

INFECTED BLOOD INQUIRY

UKHCDO SUBMISSIONS RE COMPENSATION SCHEME

- 1 The United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) is an association of medical practitioners who work within the Haemophilia Centres of England, Scotland, Northern Ireland and Wales and have an interest in the care of people with haemophilia or other inherited bleeding disorders.
- 2 UKHCDO is a Core Participant in the Infected Blood Inquiry (IBI) and has been involved in the IBI particularly in providing the inquiry with data and statistical reports based on the records held by the National Haemophilia Database (NHD), which is run by the UKHCDO.
- 3 The UKHCDO and its members have been the recipients of requests for information from people with bleeding disorders (PwBDs) and from the Infected Blood Compensation Authority (IBCA) as part of the compensation process and this has led to concerns about the compensation scheme's current functioning. The UKHCDO wishes to set out those concerns with suggestions for improvements, in the hope of improving access to the compensation long denied to the population its members serve – people with bleeding disorders.

Requests for information received by UKHCDO

- 4 The UKHCDO's NHD has received hundreds of subject access requests under the Data Protection Act 2018 (DSARs) since the Inquiry was announced and since the compensation scheme was launched. The total number of DSARs received since 2003 is approximately 1,500, with 20% of these having been received in the year the IBI report was released. There has been a further increase in the number of requests

received this year, due to the implementation of the compensation scheme, with 151 DSARs received in the first four months of 2025 alone.

- 5 For each DSAR there is a robust system for searching the database for any data related to the data subject (PwBD). This data can comprise of structured data (data that has been entered into the database and can therefore fairly easily be extracted from the database); and unstructured data (further information included in paper records that were submitted to the NHD in past years and later scanned, equally important as this can include crucial data that is no longer available anywhere else). As explained in the UKHCDO responses to the Inquiry's Rule 9 requests previously, the data held by the NHD is very variable in quality and extent. It is important to note that NHD records are not available before the inception of the database in 1969, data submissions were very limited before 1977, and the annual submission of data by Centres only became fully electronic in 2003.
- 6 For each DSAR, the structured data for the relevant PwBD is extracted from the database. If there is any unstructured data for that PwBD, the information relating to other patients must be redacted before disclosure (because the paper records often included information for more than one subject). This is a time-consuming process, which has to be checked carefully in order to ensure full disclosure and to avoid data breaches. The NHD has a legal obligation to provide DSARs to subject access requestors, as well as a requirement to meet the main functions of the database. As a result, with the NHD's current resource level, the NHD can only process a maximum of 50 sets of patient records per week (that include unstructured digitised data) for IBCA. However, IBCA have agreed to reimburse UKHCDO for this activity, and NHD will use this recovery of costs to recruit additional administrative resource to ensure that IBCA's increasing data requests can be met.
- 7 UKHCDO and the NHD have been working with IBCA to develop a methodology and data sharing agreement for sharing the data held by the NHD with IBCA, in the first

instance for those of the 3,298 claimants registered with the existing compensation schemes that are on the NHD, and then subsequently for all other PwBD eligible for compensation. The intention is that the data sharing agreement will allow the NHD to provide to IBCA data about PwBDs equivalent to the data that the PwBD would be provided with if they made a subject access request to the NHD.

Requests for information received by Haemophilia Centres

- 8 Haemophilia Centres are receiving requests for information from IBCA's Claims Managers as part of the compensation eligibility assessment. UKHCDO have significant concerns about the questions asked by IBCA, and the implications for the clinical teams and the therapeutic relationships they have with their patients.
- 9 Questions received from IBCA can be very time consuming to answer, in some cases up to four to six hours per claimant, sometimes even longer, as before confirming that the information is missing or not available, clinicians must go through the entire record page by page. The information must often be searched for in archived, often microfilmed records, making them very laborious to go through, with no guarantee of finding the information requested. In many instances, the data requested is not available or is unknowable, because records from the relevant time periods are often incomplete or missing, as noted during the course of the Inquiry itself. Clinicians are sometimes being given short deadlines (i.e. seven days) in which to respond to requests for information, which takes no account of their already considerable workloads and the length of time it may take to retrieve historical records from off-site storage. The random selection of Claimants "invited" by IBCA to make a claim is also unhelpful in terms of planning for the resource required for responding to requests for data.
- 10 In general, the questions being asked appear to be based on modern diagnostic standards and technologies that were unavailable at the time of the infections in question. The questions suggest an incomplete understanding of the issues – they

