

Reference Number: FOIAH2324/216
From: Private Individual
Date: 19 July 2023
Subject: Correspondence sent to, CC'd to or from the Haemophilia Centre Director

Under FOIA , I am requesting the following information:

- Q1 All e-mail correspondence (including any attachments) sent to, CC'd to or from the Haemophilia Centre Director during the period 5th April 2023 - 19th July 2023 which relates to the Infected Blood Inquiry or Infected Blood Compensation. The scope of this request excludes patient data.
- A1 The Trust can confirm that two emails were received during this time period that relates to the Infected Blood Inquiry. Please see attachments-
1. *Paperwork for this afternoon's Advisory_Redacted*
 2. *Infected Blood Inquiry Second Interim Report 05-04-2023 Email_Redacted*

For email 1, the attachment contains a copy of minutes of a meeting held by the UKHCDO Advisory Committee. The relevant sections of these minutes have been extracted and have been provided in attachment *Appended Minutes of the 69th Meeting of the UKHCDO Advisory Committee*. The second attachment from this email did not contain any data related to the Infected Blood Inquiry.

Email 2 contains a copy of the *Infected Blood Inquiry Second Interim Report 05-04-2023* which is attached for your convenience however can also be found published via the Infected Blood Inquiry website-

<https://www.infectedbloodinquiry.org.uk/reports/second-interim-report>

Minutes of the 69th Meeting of the UKHCDO Advisory Committee

4. CRG update

- However, it is hoped that feedback from the IBI and the Peer Review process will make this an ideal time to make more detailed specifications to aid the transition from specialised commissioning to ICBs.
- UKHCDO would have to consider what to do if NHSE specifies that the Service Specifications cannot apply to other nations. The UKHCDO closing submission to the IBI stated that it was not in the best interests of patients or clinicians to have four separate specifications and working groups

8. Peer review working party

- reiterated the vital importance of a timely process enabling a response to any IBI recommendations

11. Public Inquiry/Rule 13/Rule 9/Hepatitis C update

- The IBI closing submission and the various reports have been circulated
- Mentioned the proposal by some participants in the IBI for haemophilia 'Centres of Excellence' and possible 'passports' to fast-track healthcare for individuals impacted by infected blood
 - There was agreement that it was appropriate to await the recommendations of the IBI before taking any further action.

Actions:

- **Await IBI recommendations**

[REDACTED]

From: UKHCDO Support <support@ukhcdo.org>
Sent: 05 April 2023 15:02
To: UKHCDO Support
Cc: [REDACTED]
Subject: Infected Blood Inquiry Second Interim Report 05-04-2023
Attachments: Infected Blood Inquiry Second Interim Report 05-04-2023.pdf

Sent on behalf of the UKHCDO Executive
To: UKHCDO Members, Nurses, Physiotherapists, Data Managers
Subject: *Infected Blood Inquiry Second Interim Report 05-04-2023*

Dear Colleague,

Please find attached the second interim report published by the IBI today morning.

Best wishes,

[REDACTED]

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Second Interim Report

Compensation

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Why Make This Report Now?

It will take time to analyse and describe the facts the Inquiry has considered. But it has already been accepted by the Government that compensation should be paid, that there is a moral case to do so¹, and, on behalf of the Department of Health and Social Care, that wrongs have been done.²

Once it is accepted, as it has been, that compensation should be paid, then it should plainly be paid as soon as possible. Many who should benefit from compensation are now on borrowed time. They know too many who have already died. They know that Government Ministers have promised there will be more recompense to come. But they do not yet know the nature of the body who will determine it, how that body will assess and deal with their claims, and the boundaries of eligibility.

Sir Robert Francis KC was commissioned by the sponsoring Minister in the Cabinet Office (then Penny Mordaunt MP) to give independent advice to the Government regarding the design of a workable and fair framework for compensation for individuals infected and affected across the UK, to achieve parity between those eligible for compensation regardless of where in the UK the relevant treatment occurred or place of residence. He delivered his Compensation Study on 14 March 2022, just over a year ago.³

¹ Commons Hansard: Infected Blood Inquiry Jeremy Quin MP, Paymaster General and Minister for the Cabinet Office, 15 December 2022 Column 1250

² Eleanor Grey KC, Counsel for the Department of Health and Social Care, told the Inquiry at its preliminary hearing on 26 September 2018, referring to the words of the then Prime Minister Theresa May “*an appalling tragedy which should never had happened*”:

“On behalf of my clients, I do say those words, the acceptance that this should not have happened, is an acceptance that things went wrong. Things happened that should not have happened, and so on behalf of my clients I say, unreservedly, that we are sorry.”

The language is striking. The Department did not submit, for instance, that there was a possibility, or even a strong probability, that wrongs **might** have been done. They went further: **they had been**.

³ Infected Blood Compensation Study RLIT0001129

From closing submissions, I understood that the Government wishes to consider the recommendations of the Inquiry relevant to compensation before responding to his Compensation Study.⁴ This report supplies those recommendations.

Though consideration of the detail of the wrongs that were done must await the full and final report, two things have been accepted already by recent Secretaries of State for Health. First, wrongs were done such that infection resulted when it need not have done. Second, the initial response, maintained for some years, itself caused additional suffering. Many participants have expressed concerns that the response might yet fall short again.

People infected and affected have over decades sought recognition that wrongs had been done to them, and had been rejected; given social support, but never compensated; told that all had been done as well as it could have been, when they had reason to believe it had not. When they sought to have those views tested by a meaningful inquiry, they were told they could not have one.

When Andy Burnham gave evidence about his time as Secretary of State for Health, he said:

“... over five decades the Government had not done enough at all, failed the people who had been victims. ... I would also say, if you bring it forward to the kind of first two decades of this century, so we are going right through here, aren't we, 70s, 80s, into the 90s you know, kind of maintaining these two lines⁵ and then it is the first two decades of this century, not providing for people in very desperate circumstances, not providing financial support for them, that too damages not just physical health but mental health too, if you leave people in the wilderness in that way.”⁶

⁴ Transcript 18 January 2023 p14 INQY1000267

Note: page numbers in transcripts refer to individual pages within the transcript.

⁵ The two lines were: no wrong was done, and they had the best available treatment.

⁶ Transcript 15 July 2022 pp131-132 INQY1000228

He was explaining not only that he thought there had been unnecessary infections, but also that the response of successive Governments to this had compounded the wrongs.

Jeremy Hunt MP gave evidence about his time as Secretary of State for Health, reflecting:

*“... it took too long for the State to resolve this issue and I don’t think any of us who were in Government can escape our share of the responsibility that it took too long over successive governments to resolve it. So I’ve given you the specific circumstances during my period in office, but there were other things that happened much earlier, and I think the totality of this was a failure by the British State. I don’t think there’s any other way to describe it.”*⁷

He described what had happened as a *“terrible injustice”*.⁸

Matt Hancock MP, the then Secretary of State for Health, apologised in his evidence to the Inquiry not just for what had happened but:

*“also then how people feel they’ve been treated since, because I know ... that’s another wrong that needs to be put right ... what I can absolutely do is acknowledge the pain and suffering that has gone on for far, far too long.”*⁹

The failures of response of which these politicians spoke led to significant personal psychosocial consequences on top of those caused immediately by the infections. The psychosocial experts to the Inquiry described negative outcomes from a lack of system accountability¹⁰ and the long-term psychological consequences of campaigning for answers and an investigation over many years (and for some, for their whole adult lives)

⁷ Transcript 27 July 2022 pp164 INQY1000235

⁸ Transcript 27 July 2022 pp31 INQY1000235

⁹ Transcript 21 May 2021 p200 INQY1000121

¹⁰ Psychosocial Expert Report p4 EXPG0000003

Note: page numbers in expert reports refer to internal page numbers.

as “initial frustration and anger” progressing to “longer term distress, dejection and hopelessness.”¹¹

I cannot in conscience contribute to that further harm by delaying what I have to say about compensation. This is why I am taking the unusual step of issuing one set of recommendations in advance of all others at this stage.

My principal recommendation is: I recommend that a compensation scheme should be set up now and it should begin work this year.

Listening to Experience

Some of the milestones eventually leading to an acceptance of a moral case for compensation, and interim payments for many, have been marked by individual reactions from those in power to listening to the voices of individuals who have suffered.

John Moore, when Secretary of State at the Department of Health and Social Security, was advised by officials that there should be no payments to people with haemophilia who had been infected with HIV. He met a delegation of them, determined not to shift from this position. To his credit, he listened. What he heard brought him to tears.¹² The meeting led to the Macfarlane Trust being set up.

When Andy Burnham began as Secretary of State, he was advised against compensation payments. Closely influenced by a friend, Paul Goggins MP, he then spoke to a group of constituents.¹³ This changed his mind: he saw a parallel between the way they had been treated and the way in which the complaints of Hillsborough victims had not been listened

¹¹ Supplementary Psychosocial Expert Report pp16-17 EXPG0000042

¹² Evidence of Dr Roger Moore. Transcript 18 January 2022 pp94-99 INQY1000172

¹³ Transcript 15 July 2022 pp86-94 INQY1000228

to and had been dismissed. It has led to him being active in seeking justice for those who were infected by blood and blood products.

Jeremy Hunt MP described how at first he had been insulated by officials in the Department of Health from seeing letters from members of the public complaining about treatment they had received from the NHS. He made a point of seeing some of the letters and speaking to some of the individuals. A constituent of his was Mike Dorricott, who had been treated with infected blood products. After speaking to him¹⁴ he began to understand "*that a terrible injustice had been done*".

I hope I shall be forgiven for not mentioning those several others who, in authority, have listened, and responded to what they heard, when they heard it first hand.

It is therefore right to start by hearing people speaking for themselves. My summarising is always likely to be second best in conveying the impact of what has happened. Sir Robert obviously felt the same, for he began his Compensation Study with a selection of their voices. In my full report, I will reflect the evidence of people infected and affected more fully.

The terrible impact of being infected with HIV in the 1980s has been powerfully described by those who survived.

Stuart Gregg was infected through blood products as a child and told the Inquiry that his treatment had never been for life threatening bleeds. "*It is almost impossible to give a detailed account of how this has affected me mentally and physically. HIV, Hepatitis C and Hepatitis B have informed my whole life as I was infected at such a young age. The physical effects have been tough and at times I have been close to death. I have suffered throughout my life as a result of this. I am tired now; I am tired of fighting for answers and*

¹⁴ Before he took office, though he also had correspondence from him and met him while in office. Transcript 27 July 2022 pp31-32 INQY1000235. He also spoke to other constituents, including Melanie Richmond and Steve Nicholls.

I am tired of this being my whole life. However, it has informed who I am from a very early age and it is inescapable. It has moulded me as a person. ... The last 35 years now seem quite surreal, that we were just drifting along with this burden upon us and with nobody knowing, caring or really understanding the true depths of what really happened to us. ... The individuals, families and loved ones destroyed by this whole disaster have been irrevocably damaged by what happened. If that were not bad enough then the Government's response to this sorry affair has made the whole thing exponentially worse.”¹⁵

An anonymous witness described how she was infected in utero with HIV after her mother had a transfusion and that other family members were infected too. Her sister died first, aged five. Then her younger sister died, aged three. When she was 8, her father also died and then later her mother. She and her brother are left. She told the Inquiry: *“I just want justice for my family. I want someone to take responsibility for what has happened.”*¹⁶

Around 380 people with bleeding disorders were infected with HIV whilst children.¹⁷ More than half have died.

Colin was around a year old when he was given factor concentrate. At about two and a half he was diagnosed with HIV. His parents, Colin and Janet Smith, gave evidence to the Inquiry. His mother said: *“... he loved school but he became too ill to go really. I mean, sometimes he'd just say, 'I think I want to go school today', and we'd put him in a wheelchair, wrap him up and we'd get him literally to the door and then he'd say, 'I want to go home now.’”* His father recalled: *“... I lost my job because the boss was scared of people finding out and losing customers. So within a week I got another job. I thought*

¹⁵ WITN1252001 paras 30-31, Transcript 28 October 2019 p203 INQY1000045, WITN1252013 para 93.VIII

¹⁶ WITN3771001 para 41

¹⁷ Note by Counsel to the Inquiry on the number of children with bleeding disorders who were infected with HIV INQY0000387

I'd take a night shift job. Nobody around, nobody would know me, but the day I was going to start he called me into the office and said he couldn't start me, so from that point on I was basically unemployable. I went to the Job Centre. They wouldn't let me sign on." Colin died aged 7. His father said: *"There's no way a child should have to die the way he did. It wasn't pleasant. It still affects us now. And it's not just our son, there's lots of children have had to go through that. ... I could cope with death but not with the death of my son. I still have trouble today: the fact that he's in a grave on his own, and the guilt will never go away."*¹⁸

Susan, mother of Brian and Stephen, gave evidence to the Inquiry: *"You think what might have been. I can only still see them as 9 and 16 but it's Christmas – a couple of weeks ago it was Brian's birthday, but Christmas, we put flowers on. And right after Christmas it's Stephen's birthday, in the February, so more flowers. Then in May it's Brian's anniversary. Then in September it's Brian's birthday. And then October it's Stephen's anniversary. And then we are back to Christmas again. And it doesn't matter how many years go by, you're still asking: Why? Why? Why? And I keep going to the grave and I keep saying – sometimes I think they are not there, they are going to walk in. I just think, no, no, it can't be. ... Why? I just want someone to tell me why. It won't bring them back. I just want them back so much. I just ache for them to come back. You can't get on with your life. ... I just ache. I think it is like a heartache, your heart is aching so much, your whole body aches. I'm just mentally and physically tired, I think. I just want them back and I can't."*¹⁹

Many children lost their parents to an infection given in the course of NHS treatment, with devastating consequences.

Lauren Palmer's father was given a range of factor concentrates and tested positive for HIV when she was one; her mother was infected through him. They died within 8 days

¹⁸ Transcript 24 July 2019 pp15-16,21,32 INQY1000034

¹⁹ Transcript 29 September 2022 pp52-53 INQY1000249

of each other when she was 9. She had grown up with half-brothers. When her parents died she was separated from her half-brothers. She said: *"It was the hardest thing to deal with being separated from them. Not only did I lose my parents, I lost my brothers who were the next closest thing to me and it would rip me apart every time I would go and visit them and have to come back. I would be grief-stricken for weeks after visiting them. I just wanted to be with them. ... I was very lonely, felt quite alone, isolated, and I was going into a family where I was disrupting things. ... I lost both my parents at nine years old, at no fault of my own and, subsequently, my life has been awful and having some kind of financial support wouldn't make things better, it would never bring my parents back, but it would make my life a little bit easier and having that security of some financial support would be a great burden off of my shoulders ... it's probably held me back a lot."*²⁰

Jason Evans was 4 years old when his father died from HIV. Giving evidence, he said: *"... it just marked every aspect of life. And, you know, I've now lived my dad's entire lifespan, and I'm sat here. So it's blanketed my entire existence."* He was asked whether he was ever offered counselling or psychological support of any kind: *"No, never. And I think the thing that is particularly despicable to me is, okay, now I'm 31. But as a child, as you know, a four, five, six year old kid, how did I not have bereavement counselling? How was it never offered? I think we know from the evidence this Inquiry has heard how, it's because no one cared. The support wasn't there. But it's not right."*²¹

Many people were infected with Hepatitis C through blood and blood products.

An anonymous witness infected with Hepatitis C after giving birth in 1982 said:

"I went through years of unexplained fatigue, going back and forth to the doctor and having blood tests. I didn't know why I was feeling so tired. It was not until 2016 when I

²⁰ Transcript 7 May 2019 pp14,16,28-29 INQY1000005

²¹ Transcript 11 June 2021 pp14,20-21 INQY1000128

*found out that I had been infected. ... I was depressed. I didn't want to do anything; I couldn't be bothered. As the years progressed there was constant tiredness. Depression was brought on by tiredness. I couldn't understand why I was so tired ... It had an impact on everything we did. ... My husband would take the kids to the beach when they were younger but I would never feel like going. He felt frustrated because at that time we didn't know that I was actually ill. ... Over the years of my working life at the NHS I struggled. I had a lot of time off due to sickness because I was exhausted, picking up lots of little things because my immune system was compromised."*²²

Breda Pow was infected the previous year, again after giving birth:

*"The impact, mental and physical, this experience has had on my life has been ongoing over the past 38 years and is incalculable. I do not know where to start with balancing raising children, running a business, going to hospitals to ask for help, receiving blank looks and shrugged shoulders. The worst part has been the stigma associated with HCV and cirrhosis."*²³

People were also infected with Hepatitis B, which if chronic is a life-long disease which cannot be eradicated.

Fiona Allan was most probably infected by a transfusion in 1985 when she gave birth to a son. She said that after the birth her health was "... horrendous ... And I had nothing to gauge against, so I did put it down to it being an emergency traumatic caesarean. But I just felt so ill and I couldn't explain. ... I just felt so sick, drained, fuzzy. I just wanted to sleep all the time." She explained that she had constant fatigue over the years and "lots of brain fog". When told of her diagnosis after she went to make a blood donation and her blood was refused as Hepatitis B positive, she described how she was "absolutely scared to tell anybody at all and I was worried that I would infect people and I was worried

²² WITN0248001 paras 5,13,25,28

²³ WITN0030001 para 12

if I was holding their children. I was paranoid about everything in the house ... and it affected my personal relationship in the house quite badly."²⁴ She gave evidence in September last year. This year she has written to the Inquiry to say that she has been diagnosed with cirrhosis.

Partners and families have had to make many sacrifices in caring for their family members who were infected.

Charles Dowden's wife, Gilly, died in 2008, as a result of a blood transfusion she received after an accident. He said: "*Gilly's HCV had a huge effect on me, physically, mentally and emotionally, and on my private, family and social life. The most difficult thing is watching somebody you love falling apart day to day. ... Caring for somebody with HCV was mentally and physically exhausting. ... It is like there is a paleness, or greyness, to every day. ... this took a huge toll on my physical health. ... Gilly's death had a huge impact on me. You never expect to become a widower in your 40s and nor does society. As such, the support out there for people in my position was pretty slim.*"²⁵

Sharon Lowry's husband, Richard, died in 2011 from Hepatitis C contracted through his treatment for mild haemophilia. She said: "*I just find it incredibly lonely without him. Friends are great at the time and support you, but everyone is busy with their lives. Everyone is doing their own thing and moving on. ... I have to keep working now. I can't afford to stop work. It's just life is very different.*"²⁶

Stanley Fyffe's wife, Gill, was infected through a blood transfusion after giving birth in 1988. He said: "*Throughout Gill's illness, we have found we can only maintain one career at any time. When one of our careers began to do well, the other lagged. We found ourselves permanently in crisis mode: the more Gill tried to work, the more I had to*

²⁴ Transcript 28 September 2022 pp4,9,10 INQY1000248

²⁵ WITN1867001 paras 70,72,73,77

²⁶ Transcript 24 May 2019 p47 INQY1000012

*support her and the less work I could do. ... The work-related effects of Gill's diagnosis cannot be overstated. We have both had to make serious compromises as [to] the nature and volume of work we undertake. Gill had a very promising career as an academic ahead of her but is now permanently unable to work."*²⁷

Rekha Vaghela's husband, Suresh, was infected with HIV and Hepatitis B and C from his treatment for haemophilia. She said: "*Eventually, in 2003, I had to take the decision to leave work and to look after Suresh on a full time basis, not only for his sake but also for my own personal sanity and health. This was a sad decision but I was not being fair on myself, my family, Suresh or work. This was an extremely difficult and painful decision but there was no option but to leave work because in the current situation no one was winning. I therefore left work to become a full time carer for Suresh. ... Since leaving my job, I have seen my friends and family, of similar ages to me, soar to great heights in both their professional and personal lives. I feel that I have been left behind.*"²⁸

Summary of Conclusions

Though I shall say more about my reasoning below, the principal points I make in this report are:

- a) The moral case is a strong one. The trusts and schemes established as social support were all based upon an absence of obligation on the part of Government to make such payments. This was because Government then considered that no wrong had been done.
- b) It is now accepted that wrongs have been done. The Government was absolutely right to accept this.

