, could lead to changes in definitions and diagnostic categories. Support was voiced for a relatively wide range of diagnostic criteria to facilitate understanding of care implications.

- It was noted that under current psychiatric categorisation, ICD-11 might not be consistently applied, and the approach of categorising disorders should be examined before it was included in the regulations.

Drafting Queries

- Cabinet Office raised a query about optical neuropathy caused by cryptococcal meningitis in relation to drafting the relevant section of the regulations. A proposal was made to specify that a consultant neurologist's involvement would be necessary.
- Cabinet Office raised a query about the need to define "severe" in the regulations and queried whether it may be self-evident from the context. The group raised concerns about the clinical outcome when considering “severe” terminology in relation to mobility and disability.
- Clarity was sought regarding whether all conditions in Group 5 are considered lifetime conditions for HIV. It was noted that uplift is only applicable while receiving renal replacement therapy, and that care requirements may cease following a transplant.
- The minimum support duration was discussed, with triggers set at three months prior to care conclusion, such as a transplant or continued dialysis until the end of life.

Options for Supplementary Care Award

- A potential route for supplementary care awards was proposed for individuals wishing to receive recognition for past care based solely on actual costs incurred. Discussion occurred regarding the appropriate placement of any cap on these claims.
- The question was raised about whether past care costs should be uplifted to current values for 2024. Concerns were voiced regarding the fairness of such a system to less privileged individuals.
- It was noted that acceptance of a cap on additional amounts claimed might improve the system, although this is contingent on where the cap is set.
- The argument for inflating payments was based on the notion that the money not spent could have been invested. Caution was advised regarding this approach due to potential risks, emphasising that the aim should be to establish "reasonable costs", which the group believed had largely been accomplished, therefore there was less of a need for a top-up.

Considerations of Equality

- The setting of a cap was discussed, alongside considerations regarding differing levels of severity and how these might present equality issues across chronic infections.

Meeting of the Infected Blood Expert Group - *12 Dec 2024 17:00 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair)

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Disability

- Discussion opened regarding whether there is a local authority assessment of need and what arrangements have been made in terms of benefits and living arrangements. It was suggested that dependency could be assumed from living arrangements.
- The definition of disability was noted, with emphasis on individuals living with family rather than independently.

Financial Dependency for Siblings

- A discussion was held regarding whether the definition surrounding financial dependency applies to siblings. It was concluded that evidence of financial transfers or cohabitation would be expected. Comparisons were made with proof of earnings, indicating that while bank statements cannot be requested for every year, evidence of substantial years could suffice to infer any gaps.
- The time period for evidence supporting dependency payments was established as being at least six months prior to the death of the individual in question.

Meeting of the Infected Blood Expert Group - *19 Dec 2024 17:00 GMT*

Attendees of the Expert Group: Professor Sir Jonathan Montgomery (Chair), Professor Patrick Kennedy, Professor Alexander McNeil, Dr David Asboe, Dr Ian Williams, Professor Jane Anderson, Dr Ahmed Elsharkawy

Attendees of Browne Jacobson LLP

Attendees of the Cabinet Office

Welcome and Update

- An update on the addendum and timelines was provided. The Cabinet Office shared a link to the government response to the Infected Blood Inquiry.
- The Cabinet Office engagement period on unethical research closed that evening, with a total of 10 substantial submissions received at the time of update.

Health Impact Review

- The Cabinet Office provided an update on the health impact route, and the group was asked to review the following areas.

Group 1 – Severe Visual Impairment

- It was noted that progressive multifocal leukoencephalopathy (PML) could also cause blindness related to HIV and should be added to group 1.

Group 2 – Neurological

- Regarding Hepatitis B, the group discussed whether severe peripheral neuropathy always resulted in severe mobility challenges.
- Experts indicated that the terminology could be adjusted to either keep "severe" or remove it, with the assessment determining if criteria for additional care needs were met. It was suggested to keep "severe" in the report for clarity but consider removing it from the Infected Blood Regulations.

Group 3 – Psychotic Disorders

- It was proposed that this group should become Group 4. The classification of behaviour disorders made sense where they were located.
- The phrase "HIV brain disease" was suggested to simplify and avoid duplication.
- It was noted that D3 (PML) should be described consistently. A heading for "Cognitive Behavioural Disorders" was needed, with changes suggested for sections A (to "HIV brain disease"), B, and C.

ACTION:- Expert Group to send a list of recognised legacy opportunistic conditions.

- Experts confirmed that individuals with chronic hepatic encephalopathy typically had decompensated cirrhosis.

Group 4 – any of these disorders which are also related to a specific infection

- Interferon impacts on secondary psychotic disorders was discussed by the group. It was noted that the wording should change to "any of the disorders caused as a result of interferon."
- There was a consensus that the depressive state should be addressed without linking it to interferon; headings should reflect the condition rather than the causative factor.
- For point 3a, it was suggested that it might be relatively small and might not need inclusion.
- The need to indicate the role of blood-borne virus (BBV) infection or specific treatments, including interferon, was discussed.

- It was suggested that "interferon" in section 3c should be replaced and included in the supporting evidence section.
- It was noted that whilst HIV was not the primary cause of schizophrenia, it might impact the disease; thus, it was decided to remove section 3c completely due to the necessity of a precipitating factor.
- It was agreed that there must be a qualifier included, such as "the major role of BBV infection."

Group 5 – Diabetic Nephropathy

- Diabetic nephropathy needed to be added back into considerations for Hepatitis B and C.

ACTION:- Experts were to provide additional names under sections C and D.

Renal Replacement Therapy Discussion

- The Expert Group discussed whether to include diabetic nephropathy as a reason for renal replacement therapy.
- The relationship between blood-borne infection and the need for renal replacement therapy was debated, questioning if it was a sufficient link.
- The group agreed that dialysis should be classified under domestic care rather than low care.

Group 6 – Social Services Evidence

- The only group requesting social services evidence for domestic care was discussed.
- It was agreed that if individuals met diagnosis criteria confirmed by a specialist, they would not require a care assessment, only a local care assessment for low care or higher. Thus, inclusion of this requirement was ruled out.

Next Steps

- The Cabinet Office requested information regarding the expected proportion of individuals progressing to the health impact group and whether current discussions were likely to alter assumptions. The Expert Group expected that there would not be a change in the assumptions about how many people would be eligible to apply for this route.