are often unanswerable because the information is not available, or the answers would be misleading (see below). There is no overlap, for example, between the period of risk for hepatitis C (prior to 1987 for concentrate and 1991 for plasma) and the availability of a test (from 1992). Consequently, the date of hepatitis C infection will be unknown for almost all patients. Asking questions which cannot be answered delays the process and increases clinicians' workloads for no benefit to patients. The Inquiry has already established that historic records are in many cases missing or incomplete – putting a new generation of clinicians in a position when they have to go through the process of establishing, again, that their patients' records are incomplete or missing is damaging to the patients' therapeutic relationships with those clinicians, undermines patient trust, and is detrimental to the delivery of patient care. The risk is that clinicians will be blamed if IBCA ask for data which is not available, or blamed for delays due to the time taken by clinicians to search for that information, and this will affect the relationship between patients and the new generation of clinicians who were not involved in the original infected blood tragedy.

- 11 The time required for clinicians to respond to these requests for information can be significant and this is likely to cause delays for PwBDs awaiting compensation, particularly when larger numbers of more complex cases start to be processed by IBCA. That is particularly so in Centres which are led by newer consultants who were not in practice at the material time and/or who have not been involved in the Inquiry and are therefore less familiar with the issues.
- 12 Clinical services for bleeding disorders are already under considerable strain, with very limited consultant workforce capacity (as evidenced in the most recent UKHDO peer review). No additional resources have been provided to enable Haemophilia Centres to fulfil IBCA's requests for information.
- 13 There is no line of communication between IBCA and Haemophilia Centres. This means that when the criteria and questions change, Centres are not informed, cannot

prepare, and also cannot let IBCA know in advance when there are likely to be problems with the criteria or questions. Regular communication between IBCA and Haemophilia Centres must be established and UKHCDO would be happy to facilitate this.

- 14 At the hearings in May 2025, when Counsel to the Inquiry asked Mr David Foley, Chief Executive Officer of IBCA, about IBCA's approaches to Haemophilia Centres for information, Mr Foley answered:

"We have an ongoing organisational relationship with the haemophilia centres, and we're working about what is the best approach for transferring information. The starting point for the claims manager is the information that is held on the infected blood support schemes, and then we will work with the individual who is making the claim as to whether there's other information that we should gather."

- 15 In answer to a question from Counsel to the Inquiry about whether claims managers have any input from the clinical assessor before asking questions of Haemophilia Centres, Mr Foley said that he would check and added: *"Certainly we've got, you know, a very clear -- it's not our claims managers, it's our data team and the centre of haemophilia to see what is the best way to request and accept information and we would only want to do it where necessary, but I'll check in to see if that's the case."*

- 16 Mr Foley answered both questions on the assumption that Haemophilia Centres and the NHD are one and the same, which they are not. It is of concern that Mr Foley's understanding in this regard is incorrect. IBCA have no organisational relationship with Haemophilia Centres - they have an organisational relationship with UKHCDO and the NHD and have been working on the transfer of information from the NHD to IBCA. There is no dialogue at all with Haemophilia Centres and there has been no dialogue between IBCA and Haemophilia Centres or UKHCDO about the best way to obtain information from Haemophilia Centres and clinicians. Centres are being asked for information (whether this is before or after the claimant is contacted by

IBCA) in a manner that is not effective or efficient, and these submissions will outline some of the difficulties.

Requests for information – examples of concern

17 It may assist the Inquiry to see some examples of questions asked by IBCA claims managers of Haemophilia Centres and to understand why these may cause difficulties.

By way of summary, the concerns fall into the following categories:

- Questions which may not elicit the information required (ambiguous questions where the answer may not provide the data needed to assess the claim);
- Questions which are unanswerable because the information is not available (but a great deal of time may be spent establishing that it is not available);
- Questions asking for information that is not necessary to assess the compensation claim or which could more efficiently be obtained elsewhere.

18 Ambiguous or unanswerable questions

18.1 Infection date/date of diagnosis/date of first positive test

These questions can be interpreted in a number of different ways, including:

- Date of first exposure to any blood product during the at-risk period
- Date of first exposure to pooled concentrate (which carried a high risk of transmission)
- Date of sample which subsequently tested positive (the date the blood was taken, which if stored may have been years before a test was available)
- Date of first positive test (the date the sample was analysed, once a test for the virus had become available, which can be many years after the date the sample was taken if it was stored). If the first positive test is missing, the result of a repeat test (the first available positive test) may be used which may be much later than

the actual first positive test. In many cases there is no overlap between the at-risk period (during which the patient was infected) and the date when a test became available.