²⁷ WITN0686001 paras 5.9,5.14

²⁸ WITN3571001 paras 65,68

- c) My conclusion is that wrongs were done at individual, collective and systemic levels.
- d) Not only do the infections themselves and their consequences merit compensation, but so do the wrongs done by the way in which authority responded to what had happened.
- e) Accordingly, a compensation scheme must provide appropriate redress to all who have been wronged.
- f) Time without redress is harmful. No time must be wasted in delivering that redress.
- g) The Inquiry has examined Sir Robert Francis KC's Compensation Study carefully. With some modifications, I agree with it.
- h) Sir Robert queried whether those suffering only from infections with Hepatitis B should be covered by the scheme. I recommend that where Hepatitis B infection is chronic (i.e. it has persisted beyond six months) it should be within the scheme.
- i) Sir Robert questioned whether it was appropriate to exclude - without exception - infections contracted from a transfusion, blood product or tissue transfer after 1 September 1991 where the infection was Hepatitis C. I recommend that there should be no hard and fast rule to that effect. Instead, an approach similar to that already taken by EIBSS in respect of HIV infections should be adopted more widely: the date on which universal screening of donated blood for the relevant infection was first adopted should be taken into account in assessing whether the transfusion, blood product or tissue transfer caused the infection in question but should not be the sole determining factor.
- j) The scheme should be administered by an arm's length body independent of Government, as Sir Robert suggests. I agree, and recommend that to help reassure beneficiaries and ensure that there is true independence it would be best if: (i) the decision maker in the scheme should be the Chair, who is or has been a judge of the High Court (England and Wales, or of Northern Ireland), or of the Court of Session (Scotland). She

or he should be advised by a small advisory board which should include beneficiaries of the scheme; (ii) the principles it adopts, and its decisions, should be public and transparent; and (iii) the scheme should be accountable publicly to Parliament.

k) The structure of the scheme should be set up as soon as possible, and before the final report of the Inquiry.

l) The scheme need not await that final report to begin work, since this second interim report fully covers the Inquiry's recommendations on financial redress.

m) The scheme should take account of how courts and tribunals across the UK compensate for wrongs such as physical and mental injuries, loss of autonomy, and injury to feelings, but should not try to replicate their exact provisions in the very particular context of infected blood and blood products.

n) Each infected person should be entitled to awards calculated under the headings ("categories of loss") that Sir Robert proposes.

o) Each affected person should be entitled to awards calculated under the same "categories of loss" as Sir Robert proposes for those who are infected.

p) Because each affected person should have a claim in their own right for what they personally have lost and suffered, there is no need to treat them as if they were dependants of the deceased under the Fatal Accidents Act 1976.²⁹

q) Those who seek exemplary damages may do so by civil court action, but such an award should form no part of the scheme. However:

²⁹ A provision which applies only to England and Wales, though there is a statutory instrument of the same effect which applies in Northern Ireland. The Scottish position, however, is distinct.

r) The failures of response by authority can and should be recognised fully in the award for Loss of Autonomy as proposed by Sir Robert.

s) Interim payments should now be made to recognise deaths to date unrecognised and alleviate immediate suffering. This means that bereaved parents and bereaved children who have lost their parents, where the death(s) have not already been recognised by an interim payment, should receive interim payments.³⁰

t) Where an affected person who has not made a claim dies, the sums that they might have received if they had claimed should not become part of their estate. This takes the scope of compensation too far, and does not meet the needs of the living. It should be regarded as a purely personal claim which dies with the person who has it. People who might have benefited from the estate of an affected person and were themselves affected will already have their own individual claims.

u) I recommend that steps be taken without delay to provide a bespoke psychological service in England.

v) There are other minor modifications to Sir Robert's recommendations, which are in the Recommendations in the final section of this interim report.³¹

³⁰ See Further Interim Payments pp59-61

³¹ See Recommendations pp93-99

Delivering Compensation

The Infected Blood Compensation Study³² presented to the Government by Sir Robert Francis KC on 14 March 2022 is consistent in its approach with the thrust of the evidence before the Inquiry.

In general, I endorse the conclusions and general reasoning adopted by Sir Robert. As he anticipated, given the breadth and depth of evidence considered by the Inquiry, I have some modifications to make, and some matters to add.

Delay must be avoided: it is particularly harmful to infected and affected people. Thus:

- (1) a scheme must be set up with the minimum of delay; and
- (2) the scheme must work with the minimum of delay.

There will probably be three phases in the life of the scheme: first its initial setting up, which will involve some time and effort; the second when many one-off awards will be made; followed by a third - a regular, more predictable workstream which will require less resource. The work, time and resource involved might be said to be “front-loaded”.

Setting up the scheme swiftly

If the process is pursued with purpose and vigour, delay in setting a scheme up can be kept to a minimum: the Macfarlane Trust, an initial scheme to provide support payments to those infected with HIV from infected blood products, took four months from its announcement to there being an executed deed of trust, without the advantage of a scoping study in advance.

³² Infected Blood Compensation Study RLIT0001129

In his Compensation Study, Sir Robert noted the unique circumstances in which the "September 11 Victim Compensation Fund of 2001"³³ was established, but thought its approach to engagement with applicants was worthy of note. There were extensive consultations with all interested parties by the Special Master appointed to head it. They were completed within 90 days of his appointment, and he began his work as the sole decision maker only 8 days later. It took just over three months from the attacks to start work. This fund appears to have been a notable success, and gained significant appreciation from among the beneficiaries.³⁴

It will clearly take political will to act quickly, but the circumstances here warrant it.

Working with the minimum of delay

If a scheme works too slowly it will not necessarily deliver justice.

The underlying principle adopted by the civil courts in awarding compensation for wrongdoing is to put a successful claimant into the same position in which they would have been had they not suffered the wrong, so far as money can achieve that object. This principle is necessarily centred on the individual, and implicitly recognises that each person differs from every other. It is too easy to think, simplistically, that identifying this individually assessed figure will provide justice in itself.

However, justice concerns more than simply getting the figure "right." It has increasingly been recognised by the courts that determining it must not involve excessive cost, nor take a disproportionate share of the resources of the courts and judiciary, for this affects other cases which deserve justice too, nor must it take too long. Delay often defeats

³³ The US scheme to compensate victims of the 9/11 attacks.

³⁴ Report of the Special Master for the September 11th Victim Compensation Fund of 2001 (2004) RLIT0002013

justice. This is especially so, as here, where fairness demands swift recompense.³⁵ For this reason, therefore, a scheme such as the Irish Tribunal Scheme,³⁶ which provides individualised assessments to each claimant before it, is to be avoided. It takes some time to individualise an award. This can be seen by the length of time it takes for a claim for compensation to be prepared for the civil courts in the UK and to come to trial, while others in the queue wait their turn. The consequence of the time taken by the Irish Scheme is that it is still working through a first assessment for a number of claimants.³⁷

By contrast, it takes little time to administer a single figure lump sum award, paying the same to everyone. But this has a huge disadvantage. It cannot reflect significant differences between one person's case and another's. It does not cater for accurate repayment of past losses, nor does it provide accurately for losses of income, the level of which will vary from person to person depending on the career path each would have pursued if uninfected, or if not having to care for a loved one and sacrificing a career to do so. One thing that can be said with certainty is that a lump sum payment scheme will undercompensate many, some significantly, and overcompensate others, some significantly. It will hardly ever produce an assessment which accurately represents a sum calculated to put the claimant back precisely to the position in which they would have been but for the infections.

The best compromise, as Sir Robert identifies, between a fully individualised assessment, as in a court, on the one hand, and a single across-the-board lump sum on the other, is a scheme which in its structure has the advantages of speed conferred by predetermined fixed sums for specified categories of loss, with a degree of flexibility to achieve individualisation offered by "banding" awards for those categories. The bands should be

³⁵ Centuries of English literature have illustrated how delay in obtaining legal redress intended to achieve justice has in fact worked the opposite. Shakespeare spoke of "the Law's delay, The insolence of Office" in crafting Hamlet's soliloquy in Act 3, Sc. 1. Dickens drew heavily on the harm done by delay and cost in *Jarndyce v Jarndyce* in *Bleak House*, drawing on notorious cases of the time for his inspiration.

³⁶ Sir Robert discusses this in his study and comes to a similar conclusion.

³⁷ Evidence of Brian O'Mahoney. Transcript 8 November 2022 p45 INQY1000257

set to take into account the broad features of a case, allowing for individualised assessments within those bands to the extent the bandwidth permits. This is preferable to a wholly individualised, but slow and expensive, process on the one hand, and a one-size-fits-all, but quick, process on the other.

The justice of such a scheme can be further refined in two ways. The first is awarding payments in respect of actual financial loss on an assessed basis, as Sir Robert suggests. The second is having and exercising a discretion to award interim payments as appropriate to ensure as little delay as possible in providing at least some recompense.

For those who feel that the scheme does not sufficiently recognise their own circumstances, who would prefer a “bespoke” assessment as in a civil court case, the option of pursuing a claim in the courts should remain.

Structure of the Scheme

To achieve the setting up of such a scheme with the minimum of delay, it is necessary to say something more of my recommendations about the structure which should deliver it, since it is essentially this that should be ready up and running at the latest by the time of the final report.

In the light of the evidence to the Inquiry:

(1) It must be completely independent of Government, and must be seen to be, even though (a) the Government must fund it and (b) the accounting officer of the scheme should report annually to Parliament³⁸ upon the way in which it has discharged its duties.

(2) Independence is to be achieved in part through the appointment of a Chair and a board to advise her or him. It should be a criterion for appointment to the advisory board

³⁸ And therefore in public.

that the appointee has relevant knowledge or experience; this may seem obvious, but I propose a small board, which puts a premium on attempting to ensure an overall breadth of both qualities, and some reflection of each of the four nations of the UK.

(3) That board should include beneficiaries; it is important that decisions about those who should receive compensation are not made without them.

(4) The composition of the scheme and the way it works must be likely to command the confidence of those it is set up to benefit. Critical to this is operating with the greatest transparency compatible with the confidentiality of individual personal details.

(5) There should be an easily accessible route of appeal to an independent body.

As was advised by Sir Robert in his Compensation Study, the scheme should not be administered directly or indirectly by the Department of Health and Social Care or its equivalent in any of the four nations of the UK.

His recommendation (in his section 11) is that money should be paid to those infected and affected by two different routes: both by the existing national support schemes under the existing bodies (EIBSS, SIBSS, WIBSS, NIIBPS) as to one part, and by a new body in the other part. (There is force in the current schemes continuing, and most who receive money from them would prefer this to continue). As to the latter, he recommended it should be an Arm's Length Body ("ALB").

The reason he gives that it should be an ALB is a reflection of the beneficiaries' very significant loss of trust in Government as a whole, and the Department of Health and Social Care in particular. In his paragraph 11.1 he concludes that "*the lack of trust in Governments of any political persuasion is likely to persist whatever its conclusions.*"

I accept that he is right to identify that there is a real problem of trust. This has arisen not simply because the infections came in the course of treatment through the state

healthcare system, ultimate responsibility for which lay predominantly with the Department of Health; but also because those infected and affected feel that their campaigning has been fobbed off by inadequate responses from Governments.

It must be acknowledged that legal independence from Government may not on its own be sufficient to dispel mistrust. The Macfarlane and Eileen Trusts were set up as charitable bodies independent of Government: yet the experience of those infected and affected of the ways in which they operated was not a happy one. The Skipton Fund was specifically established as an agent of Government (so there was no independence there except when it came to the appeal structures). Experience there, too, was unhappy. This is amply demonstrated by the report in 2015 of the All-Party Parliamentary Group on the then current provision of “*support for those affected by the contaminated blood scandal*”.³⁹ This examined the operations of both the trusts and the two funds, collectively known as the “Alliance House Organisations”. Among its chief findings was that only just over half of the applicants for grant support were positive about their experience of contacting their trust; that their understanding of how the trusts operated in offering additional support⁴⁰ was low; that most applicants for additional support had little knowledge of how the trust or fund with which they were dealing made decisions, or what processes were involved, and that nearly two thirds found it difficult to understand the rules and procedures concerned. Levels of satisfaction with the overall support provided were low. Less than a third were satisfied that the organisation being considered provided support efficiently. Less than one fifth were satisfied that it was given fairly. This report led to the trusts and funds being replaced in 2017 by support schemes set up in each of the four nations of the UK.

The structure delivering the scheme must, therefore, avoid being an arm of Government, but equally must avoid the difficulties which beset the Alliance House Organisations in operation.

³⁹ APPG Report (2015) RLIT0000031

⁴⁰ i.e. support beyond the making of regular payments.

How best to ensure independence from Government and the confidence of those involved?

In order best to achieve these twin aims, (1) there must be a sufficient guarantee of independence; (2) the processes of the scheme need to be as transparent as legally possible; (3) those set to benefit from the scheme (people infected and affected) must have a central influence on its decision-making and operation; (4) there needs to be a clear, set, basis for establishing the scope within which any discretion held by the body can be exercised; and (5) its decisions should be underpinned by a proper system of appeal, which should be to a body which can take a fresh decision for itself.

To meet the five features of independent and trustworthy operation set out above it would be best to secure the appointment as Chair of the ALB someone who is or has been a judge of High Court status or equivalent within the UK (whether a Court of Session Judge⁴¹ of Scotland, a High Court Judge of England and Wales, or a High Court Judge of Northern Ireland). The judge chosen should ideally have a background of familiarity with the law and practice of personal injury or clinical negligence: and ideally be someone whose past work in practice or on the bench has involved exposure to a wide range of people. That judge should be sole or principal⁴² decision maker, assisted by an advisory board small enough to give a quick response on matters of policy and principle to the Chair. The advisory board should include beneficiaries under the scheme, and should not contain a majority of members who are civil servants currently in post. The judge should be empowered to delegate her or his decision making on any point to one or more

⁴¹ A senator of the College of Justice.

⁴² Where the judge delegates their power to another - see below - they might in one sense no longer be the sole decision maker, but they would still retain overall control. The person to whom a power is delegated acts as the agent for the person who delegates it to them; the judge here would retain overall responsibility for the decisions made. It may also make it easier to secure the appointment of an appropriate judge if it is known that they can manage their time away from any other judicial obligations by appropriate delegation.

board members or to one or more of the legally qualified assessors:⁴³ the critical point is that the Chair retains control.

As Sir Robert suggests, there should be two panels to advise the Chair and board at the outset - one of medical experts, one of lawyers. The clinical panel should encompass expertise at least in hepatitis and liver disease, HIV, transfusion, haemophilia, psychosocial aspects, and palliative care, and the Chair should consider whether it would be helpful to add advice on nursing care, occupational therapy, physiotherapy, haematology and other disciplines. The legal panel should include those who regularly practise in the field of personal injury,⁴⁴ who are familiar with assessing compensation in cases of severe injury. There should be at least one from each of the legal jurisdictions of the UK, England and Wales, Scotland, and Northern Ireland.

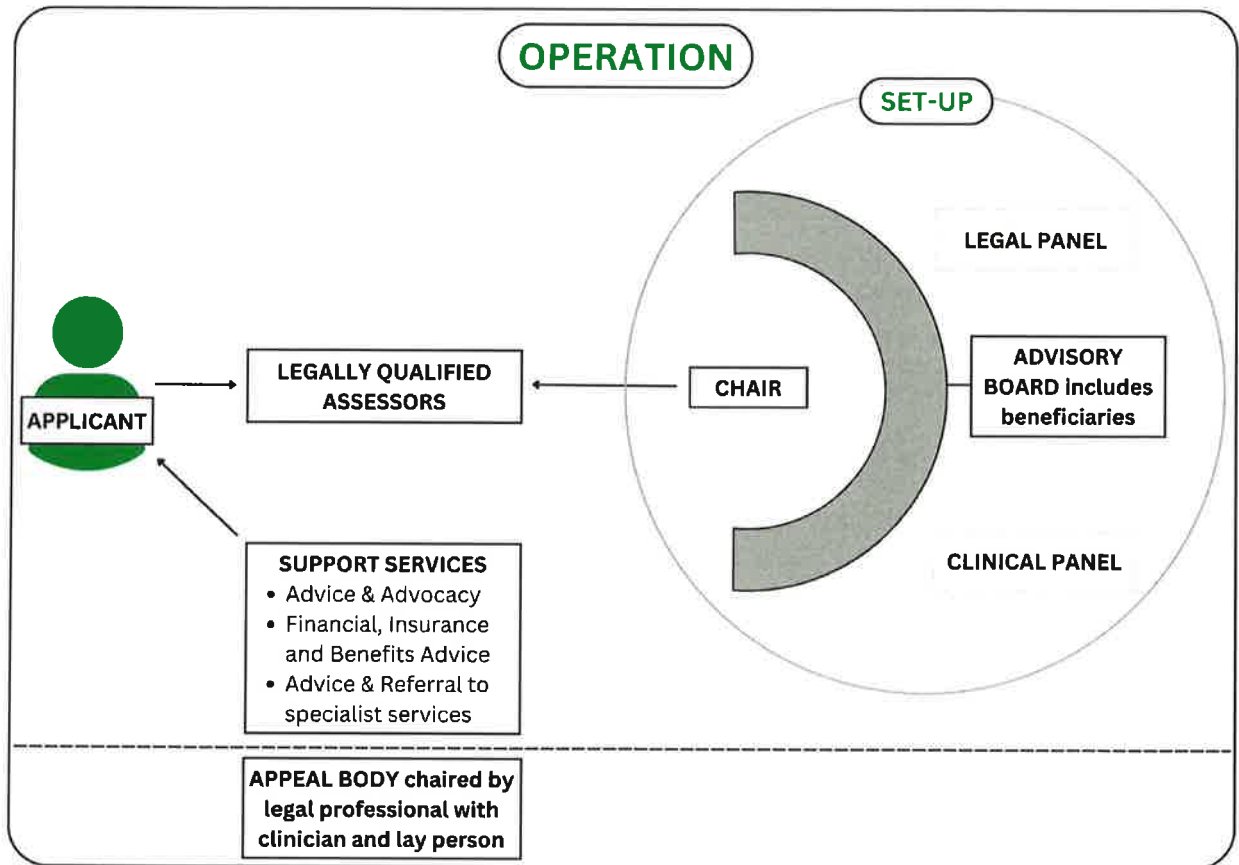
It should be for the Chair to decide who to appoint. Lawyers who have been involved in this Inquiry and have thus acquired a familiarity with the principal infections, their impacts and their causes would be well placed to apply. Since both panels are there to advise on the scheme of banding and levels of award which are appropriate, and if adopted by the Chair their views will have a direct impact on beneficiaries of the compensation scheme, the panels should be expected to talk to, engage with, and consult widely with beneficiaries. There is a parallel with this Inquiry. It set out to put people at its heart: and anyone who has observed its proceedings closely can see that doing so has added to its understanding of what happened, and why. I believe that their experiences have helped

⁴³ This may, for instance, allow for a serving judge to be able to balance the demands of work on the scheme with other judicial commitments: the knowledge that this is possible may assist in the making and acceptance of a recommendation by the Lord Chief Justice, Chief Justice, or President of the Court of Session as to an appropriate nominee. The reference to "legally qualified assessors" is a reference to people occupying that role as described by Sir Robert in his Compensation Study.