- Date of first surrogate marker for infection (i.e. abnormal liver function tests, because there was no hepatitis test available) or date of clinical diagnosis (diagnosis based on the patient's presentation with distinctive symptoms/signs rather than a test result).
- Date patient was informed of/became aware of their infection/diagnosis (in some cases, some time after the diagnosis was made by clinicians).

18.2 The information which IBCA actually needs will depend on the infection and the circumstances, and if that is not made clear to the clinician who is being asked the question, they may interpret the questions in a way that does not provide the data actually required by IBCA. There is a need for greater clarity in the questions asked so as to avoid ambiguity, ensure accuracy, avoid any element of subjectivity or need for interpretation, and prevent clinicians from inadvertently providing the wrong information and thus affecting the amount of compensation received by their patients.

18.3 In the case of HIV, the award for financial loss (loss of earnings) is made per annum, with a lower amount awarded per year from the date of infection to the date of diagnosis, and a higher amount (double) per year from the date of diagnosis onwards. The rationale for this appears to be that some harm is caused by the infection itself regardless of whether or not the patient is aware of the fact that they have been infected, whereas other harms are caused once the patient becomes aware of their infection (diagnosis). Thus in the case of HIV, there is an important distinction between these two dates and it is important that this is made clear when IBCA are asking their questions, to ensure that the correct information is provided and that the claimant receives

the correct compensation. By way of a theoretical example, a person may have been infected some time before 1980 and have a stored sample from 1980. In 1985 (when a test became available), the stored sample, or a new fresh sample, may have tested positive for HIV. The patient may then not have been informed of the positive test until a year later in 1986. At some point, a clinical diagnosis of HIV/AIDS may have been made, based on the patient's clinical presentation. The scheme states that the claimant should receive £14,828 per year from infection to diagnosis, then £29,657 from diagnosis onwards. The person will have been infected at some point before 1980 and that date is unknowable unless there is an earlier stored sample that tests negative (and even in that situation, the date of infection is only narrowed down to a time window, not definitive). A clinician asked for the date of infection will find the date of the first positive test (1985) but must then undertake a thorough review of all available records in order to establish whether that positive test was from a fresh sample (taken in 1985) or from a stored sample, and the date of the stored sample, and whether there are any other test results (positive or negative) from earlier stored samples in order to narrow down the likely window during which the patient was infected, and may also need to look for any records of treatment with blood/blood products during the at-risk period to seek to establish the likely date of exposure. The clinician is then asked for the date of diagnosis and must decide whether this is 1980 (the date the sample was taken), 1985 (the date of the test) or 1986 (when the patient was informed of their diagnosis), or the date on which the diagnosis became clear clinically. Given the impact of the dates on the amount of compensation received by the claimant, this example shows the risk of a claimant being undercompensated because a clinician has not used the same interpretation of the question as was intended by IBCA, and therefore the importance of clarity about what information is being requested and why. This example also demonstrates that

some of the questions being asked are not possible to answer, and it will require significant time to establish that they cannot be answered (or that only an approximate answer can be given). A patient who has no stored samples will be treated differently to a patient who has one or more stored samples, as a patient with no stored samples will have even less chance of an accurate date of infection and may thus be undercompensated. UKHCDO suggest that there should be consistency between all claimants (regardless of whether they have stored samples) and that all claimants infected with HIV should be given an assumed date of infection (based on clear criteria) with the option of demonstrating that the actual date of infection was earlier, if there is evidence to that effect.

18.4 In the case of HCV, the financial loss (loss of earnings) award is made based on the claimant's age, the severity of their illness, and the date effective treatment was introduced. The information that is required is the fact that the claimant has HCV, the current severity of their illness (simple to establish/demonstrate), and the dates on which they moved from one category of severity to the next. There is no need to know (or ask) the date of diagnosis, and yet that question is being asked, causing delay and adding to the workload of clinicians for no good reason. The date of infection may be relevant if the claimant cannot demonstrate the dates upon which they moved from one severity category to the next, and we return to the difficulties inherent in this below.