⁴⁴ Or clinical negligence, though this may be considered a subset of personal injury work.

open my eyes as they have the eyes of others.⁴⁵ Those experiences should be available at a formative stage of the “banding and levels” process.

The scheme can be visualised as follows:



Set-up and Operation of the Compensation Scheme

These provisions should help secure a proper independence of the scheme. The transparency to underpin this means that the recommendations of the clinical and legal panels to the advisory board, the advice of the board to the Chair, and the operations of

⁴⁵ One telling example of this is that National Services Scotland and the Scottish National Blood Transfusion Service reviewed their understanding of what had happened in the past, and in their closing submissions told the Inquiry that the evidence had developed their understanding such that they identified a number of respects in which better could and should have been done. SUBS0000044 Transcript 31 January 2023 INQY1000273

the scheme more generally should be capable of being recorded and available for scrutiny. In practice, they should be as open as permitted by the need to respect the confidentiality of individual claimants.

The vCJD Trust: a helpful precedent?

It may be that the demands of the tribunal and courts services are such that the judge appointed may be recently retired rather than currently in office. This will be a matter for the Lord Chief Justice, Chief Justice of Northern Ireland, or Lord President of the Court of Session to determine. However, I note the precedent of Sir Robert Owen who was appointed to chair the vCJD trust in 2001, very shortly after his appointment to the High Court Bench. He remains Chair to this day, despite having retired from the High Court Bench in 2014. While the first Chair of the scheme I propose should not feel obliged to serve a lengthy term, I note that Sir Robert Owen's continuity of leadership appears instrumental in the smooth running of that Trust, and the general satisfaction the beneficiaries have in it; it has ensured an independence and consistency of decision making.

What was established for the vCJD trust was a board of six other trustees. Though they were appointed by the Secretary of State, Sir Robert Owen was consulted, both as to the requisite expertise and as to the individual appointments. It is worth quoting what he said about these. *"First and foremost it was decided that there should be two 'family members' to represent the victims of their families. Their contribution to our work, both in terms of their personal experience and as a channel of communication to the victims of their families, has been essential."*⁴⁶ It is plain that he considers that part of the success of the fund in its dealings with beneficiaries has come from a continuity of membership of the Board. It is also plain that he values the input of those affected. Those who appoint to the board in the first place should bear these matters in mind.

⁴⁶ WITN6441001 para 11. The Thalidomide Trust similarly regards the trusteeship of those who have been victims as of critical importance.

Appeal body

An appropriate appeal structure underpins the independence of the scheme. Sir Robert begins his discussion by saying that “*dissatisfied applicants should have the opportunity to seek an internal review of any determination*”.⁴⁷ I agree: where an applicant is unhappy with a decision, she or he should be able to ask the scheme to review it. If the applicant wishes to appeal, she or he should notify the scheme of their intention to appeal and state the grounds. Unless the matter is resolved through internal review to her or his satisfaction, it can go on to appeal.

My only other comment on what he proposes relates to whether the appeal should be conducted by a panel set up for the purpose, or by an outside body which is part of the courts and tribunals system. The former is preferable, for a bespoke panel with some knowledge and experience of infected blood and blood products is preferable to a tribunal or court which will usually be dealing with many widely different issues far removed from blood. When Sir Robert says that he prefers “*a review panel within the structure of the ALB*” I do not think that he is suggesting the ALB should sit in judgment on its own decisions by setting up an internal panel, which would not carry the confidence of users, but is suggesting very much what I am recommending here - that it be a separate and independent body, albeit part of the same system of delivering justice to people who have been infected or affected. If so, I agree.

The panel should not simply review an existing decision, but have the power to reconsider it and make a fresh one. It should be chaired by a legal professional with experience of practice in personal injury and (if possible) in discrimination claims,⁴⁸ who should hear appeals together with at least one clinician with relevant expertise and a lay person.

⁴⁷ Infected Blood Compensation Study Para 11.13 RLIT0001129

⁴⁸ The assessment of “injury to feelings” arising out of factual circumstances analogous to some extent to the past experiences of many of those applying to the scheme will be natural to most senior employment lawyers.

The procedure should be determined by the appeal body, but in principle be kept as simple and informal as practicable.⁴⁹ Appellants should be heard in person by the appeal body if they wish to be. It should not require lawyers, but permit them to attend if the applicant wishes. Decisions must contain the core reasoning leading to them, so that the applicant can understand why the appeal is upheld or not upheld, and the ALB learn from it.

The operation and structure of the appeal body should be kept under review, and developed as desirable in the light of experience and consultation with representatives of those who have been infected or affected.

Features of the Scheme

The detailed structure of the scheme depends partly on the broad outlines of what it is expected to deliver.

I need to explain here in greater detail some of the matters I set out in my Summary of Conclusions. In particular:

- (1) Why those whose sole infection was Hepatitis B should be entitled to compensation.
- (2) Why there should be no “cut-off” date before which a transfusion causative of infection had to be given in order for the recipient to qualify for compensation.
- (3) Why affected persons should be entitled to awards comprising the same categories as apply to infected persons.

⁴⁹ Those setting up the appeal body and process may wish to consider the core procedural rules promulgated by the Tribunals Procedure Committee, which have the merit of being simple, tried and tested and are applied, with variations appropriate to the subject matter, across most Tribunals.

(4) How to resolve problems of eligibility that applicants have encountered with the support schemes.

(5) The awards that people infected, people affected and the estates of people infected should be able to claim.

(6) Why applicants should be able to choose provisional awards.

1. Hepatitis B

The second recommendation made by Sir Robert in his Compensation Study was that the scheme should offer redress “*to those infected with HCV and/or HIV, and **defined serious cases of HBV...***”⁵⁰ He confirmed in evidence to the Inquiry that he did indeed recommend that those who developed a chronic Hepatitis B infection with serious symptoms who require treatment to prevent cirrhosis or had actually developed it should be compensated.⁵¹ However, he understood that the generality of Hepatitis B infections had mild or even non-existent effects so far as quality of life was concerned.

I am clear from the greater evidence before the Inquiry than that available to Sir Robert that those who suffered Hepatitis B infection should be compensated, and that “severity of symptoms” should not be the qualifying criterion. The natural course of the disease is progression over time toward cirrhosis and liver failure.⁵²

The Inquiry has received statements from 64 people infected only with Hepatitis B through blood and blood products and no other infections. Three witnesses described the impact as follows.

⁵⁰ Emphasis added.

⁵¹ Transcript 11 July 2022 p66 INQY1000224

⁵² Hepatitis Expert Report p26 EXPG0000001

An anonymous witness wrote in her statement: *"My life now, experiencing the symptoms mentioned previously, is something I endure every day. This is the way I am living now. It makes me depressed, upset and I often cry. I ask myself repeatedly: 'Is it even worth living? What is this miserable lifeless-life of mine, dragging away, day by day?' I feel like I have a cursed life that is locked away in a gloomy confinement which will never be unlocked. All of the strong medicines that I have been taking, have side effects. These side effects are a constant reminder of the cause of my grief, from the past, present and will be for the rest of my life. When I look back and ask myself again and again, 'Why is this suffering mine?', I could never find an answer to this question."*⁵³ She has since had to have a liver transplant.

Another anonymous witness was infected with HBV through a blood transfusion in 1989. He said in his statement to the Inquiry: *"The effect over the years has been monumental both mentally and physically. Mentally, I have always felt as if I was carrying a secret. ... Physically, over 30 years the virus transformed from a simple non-invasive virus that wouldn't affect my life to a lifelong condition that would require courses of debilitating treatment, and eventually lead to many further medical complications. ... Essentially, I have gone from someone who worked a lot of hours and earned a lot of money, to someone who relies on benefits and struggles to get by. The infection has completely ruined my life."*⁵⁴ He has now died.

Linda said: *"... I feel like Hepatitis B is put at the bottom of the pile. We are under HIV, we're under Hep C. We are there, we're not anybody. When it is on the telly it is always HIV and Hep C that's mentioned. B is never mentioned. And I don't understand why, because people are suffering with it. You know, we are suffering."*⁵⁵

⁵³ WITN0727001 para 20

⁵⁴ WITN1951001 paras 19,47

⁵⁵ Transcript 28 September 2022 p32 INQY1000248

Two points need to be highlighted from the wider evidence received by the Inquiry: first, the inadequacy of measures taken to prevent the transmission of hepatitis through transfusion; and, second, its severity.

It became well known during World War II that hepatitis could be transmitted by a transfusion. "Serum hepatitis", as this was termed, was known to be a serious long-term illness which might not become obvious until some years had passed, but was incurable when it did, and was transmissible to others putting them, in turn, at risk. Its potential seriousness was recognised from the start.⁵⁶ Indeed, plasma was described as a "*potentially lethal fluid*" because it might carry hepatitis.⁵⁷ It was recognised that "*it may be so mild as to cause only transient jaundice or it may be so severe as to produce fatal hepatic necrosis*"⁵⁸ and that it could be asymptomatic for a considerable time whilst being transmissible throughout, after which it might result in cirrhosis and then cancer. Even in the 1940s, solicitors advised the transfusion service that patients should be warned.⁵⁹

By the 1970s hepatitis was known to have killed servicemen at the front, patients in hospital, and healthcare professionals. It was thus of some magnitude, making it necessary to take steps to avoid or reduce the risk of infection. Though the risk could not have been wholly avoided in the 1970s and early 1980s, it could have been kept to a

⁵⁶ In particular, yellow fever vaccine for allied troops was for a while propagated in cell cultures with human serum, and a vaccine was stabilised with serum to maintain viability. There was an outbreak of hepatitis, which caused a significant number of casualties and damaged the fighting capabilities of the force. On 15 April 1942, the US Surgeon General, upon determining that human serum could transmit hepatitis from donors to vaccine recipients, ordered the omission of human serum from yellow fever vaccine production. No further cases of hepatitis were henceforth attributable to yellow fever vaccine. RLIT0000209

⁵⁷ Letter from Dr Maycock to Dr Robb-Smith (1946) DHSC0100008_190; see also Dr Robb-Smith's letter (1946) DHSC0100008_189

⁵⁸ Directions for the use of the Blood Bank and Blood Transfusion Service (1955) WELL0000442 p10

Note: page numbers in documentary evidence refer to electronic rather than internal pages.

⁵⁹ Legal advice on liability for jaundice infections following plasma transfusion (1946) DHSC0100008_192 p1. It is also notable that this is an early reference to a need to give patients information about the serious risks they faced.

minimum. Careful selection and screening of donors, control of the size of plasma pools, and ensuring traceability by careful record keeping were known to be critical in this.⁶⁰ It was also understood that transfusions should only be given where really necessary, and where the advantages outweighed the risks.

Following the isolation of a viral particle,⁶¹ a test for the presence of Hepatitis B in blood was developed around 1970. This was known to detect only one third to one half of infected donations. Nonetheless, such was the severity of Hepatitis B that testing was introduced, despite it being known that more than half of infective donations would not be identified. Though tests improved in the mid-1970s, a test by then identifying only two thirds of infective donations was rolled out in the mid-1970s: a more accurate available test, "RIA",⁶² was not used generally until the early 1980s.

Although a proportion of infected donations might remain undetected, insufficient steps were taken to reduce their number. Riskier donations were accepted. Donations were taken from people in prison until 1984.⁶³ People who previously had jaundice were thought acceptable as donors.⁶⁴ Insufficient was done to exclude those who may have shared needles.⁶⁵ It became apparent as the evidence was examined by the Inquiry that even when would-be donors were invited to exclude themselves if they suffered from previous relevant illnesses, they might nonetheless be subject to peer pressure that might

⁶⁰ Since at least 1952 when the WHO Expert Committee on Hepatitis produced a report recommending such precautions. Expert Committee First Report (1952) RLIT0000215

⁶¹ An antigen, known as the Australia antigen, was identified in 1967, leading to the virus itself being recognised following discovery of the "Dane particle" in about 1970.

⁶² Radioimmunoassay

⁶³ In some parts of the UK. Practice varied between regions as to the date this stopped.

⁶⁴ A restriction that they should not have been infected within the past 12 months would obviously not exclude the risks from a symptomless carrier who was chronically infected.

⁶⁵ See for instance, the view of the Scottish National Blood Service in its final written submission to the Inquiry that "...it would have been better to have excluded IVDUs earlier than we did through more systematic donor selection across SNBTS regions...and we apologise for not doing so." SUBS0000044 para 61. NHSBT accept the same point. "IVDU" stands for intravenous drug user.

make it difficult not to go through with giving a donation.⁶⁶ Few donation centres were equipped with easy access to a space for private discussions which could not be overheard.⁶⁷ The resulting stock of blood for transfusion was thus always likely to contain more infected units than it should have done; and systemic failings contributed to increase the risk from them further.⁶⁸ Transfusions were too often given unnecessarily, or in too great a quantity. Too little was done to change this practice. When patients could, and therefore should, have been warned of the risk, the evidence shows they were not. They would not have known to ask for a test if they became unwell. In many cases, they would not know that they had been infected with something so potentially serious. If it became chronic⁶⁹, the infection was permanent.

Hepatitis B infection in people with haemophilia was commonplace, particularly as a consequence of taking commercial concentrates originating in the US. Co-infection with Hepatitis C or HIV or both was often the case: Hepatitis B aggravates both, making the effects of those diseases worse than they otherwise would have been, justifying a higher award in those cases. Sir Robert recognises this in his Compensation Study. However, what I am considering here is eligibility for those whose sole infection is Hepatitis B. Sole infection is then still of significance since chronic Hepatitis B cannot be eradicated and the natural course of the disease is slow deterioration of the liver towards cirrhosis and then liver cancer. It follows that people infected with chronic Hepatitis B in consequence of transfusion, blood product or tissue transfer should be compensated. They should be

⁶⁶ Examples are taking donations from the military, or in factories, where questions might be asked if fellow soldiers or co-workers did not donate when those around them were doing so.

⁶⁷ Most especially in factories/workplace settings, which were ad hoc in their physical arrangements.

⁶⁸ I note that SNBTS' final written submission says: "*We consider that there was probably an over-reliance on HBsAg testing to provide safety in this context due to an under appreciation of the concept of the window period and of the risk of transmission and severity of non-A non-B (NANB) hepatitis.*" SUBS0000044 para 68

⁶⁹ "Chronic" in this context means lasting for 6 months or more. It is to be contrasted with "acute" which is not a measure of severity, but of time: less than six months. Every chronic disease will therefore at one time have been acute, but not all acute infections progress to become chronic.

eligible for interim payments and support payments. The deaths of those who died from Hepatitis B during the acute period of infection, should also be recognised.

Hepatitis D

Delta Virus (Hepatitis D virus) does not cause infection in the absence of Hepatitis B. Its presence is an aggravating factor, because it makes it more likely that Hepatitis B will have significant health effects. It is not necessary to make it an additional class of infection, because the banding scheme adopted by the Chair and board envisaged above should allow for its effects in any individual case to be adequately recognised.

2. Cut-off Date for Infections

In the Compensation Study, Sir Robert discusses eligibility criteria for directly infected persons. He sets out four conditions, the third of which is that:

“The patient received the relevant treatment between defined dates, namely during the period when no effective screening for infections/contamination of blood or blood products was applied to blood or blood products used for the relevant treatment, or alternatively, after that period using blood or blood products likely to have been collected or produced during that period.”⁷⁰

This condition ties the date on which entitlement to compensation should cease to the date effective screening started. The evidence before the Inquiry has demonstrated that this is not so clear cut.

By contrast, the EIBSS website states, in respect of HIV: *“all NHS blood in England was being screened for HIV from October 1985 onwards so it is very unlikely, although not impossible, you would have received HIV through infected NHS blood after October 1985.”* This does not adopt a fixed cut-off date which permits of no exception. It

⁷⁰ Infected Blood Compensation Study Para 6.8 RLIT0001129

recognises, rather, that identifying the cause of infection is the test, and that while universal screening is an important factor in helping to determine this, it is not decisive. I recommend a similar approach in respect of Hepatitis C, in particular noting that there were a number of Hepatitis C infections in the period which fell just after the introduction of testing. The causes of infection with HIV, Hepatitis B, or Hepatitis C were much more than the absence of universal screening. To focus on screening alone is to miss the rest of the picture.⁷¹

After universal screening was first introduced for Hepatitis C, there were a number of infections that were very possibly transmitted by transfusion. The Skipton records show complaints of three such infections in the three months following September 1991; in the following year six, and in 1995 a further one. Whereas the airline and chemical industries had for some years ensured enviable safety records not only by examining incidents which had resulted in injury, but also “near-misses”, blood services in the UK did not formalise any such system until November 1996, and then only for cases where injury was reported. This was when SHOT (“Serious Hazards of Transfusion”) was launched. Compliance by clinicians in making reports to SHOT was initially voluntary, and was incomplete until 1999/2000. SHOT began first to consider “near-misses” in 1998/9.

In my view, eligibility should be dependent on whether a given infection was caused by a suspected transfusion, blood product or tissue transfer. The critical question is not one of date, but one of cause and effect. In essence, I recommend a similar approach to cut-off dates as that indicated by the statement on the EIBSS website, so far as HIV infection

⁷¹ The potential over-reliance on screening was contemporaneously noted: in her evidence Dr Lorna Williamson said “... we had, of course, made everyone aware that we were now screening for Hepatitis C, and so we were conscious that clinicians would think that viral infections in blood were a thing of the past and that the risk was no longer there. So we had to give them two slightly conflicting messages: blood is very safe, the risk of viral transmission is very low, but it can happen. And it was that ‘but it can happen’ message we had to try to get across.” Transcript 8 December 2021 pp140-141 INQY1000169. The BMJ for November 1996 carried an editorial which noted (having regard to a range of risks from transfusion, including transfusion transmitted infection) “there is no room for complacency. As was highlighted by an editorial in the BMJ two years ago, preventable deaths after transfusion still occur.” WITN0643051 p1

after 1985 is concerned. Condition 3 should therefore be amended to read: "*their infection was not unlikely to have been caused by administration of the relevant treatment, regard being had as to the available evidence as to the measures in place at the time to reduce the possibility of infection, including but not limited to the date of relevant effective screening tests or effective viral inactivation treatments.*"

3. Affected Persons

Persons affected by the infection of those close to them with HIV, or hepatitis, should have a personal claim for what they have suffered. I note that the Macfarlane Trust Deed in 1988 recognised as people who were to be entitled to ex gratia payments those who "*...are infected with Human Immunodeficiency Virus and are in need of assistance or the needy spouses, parents, children and other dependants of such persons, and the needy spouses, parents, children or other dependants of such persons who have died.*"⁷²

Sir Robert identified spouses, civil partners and long-term cohabitantes (for at least one year), children, parents of children infected under the age of 18, siblings who lived with infected persons during childhood, carers, others seriously affected by the consequences of the infection of the infected person, and dependants of deceased infected persons as eligible for compensation.⁷³

This reflects my view that the ordinary reasonable person would expect someone affected, who has lived alongside an infected person and shared the difficulties they have faced, to be able to make a claim in their own right from a compensation scheme. Compensation should be approached on this basis.