18.5 Counsel to the Inquiry made the same point to Mr Quinault on 8 May 2025. as follows [our emphasis]:

"Q. I can turn to a completely different aspect of the regulations now. The regulations require, and again for anyone who wants to know, it is Regulation 14(2)(c), that the application must be accompanied by evidence which establishes the date on which

the diagnosis of the infection was made. Now as I understand the scheme, that does have some relevance for some of the HIV calculations. But the position of those infected with hepatitis C and this is the case whether it's transfusion or blood products, many were not informed of their diagnosis for years, some were tested without their knowledge and not informed of their diagnosis. What's the relevance of asking for evidence of date of the diagnosis, particularly as it may well slow down that the process of assessment of their claims because it's a search for a chimera which won't exist in the records?

A. It's not relevant to the determination of a lot of the claim. It doesn't affect what happens to the injury or social impact or autonomy award or the award for care. Those are the same. They just depend on severity band under the same whenever you were diagnosed. Where it does make a difference under the scheme is for financial loss. So as we've just discussed, the scheme pays higher rates of financial loss for people in the higher severity bands for hepatitis and obviously you want that financial -- that higher financial loss paid, you know, from when it's probably reflective of people's circumstances that's to say, you know, as far back as they were suffering those extra impacts and diagnosis is the attempt to capture a kind of marker for that. Now, I acknowledge that there will be many people who don't have that information. If they do have it, great, and the scheme can work on that. If they do not, this is where IBCA's ability to look at the balance of probabilities and other evidence comes in. There might be something in medical records that on the balance of probabilities makes it likely that that was the moment, or if there's nothing at a station, that that was the moment that someone, you know, started to feel so particular impacts would do. Where this is particularly relevant I think is in claims from people, from estates where it could well be there is just no records of any kind at all, only a death certificate, sadly, and that is where the deeming provisions come in. If no other evidence exists for those estate claims the scheme will assume that they would have -- if they died of their infection

that they would have been in the top band for four years before that, and in the band below for six years before that.

Q. We'll come on to the deeming provisions –

A. In brief that is the role that diagnosis is supposed to play in the scheme but you're absolutely right that not everyone will be able to point to that which is why the scheme has got ways of dealing with it.

Q. It's not just the question of whether people can prove it. At the moment -- and it may be my fault -- I don't understand why the date of diagnosis as opposed to the date of infection is the relevant date for any calculation of financial loss. If you have someone who was infected with hepatitis C in 1985 through a blood transfusion, we know many of them suffered the ill effects of hepatitis, they suffered them both in terms of brain fog, chronic fatigue, not knowing what was wrong with them, being brushed aside by clinicians often, they suffered the impacts in terms of their liver. Some of them were not diagnosed for 20 years. They must be entitled to be compensated for that 20-year period?

A. And they are by the scheme in that as I say from the date of infection, the financial loss is counted. The scheme assumes that right from infection, your ability to work, because that's what we're talking about here will have been reduced to 60 per cent. That is where the scheme attempts to capture those effects. But it's true I think that as people get sicker, their ability to work -- they won't -- you know, they will be much less than that and, you know, some may not be able to work at all and that is why the scheme is attempting to capture that and to give more financial loss for people in a higher severity band, but to do so and to do that fairly and to take it back to the earliest point that it should be being paid, it needs some kind of marker and the marker is diagnosis or where evidence of that can't be proved, something that can stand in place of that. So that's what it's for. It's attempting to make sure that people get paid for the

financial loss they actually suffered as far as the tariff scheme can do that, as far back they should.

Q. It may be, I think, we will need to come back to you on that in writing –

A. Happily. I'm sorry if I haven't explained it clearly today."

18.6 It seems that the distinction between date of infection and date of diagnosis, and whether both/either piece of information is required, is not clear to Mr Foley (or to his claims managers) and that lack of clarity is causing delays for claimants because clinicians are being asked for information that may not be necessary.

18.7 In many cases the date of infection is unknown and unknowable, and this was understood and accepted by the Inquiry. Whether that information is available will depend on the quantity and quality of remaining medical records, which is very variable; which centre the patient was treated at (some Centres may have more or less records than others or may have stored samples for later testing, and some patients have more or less data in the NHD because of variations in the data sent in by Centres); etc.

18.8 Date of treatment which resulted in infection

In some examples, there is a query about the date of the actual blood treatment which resulted in the patient's infection. In most cases, this is not known or knowable. In a few cases of patients with mild haemophilia who were infected after their first treatment, the question can be answered, but that is not the case for the majority. Looking for this information is time consuming and unlikely to yield a result.

18.9 Questions about the severity of liver disease

The awards for financial loss in cases of infection with hepatitis are based on the number of years the claimant suffered from chronic hepatitis, cirrhosis, or decompensated cirrhosis/liver cancer. As a result, Centres are being asked for the

month and year a claimant's HBV/HCV infection first became level 2, 3 or 4. This question is often impossible to answer, for a number of reasons. To establish the date from which the disease could be categorised as chronic, the patient will have had to have had tests six months apart, which they may not have done and which in any event it will be very challenging to find in the records. There was no antibody test earlier on, and surrogate markers were used instead, which were normal for some people for many years. It is not possible to determine when a patient moved from level 2 to stage 3 unless they had a scan every year which was not the standard of care. It is sometimes possible to infer level 3 or 4 if there is an event such as a variceal bleed, or a documented abnormal ultrasound scan and notes from attendance at a liver clinic, but in those with mild bleeding disorders and infrequent attendance, it will not be possible to provide this information. If a person died of their hepatitis C infection, they will be deemed to have been level 4 for the previous 4 years and level 3 for the six years before that. However, if they died of HIV before effective highly active antiretroviral therapy (HAART) became available, there are unlikely to be results available in their clinical records to confirm the presence of hepatitis C infection or liver disease as the focus of clinical management was on ameliorating the symptoms of HIV. Being asked these questions involves the clinician going through extensive records to look for evidence (such as scan results) which may or may not exist or be sufficient to answer the question. If PwBDs or their families obtain records in order to search for the data they need, this can be retraumatising.

- 19** Questions asking for information that is not necessary to assess the compensation claim or which could more efficiently be obtained elsewhere

19.1 Requests for redundant data/duplicate requests

In cases where the PwBD is currently registered with the EIBSS, requests are being made for data which the EIBSS already has. It would be more efficient either to accept and use the EIBSS data, or to provide that data and ask for confirmation that it is

correct. In some cases, clinicians are being asked to confirm the diagnosis (of HIV or HCV) of patients who are receiving payments from the EIBSS even though they would not be receiving payments if they had not already demonstrated that diagnosis to the EIBSS.

Similarly, even if patients who have been diagnosed with Hepatitis C and treated, and have clinic letters to prove this, Centres are asked to confirm the diagnosis which seems unnecessary.

In some cases the claims manager writes to every Centre where the Claimant has been treated. This can lead to clinicians from several Centres duplicating the work of looking for the information requested. We suggest that claims managers should write to the Centre where the Claimant is currently (or was most latterly) registered in the first instance, and only contact other centres subsequently if necessary and appropriate.

19.2 Irrelevant questions

Questions have been asked about whether the claimant is a Haemophiliac, and the severity of Haemophilia (or other bleeding disorder).

Questions have been asked about current health for patients who are no longer under the care of the Centre in receipt of the question.

Suggestions

- 20** UKHCDO are committed to assisting the infected and affected community receive their compensation as quickly as possible, whilst continuing to care for their patients. We set out below some suggestions which we hope are practical and pragmatic, but start with the overarching request that IBCA should be willing to communicate with, and listen to, those from whom they will be seeking information.

Data sharing between UKHCDO/NHD and IBCA

- 21** UKHCDO and the NHD have been working with IBCA to agree on the structured and unstructured data that will be provided to IBCA for PwBDs on the NHD who are eligible for compensation, in order to minimise the burden and time taken to provide this data to IBCA, and ensure that the data is as useful as possible to IBCA (and by extension, to claimants). UKHCDO have urged IBCA to bear in mind that the unstructured data includes crucial information that may be unavailable elsewhere and it has been agreed that this will be disclosed to IBCA. When requesters (PwBD or their family members) make DSARs, the NHD makes a recommendation that the claimant may wish to pass that data to their treating Haemophilia Centre as well as to anyone else assisting them to complete the IBCA claim form, thus assisting the Centre if they are asked by IBCA to provide information about the claimant. The data (structured and unstructured, if any) will be disclosed with no clinical commentary as it is not appropriate for NHD to provide this, and claimants will need to contact their treating Haemophilia Centre for any assistance required in interpreting the data. There are concerns about the interpretation of the data (particularly the unstructured data) by IBCA because of their limited clinical advice capacity, and it is recommended that the planned increase in the number of clinical assessors should include clinicians with expertise in bleeding disorders.
- 22** UKHCDO/NHD representatives are part of an Infection Data Working Group with IBCA, together with a patient representative from the Haemophilia Society. This working group is, in the opinion of UKHCDO, a useful forum for discussing the availability of data held by the NHD and Haemophilia Centres, the practicalities of providing this to IBCA, and difficulties with the current system. There was also the intention to set up a data dictionary, to ensure a clear and common understanding of data fields. IBCA recently disbanded the Data Working Group, for reasons that were not clear – the reason given by IBCA was that the group did not represent all the