⁷² Macfarlane Trust Deed Clause 4 MACF0000003_064

⁷³ Infected Blood Compensation Study Recommendation 5 RLIT0001129

Subject to three matters, I accept the Compensation Study's description of the "eligibility for affected persons" as appropriate.⁷⁴

First, parents of children who reached adulthood before first infection should not be excluded now from a scheme which might be expected to have a wider compass than the original ex gratia scheme of support payments.⁷⁵ There would be a practical difficulty in such an exclusion. Insofar as infection with HIV is concerned, it is known there may be an appreciable passage of time between it occurring, and seroconversion becoming recognisable. For a person who received blood products regularly (as in the case of people with severe haemophilia), or transfusions regularly (e.g. sickle cell disease, thalassaemia or leukaemia patients) and turned 18 at some stage between their last negative test for HIV infection and their first positive one, it might be impossible now to tell whether they were 18 or not at the date of infection so as to qualify their parent for admission to the scheme. Moreover, adult sons and daughters who were infected and had no current partner were often cared for by their parents.

Second, I do not consider that there needs to be a class of "dependants of deceased infected persons." Those affected should be eligible to claim in their own right for their suffering and losses insofar as they are attributable to the infection of the deceased person. They should not have to tie their losses to dependency upon the deceased - i.e. to no more than they might have expected to have been given by them. A parent who has given up paid employment to care for a child, of any age, who is facing a painful decline to their death, should be entitled to have that loss assessed; a sibling whose achievements at school or college are compromised because of worries about their brother or sister may be entitled to some recompense for lost opportunity; the child who is orphaned because a parent, infected by blood or blood products, infected their other

⁷⁴ So there is no doubt about it, divorced and separated partners are included in Sir Robert's framework and this is fair since the infections contributed to the breakdown of a number of relationships.

⁷⁵ Which included parents without there being any limitation as to the age of the child who was infected.

parent, and whose life is derailed as a result, should be recognised as having a claim in their own right. A claim as a dependant focuses instead not upon the personal losses of the affected person, nor upon what they may have suffered emotionally, but upon the benefits the deceased would personally have provided in money, or money's worth to the claimant as part of a family. A dependency claim is a derivative claim, rather than one which recognises the person as an individual.

It is better in my view, that these individual losses are recognised as such and compensated directly by the individual affected person being placed in an appropriate band: it is difficult to conceive how "dependants of deceased infected persons" adds anything meaningful to the list of eligible affected persons, where they can claim in their personal right for the losses they have been caused.

My third concern relates to paragraph 6.27 of the Compensation Study. This recommends that the estate of an affected person should be able to step into the shoes of the deceased affected person and claim the sums that the deceased would have been entitled to if they had made a claim in life. I have reservations about this, and consider it a step too far. People are recognised as affected because so many had to witness the very worst effects of an illness which has caused someone close to them to waste away in their presence, to suffer abuse and stigma with that person or be pilloried because they are part of the same family, or where bereaved in early childhood, they have a particular sense of loss and indignation that the death should have happened as it did. They may themselves have had to abandon dreams which had been shared, may have had to abandon the chance of having a baby, or may have had to suffer the unpredictabilities of the changing of personality that came with treatment for the person infected, especially where the infection was Hepatitis C. In a very real sense, they will have shared much of the injury caused by the relevant diseases. It is right that these affected persons should be compensated in their own right – but to go further, and allow a claim by their estate (for the benefit of people who do not have an individual claim, since they were not

themselves seriously affected, and most likely would not have suffered the disadvantages described above⁷⁶) is to draw the circle too widely.

4. Eligibility and How it is to be Determined

I agree with Sir Robert that the compensation scheme should automatically accept anyone accepted as eligible by the existing or past support schemes.

He notes that for new applicants “*an empathetic and proactive approach needs to be taken to the assessment of eligibility*”⁷⁷ and that the starting point has to be a medical diagnosis of infection. I agree with this.

The next question is whether there was a potentially causative transfusion, blood product or tissue transfer and here we differ: Sir Robert suggested that where there is evidence of a potentially causative treatment, it should be presumed that the infection occurred at that time, unless overwhelmingly probable that there was some other cause (with the burden of proof resting on the scheme). I agree that there should be a presumption - but my concern is the phrase “*overwhelmingly probable*”, defined as “*beyond reasonable doubt*”, as that sets the standard of proof so high as to risk being unrealistic. This standard of proof makes it very difficult indeed for the scheme to reject a claim even where that claim is unlikely to be well founded. Yet it is important not to over-compensate just as it is important not to under-compensate.

A balance of probability test is well understood⁷⁸ and it is sufficient that it be coupled with a reverse of the burden – so that, unless the evidence satisfies the scheme on balance

⁷⁶ And if they suffered in those ways would have their own claim as an affected person anyway.

⁷⁷ Infected Blood Compensation Study Para 6.14 RLIT0001129

⁷⁸ In contrast, one recognised legal representative submitted that the test should be a “reasonable degree of likelihood”, possibly because the word “proof” in the expression “burden of proof” suggests near certainty, and can be misunderstood. However, whereas another way of putting “burden of proof” is to say “who has the task of proving it?”, the reasonable degree of likelihood approach is not commonly used in legal proceedings, and is open to so much uncertainty as to make it less desirable.

that a transfusion, blood product or transfer of tissue was **not** the cause of the (established) infection, the administrators of the scheme and their assessors should presume that it was. This condition would now read: "*their infection was not unlikely to have been caused by administration of the relevant treatment.*"

I also agree that it should be for the scheme administration, with the applicant's consent, to seek out relevant records if they continue to exist: and that it should have the authority to require their production. If the applicant does not consent, then it should be for that applicant to show either that there is no existing record of a treatment involving the transfusion which the applicant says they were given, or produce such documents as can be obtained.

The proof of two particular matters has been a matter of concern to a number of participants: "natural clearers", and entitlement to an award as a bereaved partner where there has been a separation.

For the avoidance of doubt as to eligibility, the death does not have to be because of the disease – the infected person will by definition have suffered from the disease, and the harm with it.

Natural clearers

The support schemes currently accept as eligible those who can prove⁷⁹ that they have had Hepatitis C more than 6 months after the causative transfusion, blood product or transfer of tissue but have since cleared it.⁸⁰ Those who cannot prove this fail. The

⁷⁹ This is a reference to the approach to the burden of proof currently adopted, in respect of which both Sir Robert and I recommend change.

⁸⁰ i.e. are shown by the most recently available test(s) no longer to have a detectable level of virus, but are also shown to have a marker in their blood (hepatitis core antibody) which shows that they were once infected.

problem is that the marker which reveals that the person once had the virus cannot show when this was.

It has thus not been easy for a person to prove to the present schemes⁸¹ that the infection persisted for more than 6 months after the event (transfusion, receipt of blood product, or tissue transfer) which probably caused it. It cannot be *assumed* that it did, since more “natural clearance” takes place within the first 6 months than after it - but nor should it be assumed that it did not form one of the minority of infections which were cleared naturally after the 6 months, since this would leave a number of chronic⁸² infections without the recognition of a remedy.

A further difficulty is that early symptoms of Hepatitis C infection are not definitive of the disease, so it is difficult to point to them and say “*because I had that symptom, I must have had Hepatitis C.*” However, this problem should not be overstated – the Inquiry has become familiar with a range of symptoms being described in evidence which, though not individually diagnostic, are indicative of Hepatitis C infection.

Justice can be achieved by adopting the approach Sir Robert recommends, of crediting an applicant’s account of symptoms, unless there is good reason not to do so. If those symptoms are consistent with the presence of Hepatitis C infection for more than six months then, given that the current test shows that the applicant had been infected, it should be assumed they were indeed symptoms of it.

⁸¹ Especially since applications have been decided entirely on paper without hearing from individuals personally. The Inquiry heard from a panel of 4 people who had cleared naturally but who each recounted significant symptoms and associated losses consistent with late clearing. Each expressed worry about recurrence of the virus and concerns for the future. Transcript 27 September 2022 INQY1000247

⁸² “Chronic” in this context means for more than 6 months.

Bereaved but separated

It would demand too much by way of resource and time, and often involve an unpleasantly awkward examination of delicate personal matters capable of producing significant upset and misunderstanding, for the scheme to hear detailed evidence as to the circumstances in which a cohabiting couple came to live apart. I suggest that where it appears that the separation was before the date of the event which caused the infection, there is simply no claim. Where it took place afterwards, the scheme should accept the eligibility of a person claiming to have been a bereaved former partner where they sign a declaration⁸³ that they had lived with the deceased for at least a year and that a principal cause of the separation was the fact⁸⁴ or effects of infection or treatment for it.

5. Categories of Injury and Loss

Section 7 of Sir Robert's Compensation Study considers the injuries, loss and detriments that compensation should address in relation to the past, present and future.

At the outset, I confirm that an infected person should be entitled to the awards Sir Robert identified in his Compensation Study.

It follows from what I have already said that affected persons also have claims in their own right. Each infected person and affected person has suffered losses. There are obvious differences that come with the nature and extent of any injury caused. However, that apart, both infected and affected suffer in a number of similar ways - emotionally, socially, financially, and in their personal and family life. Each will have suffered loss of autonomy, and is likely to experience significant psychological distress. Given that is the case, there should in principle be no difference between the categories of loss for those

⁸³ This need only be a simple signature on a pro forma, stating that the declaration is true.

⁸⁴ There is some evidence that the mere fact that the diseases were known to be spread by sex and less well known to be spread through blood caused tensions between some partners.

who are infected⁸⁵ and those who are affected, even if the amounts paid to infected people are almost always likely to be greater.

In building on what Sir Robert recommends, I note that this should be a UK wide scheme, and there is no need for it to mirror the precise legislative or legal approaches to claims of compensation that might be brought before the courts or tribunals of any particular part of the UK. Much of what gave rise to the wrongs suffered occurred at a time when there was no separate Government in each of the four home nations, so those wrongs justify payment by the UK Government in principle.

As to the period which followed, there have been separate Governments. The response of each to what gave rise to the infections has differed in detail. However, the need for parity of provision has already been accepted during the course of this Inquiry. There should be one scheme applicable to all. Though the legal panel and scheme should take into account the differing legal approaches in different parts of the UK, it should not be tied to any of them: I recommend here a scheme which best fits the justice of all the circumstances revealed by everything the Inquiry has read, heard, seen and considered. What best fits justice is the same across each of the four nations of the UK.

Both infected and affected people should therefore be entitled to the following awards:⁸⁶

a) an **Injury Impact Award** for past and future physical and mental injury, emotional distress and injury to feelings caused by the infection and treatments for it, or (whilst not

⁸⁵ Whether directly from blood, blood products, or transferred tissue, or indirectly having been in turn infected by someone directly infected; for instance, a partner, child or sibling may have been infected in this way.

⁸⁶ That does not mean the same amounts: those infected are likely to receive more because of their infection.

being personally infected) being affected by them or by the death of an eligible infected person (including, as part of this, an award for loss of society⁸⁷ of the deceased);

b) a **Social Impact Award** for past and future social consequences of the infection including stigma and social isolation, loss of educational opportunity, and loss of congenial employment;

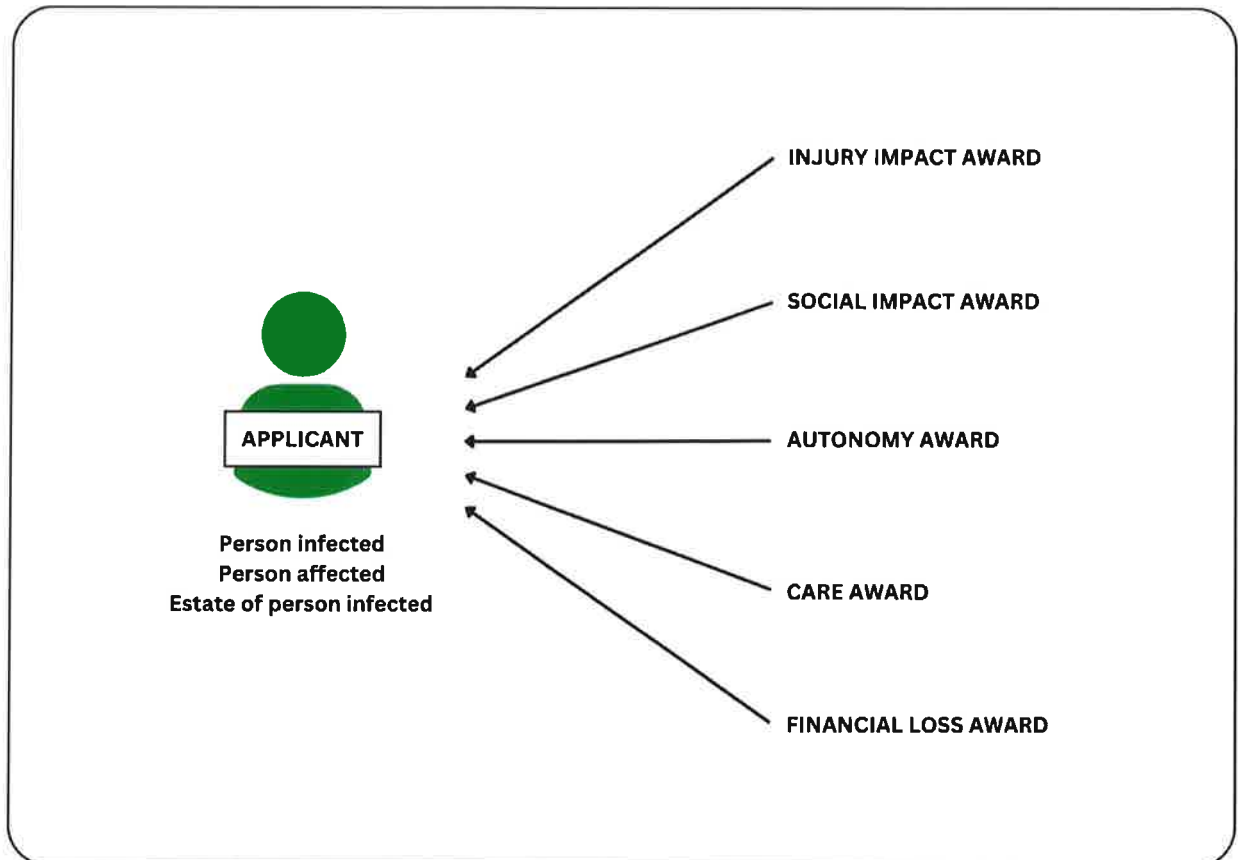
c) an **Autonomy Award** as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life, including where relevant: personal autonomy, loss of marriage/partnership prospects, loss of chance to have children. It should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. It should include the effects of lack of candour and inadequate responses by authority.

d) a **Care Award** for the future care needs of the eligible infected person, and to compensate for past losses in respect of care necessitated by their infection (to be paid directly to the infected person where they have paid for care, and/or directly to an affected person who has provided care); and

⁸⁷ This expression derives from Scottish law and practice, though it is not unique to Scotland – the Irish Act of 1996 referred to by Sir Robert in his Study provides for an award in respect of loss of society of the deceased including “*the loss of the care, companionship and affection of the deceased as a result of the death.*” The Damages (Scotland) Act 2011 provides for loss of society at section 4(3), to include “... *distress and anxiety endured by the relative in contemplation of the suffering of A before A’s death, (ii)grief and sorrow of the relative caused by A’s death, and (iii)the loss of such non-patrimonial benefit as the relative might have been expected to derive from A’s society and guidance if A had not died.*” (“Non-patrimonial” losses are those which are not caused to a person’s property or wealth, but which involve losses such as pain, suffering, distress, sorrow etc.)

e) a **Financial Loss Award** for past and future financial losses suffered as a result of the infection. This award should be given on an assessed basis, as Sir Robert suggests, whereas the other awards should be given by adopting a “banded” approach.

People infected, people affected and the estates of people infected should be able to claim for these categories of loss, as illustrated below.



The Awards Available to Applicants

I shall say more about four of these: the Injury Impact Award, the Autonomy Award, the Care Award, and the Financial Loss Award.

Injury Impact Award

A matter highlighted in some closing submissions by core participants was how any additional anxiety and distress should be treated where it was caused by notification to an individual that they were at particular risk of vCJD because of the blood transfusions or blood products they had received. This should be assessed as part of an injury impact award.

Second, the position in respect of psychological and emotional harm needs to be absolutely clear. Statement after statement has testified to the depth of the emotional distress experienced. It would not be realistic to expect applicants to have accessed such limited psychological support (if any) as was available. The starting point is that an applicant speaking of their distress and emotional upset is to be credited in the absence of sound reasons to the contrary.

It should not be thought that the scheme would be breaking new ground if it were to recognise claims by affected persons for such injuries to feelings, which may fall short of “recognised psychiatric or psychological injury”⁸⁸ or be difficult to prove given the passage of time, as deserving of compensation. County courts⁸⁹ and employment tribunals⁹⁰ have made awards of this sort for nearly fifty years. Parliament has repeatedly recognised that “injury to feelings” (without a diagnosis of psychiatric injury) may be compensated in an

⁸⁸ i.e confirmed on medical evidence as falling within one of the descriptions of psychological conditions set out in current editions of generally accepted professionally adopted manuals (such as the International Classification of Diseases (“ICD”) or the Diagnostic and Statistical Manual of the United States (“DSM”)).

⁸⁹ See now s. 119(2)(a) and s. 119(4) of the Equality Act 2010.

⁹⁰ Awarding sums which correspond to the amount that could be awarded in the county court under s. 119 Equality Act 2010: see s.124(6).

appropriate context.⁹¹ Case law⁹² has set the appropriate banding within which less serious, cases of moderate seriousness, more serious and really exceptional injuries to feelings may fall,⁹³ and offers a useful guideline for those setting the bands to consider.

Next: how to treat bereavement. An award for bereavement should form part of an Injury Impact award. Recognising an affected person as having a claim in their own right means that the calculation of appropriate compensation for them should not be dictated by the fatal injury legislation specific to any of the three jurisdictions.⁹⁴ In particular, the Fatal Accidents Act 1976 (in England and Wales⁹⁵) provides for a statutory bereavement award, in a set sum, as a recognition of the fact of death.⁹⁶ By contrast, the approach in Scotland

⁹¹ The first statutory provision allowing specifically for compensation for injured feelings was 48 years ago: s. 66 of the Sex Discrimination Act 1975; and see the Equality Act 2010 s.126(3)(a), which repeats what had been well recognised in previous statutes principally relating to discrimination.

⁹² It is worth quoting what Mummery LJ said in *Vento v the Chief Constable of West Yorkshire Police* [2002] EWCA Civ 1871, paras 50-51 (when three bands of assessment of injury to feelings were set out): “*Subjective feelings of upset, frustration, worry, anxiety, mental distress, fear, grief, anguish, humiliation, unhappiness, stress, depression and so, and the degree of their intensity are incapable of objective proof or of measurement in monetary terms. Translating hurt feelings into hard currency is bound to be an artificial exercise ... “... The award must be fair and reasonable; fairness being engaged by earlier decisions; but the award must also offer necessity the arbitrary or conventional. No money can provide true restitution.” Although they are incapable of objective proof or measurement in monetary terms, hurt feelings are nonetheless real in human terms. The courts and tribunals have to do the best they can on the available material to make a sensible assessment, accepting that it is impossible to justify or explain a particular sum with the same kind of solid evidential foundation and persuasive practical reasoning available in the calculation of financial loss or compensation for bodily injury.*”

⁹³ In 2023 the “Vento” guidelines, as they have become known, provided for a lower band of £1,100 to £11,200 (less serious cases); a middle band of £11,200 to £33,700 (cases that do not merit an award in the upper band); and an upper band of £33,700 to £56,200 (the most serious cases), with the most exceptional cases capable of exceeding £56,200. This is provided for by a joint statement of 24 March 2023 from the Presidents of Employment Tribunals in both Scotland, and England and Wales. It is revised upwards for inflation (RPI) over each twelve month period.