devolved nations, despite the fact that UKHDO is a UK organisation representing Haemophilia Centres in Scotland, Northern Ireland, Wales and England. Additional representatives from patient organisations (from the devolved nations) could have been invited to join the group without the need to disband the group and interrupt its work. IBCA have now resumed the Infection Data Working Group, which UKHCDO welcome.

- 23** UKHCDO/NHD urge IBCA to be realistic about the rate at which data can be provided to IBCA by the NHD. As outlined in the introductory paragraphs above, at present NHD estimate that they can handle the equivalent of 50 DSARs per week – in other words they can provide data to IBCA (and claimants) at the maximum rate of 50 PwBDs per week. The funding agreed with IBCA will allow the NHD to recruit more staff but it takes time to recruit and train new staff to process the data. UKHCO/NHD suggest that it would be useful if IBCA could provide them with an estimate of their plans for the increase in the number of claims they intend to process, to enable the NHD to plan accordingly.

- 24** UKHCDO understand that as well as the Infection Data Working Group (which includes UKHCDO/NHD and patient group representatives), IBCA may have a Policy Group whose membership is unclear. UKHCDO's understanding is that the Infection Data Working Group's remit is to obtain data for use by the Claims Managers, but that the Policy Group's role is to interpret the legislation, determine what data to obtain and what questions to ask, and how to interpret the data. UKHCDO urge IBCA to include clinicians in the Policy Group, to ensure that there is input from those who have an understanding of the change in standards of diagnosis and care, awareness of what data is available and can reasonably be provided, how best to obtain that data (i.e. how to word questions), and how the data can be interpreted. At present, there is no indication that there has been any clinical input into the questions that Claims Managers are asking, or any discussion of the need/value for each question with consideration of how these can be kept to a minimum. There is no

suggestion that clinicians should be involved in setting policy, but only to ensure that policies can be implemented on a practical level (i.e. the data exists and can be provided). Clinicians need to be involved in developing/approving the questions being put to treating clinicians/Haemophilia Centres and helping the Claims Managers to understand and triangulate the data received. This also decreases the time commitment for the clinicians, enabling more timely responses to IBCA. Clearly, representatives of clinicians treating patients other than those with bleeding disorders would also need to be included.

Rationalisation of requests for information by IBCA to Haemophilia Centres

25 Different pathways for deceased and living individuals

We understand that IBCA have not yet started processing claims relating to deceased individuals. UKHCDO recommend that IBCA work with all relevant stakeholders (including UKHCDO/NHD) to develop a separate pathway for claims relating to deceased patients. In many cases there will be very minimal information available and a clear, fair and realistic system needs to be established which minimises the trauma to loved ones and the burden on clinicians

26 Assumed date of infection

26.1 We understand that for claimants where the date of infection is not available, IBCA will use the date of first exposure instead. We suggest that the same methodology should apply to all claimants, as it seems fundamentally unfair for claimants to receive different compensation depending on whether or not data about the date of infection is available. For that reason, we suggest that all claimants should be allocated an assumed date of infection, based on the date of first exposure to potentially infected blood, blood products or concentrate (i.e. the first treatment with blood, blood products or concentrates occurring during the at-risk windows). This would ensure equity and consistency, and

also avoid the delay for claimants awaiting receipt of information about date of infection from clinicians when that data may not be available. IBCA should ask for information about the date of first exposure to blood/blood products during the at-risk windows rather than the date of infection. This would be clearer and less likely to be subject to interpretation, which a question about date of infection may be (as set out above).

- 26.2 Questions about the date of first exposure can be difficult for Centres to answer, particularly if the PwBD was first exposed before they started attending a Haemophilia Centre – for example in a District General Hospital, an A&E department or in a paediatric setting when they had their first major bleed. When the care of the patient is transferred from another hospital to a Haemophilia Centre, the referral letter may not give the date of first exposure or past treatment history. First exposure documented in the NHD may be many years or decades after actual first exposure, especially if that treatment occurred before the inception of the database or in a District General Hospital without a Haemophilia Centre.
- 26.3 Searching the records for the date of first exposure is a time-consuming process with no guarantee of success. Claimants (where the claimant is an infected person) can be asked when they were first treated with blood products, or the date of the procedure which required treatment with blood products, and this, in combination with data available about the time window during which blood products were infected with HBV/HCV/HIV, can be used to determine an assumed date of infection, on the balance of probabilities. If the date of first exposure is not known by the claimant, it can be requested from the Haemophilia Centre, or there may be a record with the NHD of the first treatment reported to the NHD. It should not be necessary to cross check this date with the Centre that reported the treatment information to the NHD.

26.4 If there is no data about the date of the first treatment with blood products, we suggest that the following assumptions be used, together with the data available about the at-risk windows:

Severe: Aged 1.49 years. [Ref: Pollmann H, Siegmund B, Richter H. When is severe Haemophilia A diagnosed in children and when do they start to bleed? Re-evaluation after 10 years of experience. Hamostaseologie. 2010;30(Suppl. 1):S112–S114]

Moderate: Aged 3 years. [Ref: Kloosterman F.R., Zwagemaker A.-F., Bagot C.N., Beckers E.A.M., Castaman G., Cnossen M.H., Collins P.W., Hay C.R., Hof M.H., Gorkom B.L.-V., et al. The bleeding phenotype in people with nonsevere hemophilia. Blood Adv. 2022;6:4256–4265]

Mild: Aged 8 years. [Ref: Kloosterman FR, Zwagemaker AF, Bagot CN, Beckers EAM, Castaman G, Cnossen MH, Collins PW, Hay C, Hof M, Laros-van Gorkom B, Leebeek FWG, Male C, Meijer K, Pabinger I, Shapiro S, Coppens M, Fijnvandraat K, Gouw SC. The bleeding phenotype in people with nonsevere hemophilia. Blood Adv. 2022 Jul 26;6(14):4256-4265]

26.5 At the hearings in May 2025, Counsel to the Inquiry asked Mr Foley whether IBCA would support a change in the regulations so that instead of date of diagnosis, IBCA was required to look for date of exposure. Mr Foley said that he would give this some thought. UKHCDO's view is that date of exposure should replace date of infection (rather than date of diagnosis). Infection can be assumed to have taken place due to exposure, however diagnosis (resulting in the patient becoming aware of their infection) may not have occurred until some time later (i.e. after the advent of testing).

27 Severity of liver disease.

27.1 With regard to liver disease, we suggest that it is not practical to attempt to determine how many years a claimant has spent at each level. The awards

tables state that where a person is unable to evidence their disease progression, compensation will be calculated on the basis of assumptions about the number of years spent at level 3 and 4. Currently, those assumptions are made based on the date of infection, which may not be available or accurate. The wording is unclear but these assumptions could be clarified and extended to cover all levels, and applied to all claimants. This would be quick, clear, and equitable. Anyone with positive evidence of earlier progression than allowed for by the assumptions could be invited to provide that information, which would take precedence over the assumptions.

- 27.2 UKHCDO wishes to take this opportunity to recommend that where a claimant has previously suffered with a higher stage of liver disease and then moved down a stage, their compensation should be assessed on the basis of the highest stage they have reached rather than the current stage. This would seem fair given the time spent at the higher stage and the risk of further progression of the disease back to a higher stage. UKHCDO suggest that the treatment undergone by claimants should also be factored in to the compensation scheme.

28 Hepatitis B

UKHCDO are concerned that IBCA do not appear to be addressing compensation for Hepatitis B in an equitable manner. The limited number of PwBD so far invited to make a claim do not appear to include Hepatitis B mono infected claimants because these patients were excluded from previous compensation schemes. The criteria for compensation do not treat Hepatitis B on a par with other infections. For example, patients who were infected with Hepatitis B and then cleared the infection do not get any compensation, whereas patients who were infected with Hepatitis C and cleared it naturally, do.