⁹⁴ Three, because England and Wales is one jurisdiction in legal terms.

⁹⁵ Northern Ireland is governed by similar provisions in a statutory instrument, though the text shows there are some differences.

⁹⁶ This is currently £15,100 in England and Wales, and £17,200 in Northern Ireland. It is paid not to each of the bereaved but as one lump sum to be divided between all those who have a claim for that award as “dependants” of the deceased.

is to tailor-make an award to the individual, depending upon the level of their suffering, as an award for loss of society.⁹⁷ The circumstances here are very different from the generality of fatal accidents. In setting the appropriate levels, the scheme might wish to consider the approach taken in Scotland to awards for loss of society. The fact of death of a loved one should be recognised in the Injury Impact Award which should include an award for loss of society of the deceased.⁹⁸ In the context of this scheme, its calculation should take account not just of the fact of death, but the circumstances of it: it is those circumstances that anyone following the evidence given to the Inquiry will have found so moving.

Loss of Autonomy Award

I agree with the approach Sir Robert recommends for aggravated damages⁹⁹ (at his paragraphs 7.39 and 7.40) provided it is understood as relating to people who were affected as well as people who were infected. Both should be covered, because the rationale he adopts is that aggravated damages are awarded to reflect interference with private life and autonomy. Private life involves interaction with others, particularly within one's family. To say, for instance, that an award is justified for a man who accepts advice that he should not have a baby with his wife or partner but not for the wife or partner because they do not - or did not yet - have his infection would be unacceptable. To compensate an infected person for the way his home is attacked by bricks thrown through a window, or slogans scrawled on the wall, but not their partner and children who live there too would be unjustifiable. They will have had the same response from authority,

⁹⁷ The awards there, made to each individual entitled to claim, separately, are generally higher than those provided for by the Fatal Accidents Act and its Northern Ireland equivalent.

⁹⁸ In Scotland, there is no comparable fixed sum. A sum for distress and anxiety endured in contemplation of the deceased's suffering and grief and sorrow caused by the death is assessed on the individual facts of each case. Awards tend to be higher than in England and Wales. A recent case heard before the English courts where Scots law was applied because the causative asbestos exposure had occurred in Scotland, resulted in awards of £115,000 for the deceased's widow and between £35,000 and £40,000 to each of her three sons for "loss of society": *Haggerty-Garton & Others v Imperial Chemical Industries Ltd* [2021] EWHC 2924 (QB).

⁹⁹ This is the term conventionally used to describe the award of compensation for the non-financial loss of the additional shock and distress caused by the wrongdoer's conduct.

one which three people who have held the position of Secretary of State for Health recognised years later in their evidence to this Inquiry as deserving of apology and redress.¹⁰⁰ Sir Robert notes from conversations with members of the infected and affected community that “*they believe their distress has been exacerbated by exactly [such] features.*” I propose that his recommendation 7a) is amended so that it reads “for eligible infected and affected persons”, making clear that an award that reflects interference with private life and autonomy is available to both groups. They would fall within the scope of “aggravated damages” as it is understood in principle. Though the term “aggravated damages” is not a term used in Scots law nothing turns upon the label – the award is fully justified in the whole of the UK as a “Loss of Autonomy” award as Sir Robert has identified.

Exemplary damages

When Sir Robert gave evidence to this Inquiry, he commented that exemplary damages¹⁰¹ should not be an element in this compensation scheme, because including this would introduce an adversarial approach more suited to litigation. His Compensation Study suggests (at 7.38) that this should be reviewed in light of the Inquiry’s findings. I have reviewed it, and agree that such damages would not be appropriate in a scheme which aims to process compensation claims without unnecessary delay. For clarity I should add that this would not prevent someone who wishes to bring a claim which is for, or includes a claim for, exemplary damages from doing so before the courts.

Care Awards

Care awards cover both past loss and (potentially) future loss. In personal injury cases in England and Wales, the principle adopted has been that a need for care is the need of the injured person. Accordingly, where that injured person has received care in the past

¹⁰⁰ See pp2-4

¹⁰¹ This is the term conventionally used to describe a non-compensatory award of damages designed to mark the court’s disapproval of outrageous conduct.

from others, and has paid for it, the injured person is entitled to be reimbursed. For the future, they are entitled to a sum to cover the costs of paying for any necessary care from others. However, in reality, in many cases, the injured person may have lacked the means to pay for commercially provided care, and it has been provided in a more flexible, personal and appropriate way, free of charge, by those close to the injured person. This general position is particularly representative of those suffering from HIV, Hepatitis B or Hepatitis C. Some sections of society were so hostile towards anyone with HIV in the 1980s and 90s that it would not only have been difficult to arrange appropriate care from a third party, but potentially dangerous to the family if word had got out that a member of it had AIDS or HIV. Hepatitis B was known by care professionals to be readily transmissible, and treatments for Hepatitis C, or the encephalitis it might lead to, so frequently led to unpredictable mood and personality changes that it would not have been easy to recruit and retain consistent care staff, even if funds had permitted.

As Sir Robert points out in paragraph 9.63, where care is provided voluntarily, for no reward, recompense for it can be valued by reference to what it might have cost commercially, since an injured person in need of care has saved having to spend that amount. Since the need for care is regarded in personal injury cases as the claimant's loss, payments for the value of this care are paid to them, and not directly to the person who provided the care. The claimant then holds the sum on trust to pay it to the carer or carers who have met the claimant's need.

A conceptual framework such as this, which leads to paying one person in order for them then to pay another, does not and should not apply under the scheme. Since the affected person has a claim in their own right arising out of the infection of the infected person, they should have a right to be reimbursed directly from the scheme for the value of any care they have given.

I differ from what Sir Robert says as to the valuation of such care. He suggests that in general courts will not award more than the net commercial rate to a voluntary carer even where that carer has given up more profitable employment. However, in a leading case

on compensation for care, the Court of Appeal unanimously noted that such awards should not be strait-jacketed and that "*Circumstances vary enormously and what is appropriate and just in one case may not be so in another. If a caring relation has given up remunerative employment to care for the claimant gratuitously, it may well be appropriate to assess the proper recompense for the services provided by reference to the carer's lost earnings. If the carer has not given up gainful employment, the task remains to assess proper recompense for the services provided ...*"¹⁰² This recognises that there are some cases in which it is not unreasonable for the party providing care to give up work which would bring in more money per hour than commercial care provision would cost. Such were the stigma, social circumstances and difficulties of care provision for those infected by blood, blood products and tissue, especially until the mid-90s, that it should generally be presumed that any such decision by someone voluntarily caring for them was not unreasonable.

It is also in the nature of the care provided that it is likely in this context to differ from commercial care in other respects, increasing the value of this voluntary care. Commercial care will generally be delivered at set hours during the day, and at a premium at weekends, and for unsocial hours. It is not flexible because of these pre-set hours (unless provided on a 24-hour rolling basis, in which case it is extremely costly). Yet care provided for the infected person voluntarily by their family will, in the context of infected blood and blood products, have been provided on demand, at night where needed, meeting unpredictability, and making it very difficult for a carer to continue in their own paid employment, let alone to build a career. These features should also be borne in mind when the scheme provides for the cases of carers who have not surrendered remunerative work but have provided care.

It is important that the claim for reimbursement for the value of voluntary care be recognised as a claim of the affected person (the infected person should not be

¹⁰² Evans v Pontypridd Roofing Ltd [2001] EWCA Civ 1657 para 25

recompensed for past care gratuitously provided to them, though they should be reimbursed if they have paid for a commercial carer).

In many court cases, considerable time can be spent arguing about the valuation of claims for reimbursement of past care, and over estimates of future costs. The variables can lead to significant differences in amount. However, a bespoke scheme to compensate those who have provided care in the context of blood-borne infections cannot, and should not, in my view be reduced to a spreadsheet of hours and rates derived from a commercial market designed to care for very different medical conditions, in very different social conditions; nor should it take time over such arguments. For the purposes of the scheme, for speed, and to save resources, reimbursement to carers for past work providing care over and beyond that which would have been needed if there had been no infection from blood can, and should, be banded into broad categories.

In a case where the carer did not have to sacrifice paid work to provide care, these bands should have regard to the severity of the condition(s) suffered, the nature of the care given, the difficulties of dealing with the infected person, and the length of time for which care was provided. Appropriate figures should be assessed by the advisory panels, to be applied through the bands. Where the carer has given up paid work, or not taken the opportunity of paid work they would otherwise have done, they should be paid their loss of earnings unless it was unreasonable in the particular circumstances to give up that work or the chance of it. It will perhaps only rarely (if ever) be unreasonable.

As to future costs of recurrent needs for care, these will have to be assessed – a banding approach should be used if possible – such that an infected person may rightly recover their anticipated costs as part of their own claim.

In summary: the care award will cover both past care and future care. In respect of past care, the infected person should be entitled to be recompensed for anything they have paid for. It is unrealistic to expect that there will be receipts to evidence this. A demanding process involving detailed evidence and expert support should be avoided, as Sir Robert

suggested (9.67), and (again as he thought appropriate) “a high degree of self assessment should be encouraged.” Where work or the possibility of work has not been sacrificed to provide care, the care award should be made in accordance with such pre-set tariffs as the Chair and those advising them in the setting up of the scheme consider most appropriate. There should be no assumption that the higher levels should be constrained by the commercial cost of reasonable care provision.

Financial Loss Awards

I agree with what Sir Robert says about past financial losses.¹⁰³ In particular, since a query was raised in the course of submissions, I confirm that it is my view, as it is his, that it is fair that support payments made to date by any of the support schemes should not be set off against any part of the compensation award. However, future support payments should be taken into account in respect of future loss calculations.

6. Options as to the Form of the Award

Sir Robert says both that “*the choice between a final and a provisional award, if available, should be for the applicant to make*” (Paragraph 9.116) and at paragraph 9.117 that: “*I recommend provisional awards be not made part of this scheme. The advantages of finality outweigh the theoretical benefits of flexibility.*”

Provisional awards are made upon the assumption that the applicant’s condition will not deteriorate seriously in a way which is defined in the award. What swayed Sir Robert away from the desirability of individual choice in his paragraph 9.117 to his recommendation that the scheme should in effect remove that choice is that “...*The length of time which has passed since most of the relevant infections occurred is so long that it will be possible to make reasonably confident predictions with regard to the future progress of the disease.*” Given the greater material which the Inquiry has considered, I would not be as confident. The HIV Expert Group told the Inquiry that people living long

¹⁰³ Infected Blood Compensation Study Paras 9.79-9.105 RLIT0001129

term with HIV experience an increased prevalence of non-AIDS co-morbidities, including those associated with ageing such as cardiovascular and chronic kidney disease and an increased incidence of certain cancers compared to an age matched HIV negative population.¹⁰⁴ The Hepatitis Expert Group explained that liver cirrhosis is the end result of long-standing liver disease of any cause, with the risk of liver cancer higher with more advanced liver disease and reduced by effective antiviral therapy for Hepatitis B and successful treatment for Hepatitis C.¹⁰⁵

Given these possibilities, I recommend that there should be a choice, and that choice should be left to applicants. Though there may be only a handful of cases in which the serious deterioration which is feared occurs or a new condition develops in consequence of the receipt of infected blood, blood product or tissue, I do not see why appropriate arrangements cannot be made to allow for a return to the scheme for further recompense, or if the scheme has by then concluded all its work, to Government, to pay what would then be due.

Another choice falls to be made. Awards to compensate for past losses, impact of injury, social impact, and autonomy will naturally be lump sum awards. However, I recommend that periodical payments to compensate for any future losses should be available as an alternative. If the purpose of compensation for a wrong is considered as being to put the recipient into the position in which they would have been if the wrong had never been committed, periodical payments more accurately represent the loss of income (which would have been paid periodically if the infected person had been in employment) that would have been received, or the costs of future care (payable as and when invoices become due). They neither undercompensate, if the recipient lives longer than they expected, nor overcompensate where the recipient does not survive for so long a time. A significant advantage is that the investment risk is borne by the provider of the payment, whereas an applicant receiving a large lump sum of money carries that risk, and to meet

¹⁰⁴ HIV Expert Report p47 EXPG0000004

¹⁰⁵ Hepatitis Expert Report pp26-28 EXPG0000001

it may have to meet the costs of financial advice. Further, the continuation of payments, guaranteed throughout their lifetime, facilitates lenders providing credit to the recipient since the lender can be assured that the credit sought is backed by a guaranteed income. An alternative is the receipt of a single lump sum for future losses, assessed in the same way as future losses are assessed by a court. This has advantages for those who do not wish to feel dependent for their continuing finance on the state which they consider has wronged them in the past, or for those who contemplate ensuring their future security and that of their family by making a significant capital purchase.

7. Miscellaneous Points

I leave it to the scheme to establish appropriate bands, guided by those matters to which Sir Robert refers and the contents of this Second Interim Report. To the extent that they are helped in this by guidelines, some participants have submitted that the scheme should remember that the guideline figures in personal injury cases are produced once every two years and are uprated for inflation.¹⁰⁶

I also received submissions about the importance of financial stability. Sir Robert recommended that the annual payments under the support schemes should be guaranteed for life, by legislation or secure government undertaking, and I agree.

It has been submitted to me that the impact on individuals of their campaigning should be borne in mind. I agree this deserves to be taken into account. I leave it to the Chair of the scheme to determine how it is most appropriate within the categories of loss to recognise it, since it might easily be a factor in determining an appropriate award under any or all of the first three categories of loss.

I have had conflicting submissions on paper as to whether past payments under the support schemes should be taken into account against any award now to be made under the compensation scheme. When Mr Johnston KC raised this on behalf of the Scottish

¹⁰⁶ Guidelines for the Assessment of General Damages in Personal Injury Cases (Judicial College)

Government he seemed to me not to press the argument too strongly when he was asked to consider that the payments were made as forms of social support, and thus should no more be taken into account than such payments generally are in personal injury claims. If they had not been made, then I suspect that the past losses for which an applicant may now be able to claim would be all the greater, and carry interest on top. On balance, I consider that Sir Robert was right to recommend that they should not be brought into account, but that future payments from EIBSS, WIBSS, SIBSS or NIIBPS should be.

Support Services

1. Advice and Advocacy / Legal Services

I accept that the speed, efficiency and acceptability of the scheme process would be facilitated by advice and advocacy. Sir Robert deals with this both at section 11 and under the heading "Other Issues: Legal Support". The scheme should be available for an applicant who would wish it. To operate it there should be a service staffed by a lawyer or lawyers who will give their advice confidentially to the applicant, and be under an obligation of confidence to the applicant as would be the case in private practice. With those minor additions, I agree with what Sir Robert says at section 11. I see the support unit he discusses at his paragraph 12.2 (first bullet point) as providing this service.

Where discretion is exercised to fund legal representation from independent lawyers, the fees payable should be capped at public service rates (at then current levels); a panel of firms, chosen as Sir Robert suggests to include those with "*demonstrable experience of this scandal*", should be recognised as firms which an applicant may wish to utilise; other firms should not however be excluded provided it is understood both that the same public service rates should apply, and that only very limited financial provision should be made by the scheme to fund a particular lawyer's familiarisation with the content of "*this scandal*". It would be wise to adopt an approach which authorises expenditure up to a given ceiling, with the lawyer expected to justify the expenditure of time and resource within that budget.

2. Financial Advice and Support

I agree with what Sir Robert writes at his paragraph 11.18, save that advice on the management of funds awarded as compensation can safely be left to independent financial advisers if applicants wish to use their services, under arrangements which they make independently with those advisers. However, advice on obtaining finance or

insurance services, and benefits advice, should undoubtedly be made available through the scheme at no charge to the applicant.¹⁰⁷

I agree also that the scheme may have a role in signalling or certifying entitlement to access any special arrangements made with financial and insurance sectors, as Sir Robert suggests at his paragraph 11.21.

3. Access to Health and Care Services

I agree with Sir Robert that there may be a need for advice and referral to appropriate specialist services, and in "*signalling or certifying entitlement to access any special arrangements*". I emphasise that this last should include the ability of the scheme, if the applicant wishes it, to raise any issues directly with a Department of State (for instance the Department for Work and Pensions) should it seem to be that the applicant's entitlements may not be fully recognised as they should be (for instance, by not applying disregards), or (for instance) where it may seem that the applicant is having to repeat information which has already been provided to the same body.

¹⁰⁷ Benefits and welfare advice given by a specialist advisor at their request to registrants of the Macfarlane Trust was particularly well received.

Local or National Administration?

Although I recognise the desirability in many respects of local delivery within each devolved nation which Sir Robert recommends, I differ from his conclusion.

It should be for the scheme itself to determine the extent to which it is appropriate to deliver its services locally, in the light of experience. When it starts, however, the emphasis should be on:

- a) speed;
- b) concentrating resource and expertise on implementing the scheme; and
- c) ensuring that as many applicants as possible are processed efficiently.

It must be borne in mind that the scheme is there to assess a final (or in some cases provisional) award of compensation, applying the appropriate bandings and assessing financial losses. The scheme is unlikely to have a significant ongoing relationship with individuals after payment of the final award.

Such a scheme lends itself to administration from one place within the UK rather than being localised. The latter is more likely to give rise to disparities of approach.

Since Sir Robert suggests, and I agree, that the support schemes should continue, there will be localised administrations giving the benefits which he identifies.

My recommendation - which is for central organisation, whilst keeping under review any advantages to be gained by more local administration - ought also to avoid the costs and time of creating a partnership board to oversee the ALB on a UK wide basis, as he speculates may be needed if a local structure were to be adopted.

Although it may seem at first sight odd that there should be both an ALB setting compensation on a UK-wide basis and four separate national support schemes still in operation, once it is realised that they have different functions, and can operate

independently of one another without difficulty, it becomes entirely sensible for the reasons Sir Robert identifies at his section 10 for them to do so. The only area of overlap will be where the ALB takes into account the support from support schemes in assessing future losses.

Further Interim Payments

The payment of interim awards to bereaved partners has emphasised the fact that some people have died as a result of infected blood and blood products without any payment being made in respect of their death, leaving bereaved parents, children or siblings who have suffered profound distress and loss which has to date been unremedied. They may not even have had the benefit of any payments from the trusts and schemes.¹⁰⁸ I indicated in my first interim report that I would return to this issue after I had heard submissions following the conclusion of the evidence.

Some core participants submitted that interim payments should be made to bereaved parents and children through the estates of those who have died. This proposal has the difficulties that doing this takes considerable time, involves a degree of red tape, may involve complications where the estates have been settled and distributed some time ago, and may not achieve the intended purpose.¹⁰⁹ These features would deprive an “interim” payment of any of the benefits of speed which the name suggests, and may complicate an eventual award.

Nevertheless, each affected person will, under the scheme which I have recommended, have a claim in their own right. The amount each receives will vary according to their own individual circumstances. Some but not all of these claims are likely to be quite significant because the Inquiry has heard evidence of substantial distress and serious loss. However, for an interim payment to be made by the schemes without taking time, one single figure needs to be recommended. A key part of the scheme that I (and Sir Robert) recommend is that a claim may be made on behalf of the estate of a deceased infected person. The compensation due in such cases may be significant. I take account therefore of the expectation of inheritance under the usual rules: where there is no bereaved partner it is likely that first, children, then parents, then siblings (or in Scotland

¹⁰⁸ Despite, for instance, being within the scope of the Macfarlane Trust deed in the case of HIV.

¹⁰⁹ Because entitlement to benefit depends on the will, or on the intestacy rules.

parents and siblings) will ultimately benefit from the awards due to the estate of the person infected, divided between those in the same category. An interim payment now to those who fall within these categories is a way of answering current needs which will represent no more than a reasonable proportion of the likely sums to which the individual concerned will ultimately be entitled, through a combination of a claim in their own right as an affected individual and the claim on behalf of the deceased's estate.

Accordingly, I recommend that an interim payment of £100,000 should be paid to recognise the deaths of people to date unrecognised and thereby alleviate immediate suffering. This should be done as follows:

- a) where someone infected died as a child or died as an adult without a partner or child, the interim payment should be made to their bereaved parents (split equally if separated);
- b) where someone infected has died and there is no bereaved partner but there is a bereaved child or children (including any adopted child¹¹⁰), the interim payment should be paid to the child or children (split equally); and
- c) where someone infected has died and there is no bereaved partner nor child nor parent but there is a bereaved full sibling or siblings, the interim payment should be paid to the sibling or siblings (split equally).

These interim payments should be capable of being made through the support schemes after registration and of being achieved reasonably quickly. They can and should be achievable before the compensation scheme itself is operational.

I recognise that there will be people who will not fall within these categories, whose position will require a more detailed evaluation. Unfortunately, this will have to await the compensation scheme. However, making interim payments to some on this basis does not exclude further consideration being given by the scheme when it is up and running to making interim payments to children who have lost a parent (where the surviving parent has received an interim payment), or to parents who have lost a child who at the time of

¹¹⁰ But not a step-child: under intestacy rules there is no entitlement for children who are not biological children of the deceased.

death had a partner (who has received an interim payment), or to step children and half siblings, or to others who may have a proper claim for an interim payment. Once the scheme has been set up, it should consider as a priority whether to make interim payments to people in such circumstances on account of the compensation they will in due course receive after calculation of their eventual award as affected persons.

In summary, the immediate needs of some can be addressed by interim payments and it would be right to do so.

Parity in Specialist Psychological Support

On 15 October 2018, I wrote to the Minister for the Cabinet Office and the Chancellor of the Duchy of Lancaster, then David Lidington MP. I made a point of alerting him to the considerable concern that had been expressed during the preliminary hearings, concluded only shortly before, about “*access to (and variations in) financial support, psychological support...*” I asked for decisive action to be taken at the earliest opportunity.

That was over four years ago.

Then, on 30 April 2019 Jackie Doyle-Price MP, Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention, wrote to say that the call for greater parity of support across the UK which “*...we have heard very clearly as a major issue...*” had been recognised.

The Paymaster General, Penny Mordaunt MP, wrote in May 2020 as the new minister sponsoring the Inquiry to recognise that the Inquiry was a priority both for the Government and for her personally. I replied acknowledging the positive moves that had been made towards greater parity of financial support between the four nations of the UK. However, I also wrote:

“It remains the case that the majority of people infected and affected do not have access to dedicated psychological support despite having had to struggle with the corrosive effects of infection, the debilitating side effects of treatment (often with destructive uncertainties of knowing that whether that treatment would succeed was speculative), and the brutal manifestations of stigma. All this on top of losses of career, social and educational opportunity, and finance; and in many cases, also bereavement. The evidence given to me not just from people infected and affected but also from the Inquiry’s panels of leading psychosocial HIV and Hepatitis experts is that dedicated psychological support is long overdue.”

I went on to say:

"I share the admiration and gratitude to all the people infected and affected which you expressed in your final paragraph. It will be plain from what I have said already that I too found their testimonies moving, powerful and important. It is not easy to expose intimate details of one's life to public gaze. I have asked them to take all the risks of doing so, in the interests of the Inquiry. You will understand then, why it is, that I feel a particular sense of responsibility for ensuring that the support is there for them, on a professional and long-term basis, not only to assist in dealing with the problems of the past, but with the added pressures that participating in the Inquiry would have brought to bear on them. I hope that with ministerial colleagues in the four nations you are able to cut through whatever problems have prevented greater progress to date."¹¹¹

Those words were heeded in Scotland, Northern Ireland, and Wales, each of which has developed a bespoke psychological service dealing with the specific needs of the infected and affected community. No such service has yet been provided in England.

I feel a keener sense of responsibility now compared to that which I felt then, because those who have participated in the Inquiry, for whom painful memories will in many cases be re-awoken, now have to deal with the period of uncertainty and insecurity which waiting for a final report is bound to engender. I would be failing in my duty in what is likely to be a difficult time for them if I did not take the opportunity to repeat my call first made over four years ago that there be parity of provision.

1. Specialist Provision

In Northern Ireland, after my letter of 2018, a specialist psychological service for infected and affected patients was established. It is open to anyone affected. Nearly all referrals are seen within six weeks. There is no cap on the length of time or the number of sessions

¹¹¹ These letters can be found on the Inquiry website.

a person can access. There is direct access to the service without having to go through a health professional.

By November 2022¹¹² the service had served the needs of 38 people. The benefits were such that Caroline Leonard¹¹³ who has strategic and operational responsibility for the service which Dr Sarah Meekin heads up in the Belfast Health and Social Care Trust had been in discussion with the commissioners to see the service embedded as a core business in the Haemophilia Centre for all individuals with inherited bleeding disorders: the expectation is that there will be a continuing need to address the needs of people infected and affected, but the referral criteria will be widened to look at all individuals with inherited bleeding disorders to provide a more holistic service to that population going forward.¹¹⁴ Dr Sarah Meekin commented:

*"I think we're very mindful, in terms of even the evidence base, as to the need for psychological support in the inherited bleeding disorders, and I am keen to ensure that that is part of the MDT¹¹⁵ provision moving forward."*¹¹⁶

In Wales, a service was set up similar to that in Northern Ireland at about the same time. It has no cap on the number of sessions that people can access. The service is open for referrals for the infected and affected. It is flexible and wide reaching. It conducts individual sessions in person, online, by phone, in couple therapy, and family therapy. It may see as many as three generations of one family in response to one initial request. The service has even offered home visits where it can and where it is appropriate. Those wishing to access the service may refer themselves to it, without having to go through a health professional.¹¹⁷

¹¹² When oral evidence was given to the Inquiry about specialist psychological support.

¹¹³ Director of cancer and specialist services in the Belfast Health and Social Care Trust

¹¹⁴ Transcript 11 November 2022 pp72-79 INQY1000260

¹¹⁵ The multi-disciplinary team delivering care to those with bleeding disorders.

¹¹⁶ Transcript 11 November 2022 p84 INQY1000260

¹¹⁷ Transcript 11 November 2022 p85 INQY1000260

By 22 November 2022 there had been some 80 referrals, over half of which remain active cases. Some access the scheme for a few sessions, some for a number, and some have been seen from the beginning and continue to be seen. Although funding was originally for three years, it is now ongoing. It is an all-Wales service working closely with the finance department and the benefits advisors. Dr Caroline Coffey, a consultant clinical psychologist, considered it an advantage for the service to sit within the larger structure of the payment scheme, WIBSS. Feedback has been “*really positive*”.¹¹⁸

The Scottish Government and NHS National Service Division¹¹⁹ saw a need for such psychological support specifically for those who had inherited bleeding disorders in 2016. It funded a full-time psychologist, Dr Gráinne O’Brien, and a liaison psychiatrist at one session per week, initially in the Lothian area but now extended to the whole of Scotland. It liaises through haemophilia centres¹²⁰ with those suffering from inherited bleeding disorders.

An initial two year pilot was successful, and has been extended since 2018 with joint funding from the Scottish Government and NHS National Services Division. Dr Gráinne O’Brien commented that: “...*recently we have had positive indications that funding will continue long-term, permanently, for this particular service, which is excellent news as it is a very well used service.*”¹²¹ The fact that it has been embedded within the multi-disciplinary team makes a “*big difference*” says Dr Gráinne O’Brien. There have been well over 100 referrals concerning people infected and affected, though the service is available to all patients with an inherited bleeding disorder and their family members. It aims to be person centred, and referrals are seen always within 10 weeks and normally

¹¹⁸ Transcript 11 November 2022 p89 INQY1000260

¹¹⁹ Responsible for commissioning specialist services on behalf of Scotland’s health boards and the Scottish Government.

¹²⁰ Of which there are five in Scotland.

¹²¹ Transcript 11 November 2022 p91 INQY1000260

a lot sooner. There is no cap on the number of appointments nor limit on what will be provided at each.

Dr Gráinne O'Brien described the service, and what it had to deal with in these terms:

“So within our service we have provided one-to-one therapy, and as for the number of different therapeutical modalities, dependent on what somebody is presenting, what the issues are, what is causing the stress or impacting the quality of life. As was mentioned previously, that is a wide array of issues, that might be anything from anger, stigma, shame, guilt, around possibly being a sibling who didn't receive contaminated blood product. It might be working with a parent who, perhaps, was perhaps involved in giving treatment to a child. We work with depression, suicidality, trauma, PTSD, issues that people might have in seeking help from the NHS due to some of the experiences they have had. We might work with somebody to help them re-engage with treatment to help themselves physically or psychologically...and obviously bereavement, loss, grief...and we work individually. As in both Northern Ireland and Wales the service tried to get rid of as many barriers as possible to enable people to access the service.”¹²²

The wide variety of issues she listed have resonated throughout the evidence given by infected and affected participants in the Inquiry.

In September 2021 the “Scottish Infected Blood Psychology Service” began, again as a pilot scheme, aiming to support those who had been infected through a blood transfusion. Negotiations are currently underway to ensure that the pilot is adopted on a more permanent basis. Again, it provides open access and referrals are to a dedicated clinical psychologist. Anybody who is registered with SIBSS can access this service. Thus far, it has had over 50 cases, roughly half of which have been self-referrals.¹²³

¹²² Transcript 11 November 2022 pp93-94 INQY1000260

¹²³ Transcript 11 November 2022 p99 INQY1000260

Wales, Scotland and Northern Ireland have established the “Infected Blood Psychology Network” between them. This aims to make professional links and share ideas about how best to run the services and, what is most helpful, to learn from each other and think whether there are ways of combining some ways of working. This also means that they can support people who move between countries.¹²⁴

When asked by Counsel whether she thought that parity in access to specialist psychological support services was important Dr Caroline Coffey said she did.¹²⁵ That was because:

“...some of the difficulties that people present with are quite specialist and quite long-term, and some of the feelings are quite entrenched, understandably, and I think it does need a specialist level of intervention.”

Dr Sarah Meekin agreed, adding:

“I think the other issue in terms of parity is people are already struggling with having felt – I suppose we often hear people talking about people feeling like lower-class citizens in terms of how they feel that they were treated, and any lack of parity contributes to those feelings and to that experience, and so that has a sort of on-going psychological impact as well, in terms of feeling, again that you are not...receiving the support that someone in a similar situation would be...the parity issue becomes, I suppose, an additional stressor and challenge in terms of how people feel they are being supported on the back of the issues that have arisen.”¹²⁶

Dr Belinda Hacking, Chair of the Heads of Psychology Services across Scotland, agreed too:

¹²⁴ Transcript 11 November 2022 pp102-104 INQY1000260

¹²⁵ Transcript 11 November 2022 pp104-105 INQY1000260

¹²⁶ Transcript 11 November 2022 p106 INQY1000260

*"I think it is important that the provision is specialist in the context of working within medical services and so that the clinicians have an understanding and credibility about understanding the background that people experienced, they are understanding the systems of care in which these individuals are being treated, and it enables the – those who are getting care through the service provision not to have to keep on repeating their story, which, in effect, can become re-traumatising, to have to explain to multiple professionals all that they had been through and all that their families had been through, so that retaining the specialisation of the services to me is very important in terms of the quality of care that is provided."*¹²⁷

Dr Gráinne O'Brien added that general psychological support services could underestimate or not quite understand the impact of what has happened. She supported the views of many of those who have given evidence to the Inquiry that they had been frustrated having to spend one or two sessions getting someone up to date, particularly if the sessions are capped in number. All the witnesses (apart from Luisa Stewart from NHS England who, since England did not have a dedicated bespoke psychological support scheme, was not in a position to comment) agreed that a clinician delivering psychological services to someone infected or affected should have an understanding of the historical context, the stigma, the history in terms of the sense of injustice that had been felt, and the consequences to some of not being able to access NHS care and treatment, and to others who had spent decades campaigning.

Each of Wales, Scotland and Northern Ireland has a service which is flexible to the needs of patients. They regard the issues as ongoing. As Dr Caroline Coffey said:

"You know, the Inquiry is happening, people's health, you know is poor. It's not something that's kind of finished and completed. It's something that's reactivated at different points in their life, ... I think it's not something that you can necessarily kind of package up into

¹²⁷ Transcript 11 November 2022 pp106-107 INQY1000260

ten appointments. It's not a 'here and now' issue like some psychological difficulties might be. It's something ... long term and some of these feelings are understandably very entrenched."¹²⁸

She thought flexibility far better than an approach which limited the number of sessions available to a patient.

In summary, the approach taken by the three nations recognises that there is a requirement for consistent, holistic and long-term specialist psychological support to the infected and affected. Dr Caroline Coffey for her part could not see a time when this service would not be needed. In each case a pilot scheme showed that the service was worthwhile, value for money, and necessary to meet the special clinical needs of the infected and affected. Finally, before I turn to the position in England, I note that both the Welsh and Scottish evidence identified the trust of individuals in the healthcare system as being a key issue, such that it was important that services of the bespoke nature described were maintained.

2. The Position in England

The English provisions for meeting the psychological needs of the infected and affected stand apart. The service is not a bespoke one. Psychological support is available, but of the general nature (in the form of "IAPT"¹²⁹) available to the general public. This is not delivered by psychologists or psychiatrists who have developed detailed personal knowledge of those issues affecting people who were infected by blood, blood products or tissue, and their families.¹³⁰ A grant of up to £900¹³¹ is available from EIBSS to fund

¹²⁸ Transcript 11 November 2022 pp112 INQY1000260

¹²⁹ Improving Access to Psychological Therapy

¹³⁰ The nearest to that has been a suggestion that there be online resources which clinicians can access to inform themselves about the history of infected blood and blood products and the issues raised by it.

¹³¹ There is some unadvertised flexibility to exceed this sum, but the criteria for exercising it are unclear.

access to private counselling, but it is unclear how an applicant is expected to choose a practitioner with any specific knowledge of the detail and history of infected blood and blood products. The aspects, described above, which the Scots, Welsh and Northern Irish valued in their schemes do not feature.

The history of moves towards bespoke support in England

In January 2020 the Parliamentary Under Secretary in the Department of Health and Social Care (Nadine Dorries MP) and the Cabinet Office Minister (Oliver Dowden MP), met campaigners from the infected and affected community. As has been the case on previous occasions when a minister has met and spoken to people who were affected and infected, Nadine Dorries MP was plainly moved by what they had to say, for a week later she met the civil service team responsible and said that she was *“keen to demonstrate progress on this issue, and would like to press ahead and consider specific proposals to deliver a bespoke offer of support.”*¹³²

The Mental Health Team at NHS England and NHS Improvement worked up proposed options. These were not quite options to provide a bespoke service - there were three options, true, but only one of those was for a bespoke service. It was however that which was recommended to the Minister.

The three options¹³³ were, in the words in which they were described by officials:

“Option 1: Improved access to existing NHS services through the England Infected Blood Support Scheme (EIBSS website). This would be a marginal improvement of current signposting, by improving the linkup between the EIBSS website and the NHS website for finding local IAPT Services. This will have minimal additional benefit to those affected, as IAPT Services do not offer bespoke services for conditions related to contaminated

¹³² Email from the NHS England and NHS Improvement Head of Mental Health (Delivery) EIBS0000696 p3

¹³³ Department of Health and Social Care submission EIBS0000709 p3

blood or any specific physical health conditions. This option would not meet the expectations of stakeholders.

Option 2: Expansion of existing services. An extension of option 1 we could further strengthen signposting by extending some existing services, such as the existing Red Cross counselling and support line which offers telephone psychological support for those who are participating in the Inquiry. However, this again would only have a marginal impact, would require a significant extension of the current remit of those services, and would not meet the expectations of stakeholders in the Inquiry.

Option 3: Bespoke NHS psychological support services for people with infected blood. The most ambitious, and our preferred option, would be to develop a bespoke service for those affected by infected blood. Similar to the models already in place in Wales and Northern Ireland,¹³⁴ this service could offer initial psychological assessment and formulation, signposting to existing local services for most service users, and then some specific psychological therapy service for those issues unlikely to be met by specific local services. The scale of demand for this service is not yet known, but initial estimates suggest that a team of three staff could provide a national telephone based service offering the mix of services outlined above would cost an estimated £360k per year. The costings for this are set out in Annex B.”

The conclusion was:

“We recommend that you ask DHSC officials and NHSE to develop the proposals for a bespoke NHS psychological support services for people with infected blood (option 3). This is the only one of the three options that is likely to meet the demands of those involved in the Inquiry.”

¹³⁴ There is no mention of the Scottish service anywhere in this document.

The Minister's private office was sent the options, and on 17 March 2020 replied to say she had reviewed them *"and would like to progress Option 3, noting however that we should be trying to do this within existing funding for services if possible."*¹³⁵

By 21 May the following year, 2021, nothing tangible had happened to put the Minister's wish into operation. Of course, Covid had intervened.

William Vineall, a senior civil servant then attending the Inquiry to give evidence together with the Secretary of State for Health, Matt Hancock MP, said:

*"What I can say is we've now picked that work back up in earnest and we held a meeting last week with EIBSS and NHS England where the gist of the discussion was that we wanted to move to a bespoke service that effectively had - I mean in simple terms, a clinician embedded within EIBSS who could act as a signposting pathway for people who need psychological support with expert input, ... So yes, we don't have a service but yes, we want to get a service."*¹³⁶

He confirmed that work was *"underway in relation to implementing option 3."* The Secretary of State was asked whether he would give an assurance to make the funding available to allow the bespoke psychological service to be implemented. He answered: *"Yes. And this amount of funding that could possibly be needed is small in the overall scheme of the mental health services that we provide."*

At this stage, all that appeared to remain was for the detail of the service to be drafted. The principle was accepted; the aim was clear; the money had been assured.

However, seven months later the NHS Business Service Authority (NHSBSA), responsible for EIBSS, told the Department of Health and Social Care that when starting

¹³⁵ Email from Senior Private Secretary to Nadine Dorries MP EIBS0000697 p1

¹³⁶ Transcript 21 May 2021 pp137-138 INQY1000121

to prepare a service specification it had reached a conclusion that signposting beneficiaries to appropriate services would involve a clinical assessment. It asserted that since NHSBSA did not provide clinical services, it would not be possible for it to commission such a service. Thus, on what could possibly be seen as a technicality, the route which William Vineall and the Secretary of State had mapped out in May was followed no further.

A bespoke service was not entirely abandoned. Departmental officials worked up a research proposal to inform the development of a bespoke service and this was initiated in January 2022.¹³⁷

On 14 March 2022, Sir Robert submitted his Compensation Study. At paragraph 11.32 he concluded that:

“The scheme¹³⁸ should have a support unit which is available to provide or arrange the provision of medical, psychological and social support to infected and affected persons appropriate to the needs caused by the consequences of the infection.”

This echoed what I had called for, what Nadine Dorries MP had endorsed, and what she had tasked her officials to deliver two years before.

Two weeks after this renewed call for bespoke support a new Parliamentary Under Secretary, Maria Caulfield MP, received a submission from her officials.¹³⁹ It noted that take up of the £900 grant for privately paid psychological support from EIBSS was low, and that there was lack of firm evidence to explain the reasons for this. The submission did however contain some feedback from beneficiaries which highlighted three criticisms of what was available through EIBSS at the time – first, that some complex needs required

¹³⁷ Evidence of William Vineall. WITN4688076 para 1.23

¹³⁸ i.e. in this context, the compensation scheme he was proposing.