29 Format of queries

Queries are received from IBCA in a variety of formats – emails and forms – with a variety of questions (some of which are outlined above). UKHCDO suggest that it would be more efficient for the format to be systematised, and in particular, suggest that the standard questions should be reviewed and approved by IBCA's expert group to avoid some of the issues outlined above. Questions also need to be clearer and less likely to be subject to interpretation to ensure that the information required is provided. For example if IBCA require the date upon which the claimant became aware of their infection/diagnosis, that is the question which should be asked (ideally, of the Claimant rather than the Centre), rather than asking for the "date of diagnosis" which can be interpreted/answered in a number of different ways as outlined above.

30 Information requests overall

UKHCDO urge IBCA to consider requesting the minimum dataset possible rather than asking for all information that may potentially be available, and to develop a clear process and hierarchy of processing information, as well as avoiding redundancy of requests.

More engagement between IBCA and clinicians

- 31** UKHCDO entirely supports the calls for more engagement by IBCA with the infected and affected community. UKHCDO also calls for more engagement with clinicians, who are/will be involved in the compensation process in a number of ways, including assisting claimants in completing application forms and in answering questions/requests for information from IBCA or claimants. UKHCDO are very willing to represent their members (clinicians working in Haemophilia Centres) in discussions with IBCA about the most effective and efficient way for Centres and clinicians to provide the information IBCA require, and to cascade information to clinicians.

- 32 UKHCDO will provide training to colleagues, including regular panel meetings to which clinicians can bring questions, so that the more experienced can support more recent appointees.
- 33 At the hearings in May 2025, in response to a question from Counsel to the Inquiry about which claims take longer than others, Mr Foley said that *“the component part that elongates it is when we need to go somewhere else for information and that is usually the longest part”*. Sir Robert Francis added that: *“our experience has been that as things stand practitioners, busy practitioners, in the National Health Service, or busy administrators don't necessarily give this the priority that we would like and we are seeking -- and that's no criticism of them because we all know what pressure the NHS is under. But we are engaging with the Department of Health to see whether some more clear guidance can be given to practitioners to assist us in the way that we've asked.”* Whilst UKHCDO understand the frustration caused by any delay in the compensation system, it is perhaps not surprising that there may have been delays on the part of some practitioners and administrators given the lack of any engagement by IBCA with practitioners and administrators about how best to ensure that IBCA is provided with the information needed. UKHCDO endorse the call for clearer guidance, although there is some doubt as to whether the Department of Health is the right organisation to provide this. In addition, any guidance must be accompanied by better engagement with those practitioners and administrators in the NHS who will be called upon to find the information requested by IBCA, to enable the most efficient and effective process to be adopted. There is a need for collaboration, rather than seeking to pass the blame for delays from IBCA onto NHS practitioners and administrators who are already under considerable (clinical and financial) pressure. Whilst UKHCDO would endorse Sir Robert's desire that this work should be given priority, that priority has to be backed up with resource – without that, other work (of equal priority to those patients for whom it is done) will be deprioritised.

- 34 UKHCDO are aware of examples of Claims Managers copying in claimants when they are emailing consultants to ask for data. This is inappropriate – the claimant may have given their consent to share their email address with the consultant, but the consultant has not been asked. If the consultant is on leave, or away from the hospital at a conference, the Claimant will not be aware and will simply believe that the clinician is delaying their response. Claims Managers need to have standard operating procedures, including guidance about these communications and setting realistic timelines for a response.
- 35 UKHCDO also calls for a bleeding disorders specialist to be invited to join IBCA's expert group, as originally recommended by the Inquiry.

Prioritisation of claims

- 36 The Inquiry has invited submissions on a proposal to help establish the most appropriate way of achieving a fair scheme for prioritisation. UKHCDO consider that patient groups and representatives are best placed to comment on these. However, there are some practical considerations to bear in mind in relation to the first proposed factor “less than 12 months to live”, and how this will be established. Writing to a patient to ask the question may be offensive, and estimates of life expectancy by doctors are notoriously inaccurate. It should also be borne in mind that if a claimant is aware that priority is being given to those who are dying, and they receive a letter from IBCA asking them to lodge their claim, they may be distressed by the thought that they have been assessed as being in the last 12 months of life.

Tania Francis

HEMPSONS

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Hempsons LLP | London

Third Floor

3 Dorset Rise

London EC4Y 8EN

t: +44 (0)20 7839 0278

f: +44 (0)1423 724047

DX307430 Cheapside

www.hempsons.co.uk