¹³⁹ WITN4688076 paras 1.17-1.23

longer-term or ongoing support costing more than £900 a year and counselling was not the most appropriate treatment for everyone; second, that it could be difficult for an individual to know how to find an appropriate healthcare practitioner, and the application process might be daunting; and third, that a lack of knowledge on the part of practitioners, or a lack of bespoke services, meant that some individuals were left feeling that they needed to educate healthcare practitioners about infected blood.¹⁴⁰

Three options for change were put forward. (There was a fourth option, but that was “no change”). Option one was expanding the £900 grant to permit access to a wider range of evidence-based talking therapies beyond counselling. Option two was option one plus the formalising of discretionary arrangements to enable beneficiaries to apply for funding to access longer term treatment, providing better information to help people choose the appropriate practitioner, and working with practitioners to develop a resource to better understand “*the infected blood context*.” Option three included option two with the addition of using a charity to deliver a non-clinical support service to assist beneficiaries in choosing an appropriate practitioner and in applying to EIBSS.

The recommendation was to implement option one, together with further scoping to understand how the second and third options could be delivered and their cost implications, and to continue to explore how to address the difficulties associated with introducing a bespoke psychological support service for beneficiaries. The Minister accepted this recommendation.

It should be noted that no option was put forward for a service along the lines of that operating in Northern Ireland, Wales and Scotland, because it was said that there were difficulties with establishing a bespoke service “*at this time*”: these were a lack of precise detail as to its specification, and how it might integrate with existing mental health services; identifying a viable route to commissioning such services; and the concern that

¹⁴⁰ These three points have each been echoed in evidence to the Inquiry from people infected and affected.

a bespoke service might run contrary to the core NHS principle of prioritising access to services on the basis of clinical need.

It might be thought that the first two difficulties are practical ones which should not be difficult to overcome given sufficient will; and the third is open to the comment not only that it has seemed to have posed no problem within the NHS in Scotland, Wales and Northern Ireland, but also that the psychosocial experts and clinical experts who gave evidence before the Inquiry were clear that there is an unresolved and specific clinical need, a view which has been shown by experience in Northern Ireland, Wales, and Scotland to be well founded.

In August 2022, the Department of Health and Social Care told the Minister it had commissioned¹⁴¹ the Policy Innovation and Evaluation Research Unit (“PIRU”) to conduct research into the current and likely needs for support, and how it might need to change as the Inquiry concludes and Government responds to its recommendations; the extent to which existing services are able to meet current needs; routes taken to access support; experiences of accessing those services; and any barriers or enablers to access, along with allied matters.¹⁴² The proposed end date for the study is May 2023, though PIRU told the Inquiry that they have requested it be moved back to July 2023 due to delays in data collection.¹⁴³

On 11 November 2022, in the course of her evidence to the Inquiry, Dr Caroline Coffey, said with particular reference to the use of IAPT services to meet the needs of the infected and affected that:

¹⁴¹ Through the National Institute of Health Research. This followed from the work done in January 2022 mentioned in the text.

¹⁴² WITN4688076 para 1.23

¹⁴³ Evidence of Professor Ellen Nolte, Deputy Director of PIRU. WITN7686001 para 4.3. Para 4.4 explains that the study assigns the experience of specialist practitioners in Scotland, Wales and Northern Ireland as relevant to the **supply** and not the **demand** for psychological support.

“... I think that we had several requests from service managers for the EIBSS service about how our service was being run. One of the service managers joined us at a network meeting, which was with Scotland and Ireland, and we were very, I guess, passionate about our, I suppose, uncomfortableness with the IAPT involvement, because I suppose, from our perspective, ... we didn't think it was an appropriate way for it to kind of be managed, but yeah, we had lengthy discussions about it and we did provide some kind of written accounts of why we thought the specialist service in-house would be more appropriate, really.”¹⁴⁴

Luisa Stewart confirmed that IAPT would not currently be able to provide the more complex treatment described as being on offer under the specialist services in the other nations.¹⁴⁵

Finally, in February 2023 at an EIBSS focus group, a beneficiary asked about the £900. EIBSS noted that this had been asked in August 2022 too and the response from the Department was: *“We are working with the EIBSS team and NHS England and Improvement to consider how the current psychological support offer could be improved. In the meantime, beneficiaries with greater need should contact EIBSS to apply for discretion to be applied in their case.”¹⁴⁶*

3. Summary and Recommendation

At the start of this section of this interim report I set out the three options offered to the Minister, Nadine Dorries MP, in March 2020. That which has currently been delivered effectively equates to option one, which is worth re-reading:

“Option 1: Improved access to existing NHS services through the England Infected Blood Support Scheme (EIBSS website). This would be a marginal improvement of current

¹⁴⁴ Transcript 11 November 2022 pp160-161 INQY1000260

¹⁴⁵ Transcript 11 November 2022 pp126 INQY1000260

¹⁴⁶ EIBSS Focus Group minutes (February 2023) EIBS0000712 p12

signposting, by improving the linkup between the EIBSS website and the NHS website for finding local IAPT Services. This will have minimal additional benefit to those affected, as IAPT Services do not offer bespoke services for conditions related to contaminated blood or any specific physical health conditions. This option would not meet the expectations of stakeholders.”

Having heard the evidence of the psychosocial expert group and the practitioners in the other three nations, and taken into account all that Luisa Stewart said, I believe the summary in March 2020 of officials about the current minimal benefits of IAPT for this particular wronged community was and is accurate.

The chronology of what has happened since speaks for itself. Whilst I do not underestimate the demands of the Covid-19 pandemic, they do not excuse the failure to establish a bespoke psychological support service for England; nor is the failure excused by difficulties in finding a suitable service model, which should, in my view, have been capable of being overcome before now. The decision to commission research in 2022, some two years after the Minister had called for proposals for a bespoke service, does not provide a wholly satisfactory explanation for the lack of progress.

A serious need remains. It is likely to intensify as the Inquiry reaches the conclusion of its final report. The evidence is clear that a bespoke scheme similar to that operated by the NHS in Northern Ireland, in Wales, and in Scotland is desirable and needed. Parity is important. Meeting the very particular need for support amongst a particular group of people is overdue, and I recommend that without delay steps be taken to provide a bespoke psychological service. It is difficult to see why the practicalities referred to in advising Maria Caulfield MP cannot be overcome. The principle of ensuring priority to services on the basis of clinical need should be no barrier, given that providing access to a bespoke group has been recognised by senior politicians throughout, it has posed no barrier in any nation except England, and it seems clear that there is a real as yet unmet need for this, too, to be achieved as soon as possible.

I still look forward to being able in my final report to acknowledge that proper psychological support and follow-up is in place across the UK.

Recommendations

Comparison with Compensation Study

For ease of reference and comparison, the recommendations that Sir Robert makes in the Infected Blood Compensation Study are set out in italics, and then the corresponding recommendation made by the Inquiry in bold. Footnotes identify where detailed reasoning may be found to support the changes to Sir Robert's formulation. For readers who would prefer to see the Inquiry Recommendations as a list, this is provided at the end of this section.

Compensation Study Recommendation 1: I recommend that the Government accepts that, irrespective of the findings of the Inquiry, there is a strong moral case for a publicly funded scheme to compensate both infected and affected victims of infected blood and blood products infected with HCV or HIV, and that the infections eligible for compensation be reviewed on a regular basis in the light of developing knowledge.

This recommendation has already been accepted in full by the Government.

Compensation Study Recommendation 2: I recommend that the scheme should offer redress to those infected with HCV and/or HIV, and defined serious cases of HBV [relevant diseases], and defined categories of persons indirectly affected by such infections [relevant affected persons].

Inquiry Recommendation 1: I recommend that the scheme should offer redress to those infected with HCV and/or HIV, and/or HBV¹⁴⁷ (limited to chronic HBV unless the infection has resulted in a fatality in the acute period), and to defined categories of persons indirectly affected by such infections.

¹⁴⁷ For more information see Hepatitis B pp27-32

Compensation Study Recommendation 3: I recommend that the conditions of eligibility for admission of relevant infected persons to the scheme should be that:

- a) they have been diagnosed as being infected with one or more of HCV, HIV, or HBV of the defined level of severity;*
- b) they received one or more blood transfusions or blood products known to be capable of transmitting one or more of the relevant diseases [the relevant treatment];*
- c) the patient received the relevant treatment within - or from stocks created within - the periods of eligibility employed by the current support schemes or a period to be defined (subject to any findings of the Inquiry with regard to such dates) during which in retrospect and without necessary attribution of culpability or negligence, in the light of the knowledge at the time or subsequently, the relevant technology or science could have been available to avoid infection/contamination of blood or blood products and/or of transmitting such infection to patients [the relevant period], alternatively, after the relevant period using blood or blood products likely to have been collected or made during it; and*
- d) their infection was likely to have been caused by administration of the relevant treatment or they fulfil condition a) above and their infection was likely to have been transmitted to them by a person who fulfils conditions a) to c) above.*

Inquiry Recommendation 2: I recommend that the conditions of eligibility for admission of relevant infected persons to the scheme should be that:

- a) they have been diagnosed as being infected with one or more of HCV (including natural clearers who have suffered loss), HIV, or HBV (limited to chronic cases of HBV unless the infection has resulted in a fatality in the acute period);**
- b) they received a transfusion of blood or components of blood, blood products or transfer of tissue capable of transmitting one or more of the relevant diseases; and**
- c) their infection was not unlikely to have been caused by administration of the relevant treatment, regard being had as to the available evidence as to the measures in place at the time to reduce the possibility of infection, including but**

not limited to the date of relevant effective screening tests or effective viral inactivation treatments;¹⁴⁸ or

d)(i) it was not unlikely to have been caused by transmission to them by a person who fulfils conditions (a) to (c) above, or (ii) by transmission to them by a person who fulfils condition (d)(i), such as a child or children infected by their mother who had previously been infected by her partner, who in turn had been infected as in (a)-(c).

Compensation Study Recommendation 4: I recommend that the scheme should, so far as possible, avoid legalistic and adversarial concepts of the burden and standard of proof: establishing eligibility under the scheme should be either: a) automatic in the case of infected persons already accepted for eligibility under the support schemes; or b) a collaborative process in which:

- *the applicant is sympathetically supported by the scheme in obtaining any required information and documentation;*
- *in general a presumption is applied that statements of fact made by an applicant are correct;*
- *applicants are not required to repeat information already provided to the support schemes;*
- *eligibility is accepted if the information available points towards eligibility and there is no strongly persuasive evidence which contraindicates eligibility.*

Inquiry Recommendation 3: As above, save that (a) the last bullet point should read: “eligibility is accepted if the information available points towards eligibility and the opposite cannot be shown to be more likely”¹⁴⁹ and (b) eligibility should be automatic for individuals already accepted under an existing support scheme.

¹⁴⁸ For more information see Cut-off Dates for Infections pp32-34

¹⁴⁹ For more information see Eligibility and How it is to be Determined pp37-40

Compensation Study Recommendation 5: I recommend that the following relevant indirectly affected persons should be admitted to the scheme:

- a) spouses, civil partners and long term cohabitees (for at least one year) of living or deceased eligible infected persons;*
- b) children of an eligible infected person;*
- c) parents of eligible infected persons whose eligibility started in childhood;*
- d) siblings living, while under the age of 18, as a family with an eligible infected person;*
- e) providers of care to an eligible infected person, as a result of the infection;*
- f) members of the family, or friends of an eligible infected person, whose relationship with them was so close that it could reasonably be expected that their mental or physical health would be seriously affected by the consequences of the disease, and who has in fact suffered a mental or physical injury as a result;*
- g) the estates of deceased affected persons who would, if alive, have been an eligible affected person for the compensation to which they would have been entitled during their lifetime; and*
- h) dependants (as defined by the Fatal Accidents Act) of deceased infected persons whose death was caused by the infection or its consequences.*

Inquiry Recommendation 4: I recommend that the following relevant affected persons¹⁵⁰ should be admitted to the scheme:

- a) spouses, civil partners and long term cohabitees (for at least one year in the case of the latter) of living or deceased eligible infected persons;**
- b) children of an eligible living or deceased infected person;**
- c) parents of an eligible living or deceased infected person;**
- d) siblings of an eligible living or deceased infected person;**
- e) providers of care to an eligible living or deceased infected person, as a result of the infection; and**
- f) members of the family, or friends of an eligible living or deceased infected person, whose relationship with them was so close that it could reasonably be**

¹⁵⁰ For more information see Affected Persons pp34-37

expected that their mental or physical health would be seriously affected by the consequences of the disease, and who have suffered emotionally, mentally and/or physically as a result.

Compensation Study Recommendation 6: I recommend that infections eligible for compensation should be classified in the following manner:

- a) there should be defined categories for each type of eligible infection, and the stages through which it progresses, and for each category defined degrees of severity to which a range of possible awards for the impact of the disease can be applied;*
- b) the stages and degrees of severity for each disease should be defined by an independent clinical expert advisory panel, by reference to clinical professional consensus;*
- c) the range of potential awards for the impact should be determined by an independent legal expert advisory panel, to be consistent with what would be awarded in common law personal injury litigation.*

Inquiry Recommendation 5: As above, save that (c) should read:

“c) the range of potential awards for the impact should be determined by an independent advisory panel of legal experts, taking account of but not limited by current practice in courts and tribunals across the UK.”

Compensation Study Recommendation 7: I recommend that, with reference to aggravated and exemplary damages:

- a) the scheme should allow, as part of the autonomy award, for eligible infected persons an award equivalent to aggravated damages for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, information about the risks of treatment, and about diagnosis, treatment and testing; and*
- b) the issue of exemplary damages be reviewed in the light of the findings of the Inquiry.*

See Inquiry Recommendations 6 and 7 below

Compensation Study Recommendation 8: I recommend that the following available heads of award should be available to eligible infected persons, recognising that while guided by them, compensation will need in some instances to be of broader scope than permitted by the principles of common law, to recognise the particular social and psychosocial impacts relevant to the relevant infections:

- a) an injury impact award for past and future physical and mental injury caused by the infection and its consequences injury;*
- b) a social impact award for past and future social consequence of the infection including stigma and social isolation;*
- c) a care award for the past and future care needs of the eligible infected person;*
- d) an autonomy award as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life, including where relevant: loss of marriage/partnership prospects, loss of chance to have children, personal autonomy, the right to informed consent and candour from healthcare professionals and providers; and*
- e) a financial loss award for past and future financial losses incurred by the eligible infected person because of the infection.*

See Inquiry Recommendation 6 below

Compensation Study Recommendation 9: I recommend that the following heads of award should be available for eligible affected persons, recognising that while guided by them, compensation will need in some instances to be of broader scope than permitted by the principles of common law, to recognise the particular social and psychosocial impacts relevant to the relevant infections:

- a) an injury impact award for past and future physical and mental injury caused by their experience of the effect of the infection on the relevant eligible infected person;*
- b) a social impact award for the adverse social consequences of being associated with the eligible infected person;*

c) a family care award, available where a Care Award is not made to the eligible infected person directly, for care provided free of charge to the infected person or likely to be provided by them in the future;

d) an autonomy award for interference with family and private life; e) a bereavement award to the eligible affected persons in categories a) to c) above (recommendation 5, above) in the event of the death of the relevant eligible infected person by reason of the disease; and

e) a bereavement financial loss award to the eligible affected persons in categories a) to c) above (recommendation 5, above) in the event of the death of the relevant eligible infected person by reason of the disease, for the loss of financial benefits they would have enjoyed but for the death.

Inquiry Recommendation 6: I recommend that the appropriate award in any case should be composed under the following categories of loss,¹⁵¹ applicable to both eligible infected and affected persons:

a) an Injury Impact Award for past and future physical and mental injury, emotional distress and injury to feelings caused by the infection and treatments for it, or (whilst not being personally infected) being affected by them or by the death of an eligible infected person (including, as part of this, an award for loss of society of the deceased);

b) a Social Impact Award for past and future social consequences of the infection including stigma and social isolation;

c) an Autonomy Award as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life, including where relevant: personal autonomy, loss of marriage/partnership prospects, loss of chance to have children. It should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of

¹⁵¹ For more information see Categories of Injury and Loss pp40-51

research without their informed consent. It should include the effects of lack of candour and inadequate responses by authority.

d) a Care Award for the future care needs of the eligible infected person, and to compensate for past losses in respect of care necessitated by their infection (to be paid directly to the infected person where they have paid for care, and/or directly to an affected person who has provided care); and

e) a Financial Loss Award for past and future financial losses suffered as a result of the infection.

Inquiry Recommendation 7: I recommend that there should be no award for exemplary damages, though it should remain open to a claimant to pursue such a claim in the courts irrespective of whether they make a claim on the scheme.¹⁵²

Compensation Study Recommendation 10: I recommend that the Government should set out a framework of tariff based compensation for eligible infected and affected persons, at rates which broadly reflect comparable rates of common law damages and other UK compensation schemes, and in addition allowing an assessed basis for defined financial losses. The factors described in this report should inform the matters for which compensation is awarded. The rates of compensation should be based on the advice of the independent clinical and legal panels.

Inquiry Recommendation 8: I recommend that the Government should approve a scheme setting out a framework of tariff based compensation for eligible infected and affected persons, at rates which broadly take account of but are not limited by current practice in courts and tribunals across the UK and sums payable in other UK compensation schemes, and allowing an assessed basis for defined financial losses. The rates of compensation should be based on the advice of the independent clinical and legal panels and set by the scheme.

¹⁵² For more information see Categories of Injury and Loss: Exemplary Damages p47

Compensation Study Recommendation 11: I recommend that, with reference to the status of awards:

- a) eligible infected and affected persons should not be required to accept the offer of an award in full and final settlement of any right to pursue legal actions related to the infection;*
- b) any accepted scheme award should be set off against any entitlement to damages for the same subject matter;*
- c) the availability of an award under the scheme should be a factor to which the court could have regard when determining liability for costs in any court proceedings related to the infection.*

Inquiry Recommendation 9: As above

Compensation Study Recommendation 12: I recommend that, with regard to the type of award made:

- a) all awards should be final;*
- b) at the option of the eligible person, awards be made in a lump sum, or, in respect of awards for continuing future losses, by way of guaranteed periodical payments uplifted annually for inflation for life, or the predicted period of the loss, if earlier.*

Inquiry Recommendation 10: I recommend that:

- a) awards should be made in a lump sum in respect of an Injury Impact Award, Social Impact Award, Autonomy Award, and an award to compensate for past losses under the Care Award and Financial Loss Award for infected and affected persons;**
- b) at the option of the applicant, for continuing future losses under the Care Award and Financial Loss Award, there should be paid either a lump sum award or payment by way of guaranteed periodical payments uplifted annually for inflation for life, or the predicted period of the loss, if earlier;**
- c) an infected person should have the option of receiving a lesser lump sum as a provisional award (i.e. one assessed on the footing that as a result of receiving**

infected blood or blood products or tissue transfer there is a chance that at some definite or indefinite time in the future they will develop some serious disease or suffer some serious deterioration in their physical or mental health) such that in that case they may return to the scheme, or in accordance with arrangements to be made by the scheme, for further compensation then to be paid in respect of the newly developed disease or deterioration; and

d) unless the option to have a provisional award is taken, all awards should be final.¹⁵³

Compensation Study Recommendation 13: I recommend that interest be payable on awards for past financial losses and past provision of care, from the date of infection to the date of the award, in accordance with the practice in personal injury damages claims; alternatively, that such awards are uplifted for inflation during that period.

Inquiry Recommendation 11: As above

Compensation Study Recommendation 14: I recommend that the Government should immediately consider offering a standard figure by way of substantial interim payments, on account of awards likely to be made under the scheme, to infected persons currently in receipt of support under any support scheme. The figure offered should represent broadly the minimum amount an infected person could be expected to receive by way of a final award.

The Inquiry's recommendation for interim payments to those infected and bereaved partners was accepted in full and implemented.

Inquiry Recommendation 12: I recommend that an interim payment of £100,000 should be paid to recognise the deaths of people to date unrecognised and alleviate immediate suffering. This should be done as follows:

¹⁵³ For more information see Options as to the Form of the Award pp51-53

- a) where someone infected died as a child or died as an adult without a partner or child, the interim payment should be made to their bereaved parents (split equally if separated);**
- b) where someone infected has died and there is no bereaved partner but there is a bereaved child or children (including any adopted child¹⁵⁴), the interim payment should be paid to the child or children (split equally); and**
- c) where someone infected has died and there is no bereaved partner, child nor parent but there is a bereaved full sibling or siblings, the interim payment should be paid to the sibling or siblings (split equally).¹⁵⁵**

Compensation Study Recommendation 15: I recommend that, with regard to the relationship between compensation, support payments and benefits:

- a) in assessing compensation under the scheme, no account should be taken of any past payments made under the support schemes or their predecessors;*
- b) the current annual payments under the support schemes should be continued (or merged into the compensation scheme) and guaranteed for life, by legislation or secure government undertaking;*
- c) such continued payments should be taken into account in assessing awards for future financial loss or care provision;*
- d) such deductions as would be made from damages under the Social Security (Recovery of Benefits) Act 1997, but no other, should be made in respect of equivalent awards under the scheme;*
- e) awards of financial loss should be made net of tax, but the awards themselves should not be liable to taxation, and should be regarded for tax purposes as if they were support payments;*
- f) any lump sum award under the scheme should be made exempt from inheritance tax by an equivalent addition to the inheritance tax free allowance of the recipient.*

¹⁵⁴ But not a step-child: under intestacy rules there is no entitlement for children who are not biological children of the deceased.

¹⁵⁵ For more information see Further Interim Payments pp59-61

Inquiry Recommendation 13: As above

Compensation Study Recommendation 16: I recommend that an Arms Length Body (ALB) should be set up to administer the compensation scheme, with guaranteed independence of judgement and accountable directly to Parliament for the expenditure of public funds and the fulfilment of its terms of reference, and with a procedure in accordance with the principles set out in this report and in particular which:

- a) have regard to the need of applicants for simplicity of process, accessibility, involvement, proactive support, fairness and efficiency;*
- b) create a review and independent, preferably judicially led, appeal process;*
- c) involve potentially eligible persons and their representatives in the review and improvement of the scheme, for example, by way of an advisory forum;*
- d) has access to the records held by or on behalf of any previous publicly funded support scheme.*

Inquiry Recommendation 14: I recommend that an Arms Length Body (ALB) should be set up to administer the compensation scheme, with guaranteed independence of judgement, chaired by a judge of High Court or Court of Session status as sole decision maker, transparent in its procedures so far as the law permits and accountable directly to Parliament for the expenditure of public funds and the fulfilment of its terms of reference. Appeals should be to a bespoke independent appeal body with a legal chair which will reconsider the decision of the scheme in any case appealed to it. The scheme should have procedures in accordance with the principles set out in this report and in particular which:

- a) have regard to the need of applicants for speed of provision, simplicity of process, accessibility, involvement, proactive support, fairness and efficiency;**
- b) involve potentially eligible persons and their representatives amongst those in a small advisory board, and in the review and improvement of the scheme; and**
- c) permit the hearing of applicants in person.**

d) should have access to the records held by or on behalf of any previous publicly funded support scheme (subject to any necessary consents by the data subjects), and take into account the reasoning of any appeal from the decisions it takes.¹⁵⁶

Compensation Study Recommendation 17: I recommend that the scheme should include provision of the following support services:

- a) an advice and advocacy service, supplemented where necessary by discretionary access to independent legal advice and representation, to assist and advise applicants;*
- b) a financial advice and support service to assist recipient in the management of awards and in accessing financial services; and*
- c) facilitation of access to appropriate health, care and counselling services.*

Inquiry Recommendation 15: I recommend that the scheme should include provision of the following support services to be provided without charge to the applicant:

- a) an advice and advocacy service, supplemented where necessary by discretionary access to independent legal advice and representation, where necessary and within a pre-authorised budget, to assist and advise applicants;**
- b) a financial, insurance and benefits advice and support service, to assist recipients in accessing financial and insurance services and obtaining any relevant benefits; and**
- c) advice and referral to appropriate specialist services, signalling or certifying access to any special arrangements.¹⁵⁷**

Compensation Study Recommendation 18: I recommend that the compensation scheme should be delivered locally within each devolved nation. Consideration should be given by the UK and devolved governments to entering an agreement under which either a partnership board is created to oversee the compensation scheme's ALB, into which the

¹⁵⁶ For more information see Structure of the Scheme pp18-26

¹⁵⁷ For more information see Support Services pp55-56

administration of the local support schemes be merged, or the ALB commissions or delegates the local administration of the compensation scheme to the devolved support schemes.

Inquiry Recommendation 16: I recommend that the compensation scheme should be delivered by one central body, appropriately resourced and staffed. Current support schemes should however continue to be provided as at present by schemes local to each nation.¹⁵⁸

Inquiry Recommendation 17: I recommend that without delay steps be taken to provide a bespoke psychological service in England.¹⁵⁹

Compensation Study Recommendation 19: I recommend that the proposals for the design and administration of the Scheme, contained within this report, should be reviewed by the Government in the light of the findings and recommendations of the Inquiry, and thereafter, on a periodic basis and reported on to Parliament.

Conclusion: The need for a compensation scheme is accepted. Both Sir Robert Francis KC, charged by the Government to consider it, and I agree on the fundamentals of its design and operation.

Inquiry Recommendation 18: I recommend that a compensation scheme should be set up now and it should begin work this year.

¹⁵⁸ For more information see Local or National Administration? pp57-58

¹⁵⁹ For more information see Parity in Specialist Psychological Support pp62-78

Inquiry Recommendations

Inquiry Recommendation 1: I recommend that the scheme should offer redress to those infected with HCV and/or HIV, and/or HBV (limited to chronic HBV unless the infection has resulted in a fatality in the acute period), and to defined categories of persons indirectly affected by such infections.

Inquiry Recommendation 2: I recommend that the conditions of eligibility for admission of relevant infected persons to the scheme should be that:

- a) they have been diagnosed as being infected with one or more of HCV (including natural clearers who have suffered loss), HIV, or HBV (limited to chronic cases of HBV unless the infection has resulted in a fatality in the acute period);
- b) they received a transfusion of blood or components of blood, blood products or transfer of tissue capable of transmitting one or more of the relevant diseases; and
- c) their infection was not unlikely to have been caused by administration of the relevant treatment, regard being had as to the available evidence as to the measures in place at the time to reduce the possibility of infection, including but not limited to the date of relevant effective screening tests or effective viral inactivation treatments; or
- d)(i) it was not unlikely to have been caused by transmission to them by a person who fulfils conditions (a) to (c) above, or (ii) by transmission to them by a person who fulfils condition (d)(i), such as a child or children infected by their mother who had previously been infected by her partner, who in turn had been infected as in (a)-(c).

Inquiry Recommendation 3: I recommend that the scheme should, so far as possible, avoid legalistic and adversarial concepts of the burden and standard of proof: establishing eligibility under the scheme should be either: a) automatic in the case of persons infected and affected already accepted for eligibility under the support schemes; or b) a collaborative process in which:

- the applicant is sympathetically supported by the scheme in obtaining any required information and documentation;

- in general a presumption is applied that statements of fact made by an applicant are correct;
- applicants are not required to repeat information already provided to the support schemes;
- eligibility is accepted if the information available points towards eligibility and the opposite cannot be shown to be more likely.

Inquiry Recommendation 4: I recommend that the following relevant affected persons should be admitted to the scheme:

- a) spouses, civil partners and long term cohabitantes (for at least one year in the case of the latter) of living or deceased eligible infected persons;
- b) children of an eligible living or deceased infected person;
- c) parents of an eligible living or deceased infected person;
- d) siblings of an eligible living or deceased infected person;
- e) providers of care to an eligible living or deceased infected person, as a result of the infection; and
- f) members of the family, or friends of an eligible living or deceased infected person, whose relationship with them was so close that it could reasonably be expected that their mental or physical health would be seriously affected by the consequences of the disease, and who have suffered emotionally, mentally and/or physically as a result.

Inquiry Recommendation 5: I recommend that infections eligible for compensation should be classified in the following manner:

- a) there should be defined categories for each type of eligible infection, and the stages through which it progresses, and for each category defined degrees of severity to which a range of possible awards for the impact of the disease can be applied;
- b) the stages and degrees of severity for each disease should be defined by an independent clinical expert advisory panel, by reference to clinical professional consensus;

c) the range of potential awards for the impact should be determined by an independent advisory panel of legal experts, taking account of but not limited by current practice in courts and tribunals across the UK.

Inquiry Recommendation 6: I recommend that the appropriate award in any case should be composed under the following categories of loss, applicable to both eligible infected and affected persons:

a) an Injury Impact Award for past and future physical and mental injury, emotional distress and injury to feelings caused by the infection and treatments for it, or (whilst not being personally infected) being affected by them or by the death of an eligible infected person (including, as part of this, an award for loss of society of the deceased);

b) a Social Impact Award for past and future social consequences of the infection including stigma and social isolation;

c) an Autonomy Award as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life, including where relevant: personal autonomy, loss of marriage/partnership prospects, loss of chance to have children. It should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. It should include the effects of lack of candour and inadequate responses by authority.

d) a Care Award for the future care needs of the eligible infected person, and to compensate for past losses in respect of care necessitated by their infection (to be paid directly to the infected person where they have paid for care, and/or directly to an affected person who has provided care); and

e) a Financial Loss Award for past and future financial losses suffered as a result of the infection.

Inquiry Recommendation 7: I recommend that there should be no award for exemplary damages, though it should remain open to a claimant to pursue such a claim in the courts irrespective of whether they make a claim on the scheme.

Inquiry Recommendation 8: I recommend that the Government should approve a scheme setting out a framework of tariff based compensation for eligible infected and affected persons, at rates which broadly take account of but are not limited by current practice in courts and tribunals across the UK and sums payable in other UK compensation schemes, and allowing an assessed basis for defined financial losses. The rates of compensation should be based on the advice of the independent clinical and legal panels and set by the scheme.

Inquiry Recommendation 9: I recommend that, with reference to the status of awards:

- a) eligible infected and affected persons should not be required to accept the offer of an award in full and final settlement of any right to pursue legal actions related to the infection;
- b) any accepted scheme award should be set off against any entitlement to damages for the same subject matter;
- c) the availability of an award under the scheme should be a factor to which the court could have regard when determining liability for costs in any court proceedings related to the infection.

Inquiry Recommendation 10: I recommend that:

- a) awards should be made in a lump sum in respect of an Injury Impact Award, Social Impact Award, Autonomy Award, and an award to compensate for past losses under the Care Award and Financial Loss Award for infected and affected persons;
- b) at the option of the applicant, for continuing future losses under the Care Award and Financial Loss Award, there should be paid either a lump sum award or payment by way of guaranteed periodical payments uplifted annually for inflation for life, or the predicted period of the loss, if earlier;
- c) an infected person should have the option of receiving a lesser lump sum as a provisional award (i.e. one assessed on the footing that as a result of receiving infected blood or blood products or tissue transfer there is a chance that at some definite or indefinite time in the future they will develop some serious disease or suffer some serious deterioration in their physical or mental health) such that in that case they may return to

the scheme, or in accordance with arrangements to be made by the scheme, for further compensation then to be paid in respect of the newly developed disease or deterioration;
and

d) unless the option to have a provisional award is taken, all awards should be final.

Inquiry Recommendation 11: I recommend that interest be payable on awards for past financial losses and past provision of care, from the date of infection to the date of the award, in accordance with the practice in personal injury damages claims; alternatively, that such awards are uplifted for inflation during that period.

Inquiry Recommendation 12: I recommend that an interim payment of £100,000 should be paid to recognise the deaths of people to date unrecognised and alleviate immediate suffering. This should be done as follows:

- a) where someone infected died as a child or died as an adult without a partner or child, the interim payment should be made to their bereaved parents (split equally if separated);
- b) where someone infected has died and there is no bereaved partner but there is a bereaved child or children (including any adopted child¹⁶⁰), the interim payment should be paid to the child or children (split equally); and
- c) where someone infected has died and there is no bereaved partner, child nor parent but there is a bereaved full sibling or siblings, the interim payment should be paid to the sibling or siblings (split equally).

Inquiry Recommendation 13: I recommend that, with regard to the relationship between compensation, support payments and benefits:

- a) in assessing compensation under the scheme, no account should be taken of any past payments made under the support schemes or their predecessors;
- b) the current annual payments under the support schemes should be continued (or merged into the compensation scheme) and guaranteed for life, by legislation or secure government undertaking;

¹⁶⁰ But not a step-child: under intestacy rules there is no entitlement for children who are not biological children of the deceased.

- c) such continued payments should be taken into account in assessing awards for future financial loss or care provision;
- d) such deductions as would be made from damages under the Social Security (Recovery of Benefits) Act 1997, but no other, should be made in respect of equivalent awards under the scheme;
- e) awards of financial loss should be made net of tax, but the awards themselves should not be liable to taxation, and should be regarded for tax purposes as if they were support payments;
- f) any lump sum award under the scheme should be made exempt from inheritance tax by an equivalent addition to the inheritance tax free allowance of the recipient.

Inquiry Recommendation 14: I recommend that an Arms Length Body (ALB) should be set up to administer the compensation scheme, with guaranteed independence of judgement, chaired by a judge of High Court or Court of Session status as sole decision maker, transparent in its procedures so far as the law permits and accountable directly to Parliament for the expenditure of public funds and the fulfilment of its terms of reference. Appeals should be to a bespoke independent appeal body with a legal chair which will reconsider the decision of the scheme in any case appealed to it. The scheme should have procedures in accordance with the principles set out in this report and in particular which:

- a) have regard to the need of applicants for speed of provision, simplicity of process, accessibility, involvement, proactive support, fairness and efficiency;
- b) involve potentially eligible persons and their representatives amongst those in a small advisory board, and in the review and improvement of the scheme; and
- c) permit the hearing of applicants in person.
- d) should have access to the records held by or on behalf of any previous publicly funded support scheme (subject to any necessary consents by the data subjects), and take into account the reasoning of any appeal from the decisions it takes.

Inquiry Recommendation 15: I recommend that the scheme should include provision of the following support services to be provided without charge to the applicant:

- a) an advice and advocacy service, supplemented where necessary by discretionary access to independent legal advice and representation, where necessary and within a pre-authorised budget, to assist and advise applicants;
- b) a financial, insurance and benefits advice and support service, to assist recipients in accessing financial and insurance services and obtaining any relevant benefits; and
- c) advice and referral to appropriate specialist services, signalling or certifying access to any special arrangements.

Inquiry Recommendation 16: I recommend that the compensation scheme should be delivered by one central body, appropriately resourced and staffed. Current support schemes should however continue to be provided as at present by schemes local to each nation.

Inquiry Recommendation 17: I recommend that without delay steps be taken to provide a bespoke psychological service in England.

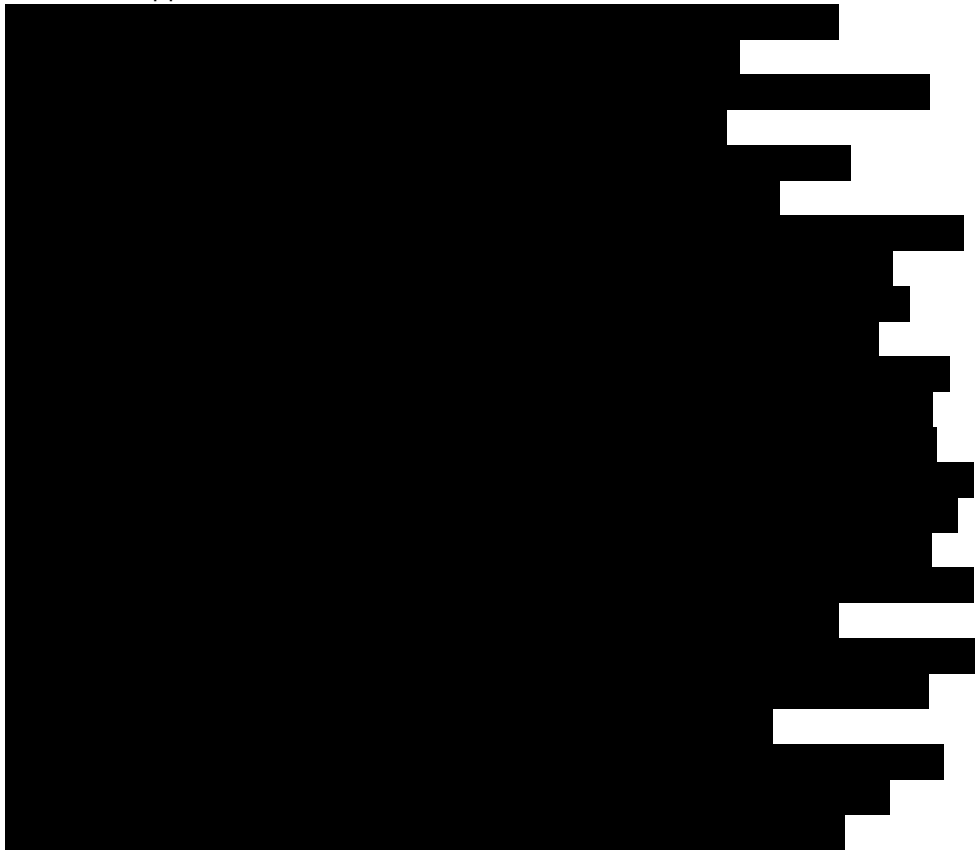
Conclusion: The need for a compensation scheme is accepted. Both Sir Robert Francis KC, charged by the Government to consider it, and I agree on the fundamentals of its design and operation.

Inquiry Recommendation 18: I recommend that a compensation scheme should be set up now and it should begin work this year.

A handwritten signature in black ink that reads "Brian J. Langstaff". The signature is written in a cursive style and is underlined with a single horizontal stroke.

Sir Brian Langstaff
Chairman
Infected Blood Inquiry
5 April 2023

From: UKHCDO Support <support@ukhcdo.org>
Sent: 16 June 2023 11:21
To: UKHCDO Support
Cc:



Subject: Paperwork for this afternoon's Advisory
Attachments: 69 Advisory Committee Minutes 27 Feb 2023 PROVISIONAL.docx; DRAFT Agenda 70th Advisory Committee Friday 16 June 2023.docx

Sent on behalf of [redacted], **UKHCDO Secretary**

To: UKHCDO Advisory Members

Subject: UKHCDO Advisory Agenda

Note: *Please forward on this message if your nominated representative will be attending in your place.*

Dear all,

Please find the minutes from February's Advisory attached. I have also reattached the agenda for this afternoon.

Microsoft Teams meeting

Join on your computer, mobile app or room device



Best wishes,



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National Haemophilia Database | UK Haemophilia Centre Doctors' Organisation

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