

Witness Name: Lord John Reid
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LORD JOHN REID

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Section 0: Preface

I, Lord Reid of Cardowan, will say as follows: -

- 0.1. I am a former Secretary of State for Health. I make this Statement pursuant to a R9 request from the Inquiry dated 1 March 2022, which has asked me questions about my period in office at the Department of Health (“DH”), in 2003 - 2005.

Recollections and the Statement Process

- 0.2. The events with which this Statement is concerned occurred approaching 20 years ago. After leaving the Department of Health, I acted as Secretary of State for Defence and then as Home Secretary. After leaving government in May 2007, I became a member of the House of Lords in 2010. Both as a result of the passage of time and the number of matters with which I have been concerned over the years, my memory of the events with which the Inquiry is concerned is very limited. I have tried to refresh it by reviewing the papers that I have been sent, referred to in this Statement. These are a mixture of papers sent by the Inquiry and additional documents found by my legal advisors. They are not a complete record of the papers which passed over my desk in the years with which the Inquiry is concerned. I have referred in my statement to points where it is apparent that various notes or submissions have not been retrieved, and there may be others whose absence has not been identified. In addition, the written record will not always capture the discussions, meetings and conversations that took place orally. Finally, the confidentiality undertakings attached to this process have meant that I have not discussed the contents of this statement with those, such as my Special Advisors, my former Ministers or members of my Private Office who would have been involved in decisions, etc, at the time and who might have been in a good position to help me to remember more about what was discussed and decided. Whilst I understand the reasons why the Inquiry wishes to hear my recollections, and my recollections alone, I suspect that they are less complete, and perhaps potentially less helpful, as a result.

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- 0.3. I have done my best to provide complete and accurate answers to the Inquiry's questions, but they are inevitably affected by all these issues. If further documents or other evidence is brought to my attention, I may need to revise this statement accordingly.
- 0.4. In practical terms, the Statement follows the order and structure of the Inquiry's requests.

Section 1: Introduction

Q1: Title, qualifications

- 1.1. My name is John Reid (Lord Reid of Cardowan). I was the Secretary of State for Health between 12 June 2003 and 6 May 2005. My date of birth and address are known to the Inquiry.
- 1.2. I have, and had, no professional qualifications relevant to my role as Secretary of State for Health. My title as recorded in parliamentary proceedings (Hansard) was recorded as Dr John Reid; this derives from a Doctorate (PhD) in History and should not be taken to refer to any medical qualifications.

Q2: Employment History and Parliamentary Career

- 2.1. Prior to entering Parliament, I worked in a number of occupations, took a BA (Hons) degree in History and a PhD in Economic History and latterly worked as a Research Officer for the Labour Party.
- 2.2. With respect to my history as a Member of Parliament, I was elected to Parliament in 1987, representing the constituency of Motherwell North in Lanarkshire, Scotland, for the Labour Party. I served as a constituency MP for approximately 23 years.
- 2.3. The table below outlines my appointments as a Minister:

Government appointments

6 May 1997 – 27 July 1998	Minister of State (Ministry of Defence)
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27 July 1998 – 17 May 1999	Minister of State (Department for Environment, Transport and the Regions)
17 May 1999 – 25 January 2001	Secretary of State for Scotland
25 January 2001 – 24 October 2002	Secretary of State for Northern Ireland
24 October 2002 – 4 April 2003	Minister without Portfolio and Labour Party Chair
04 April 2003 – 12 June 2003	Lord President of the Council and Leader of the House of Commons (Privy Council Office)
12 June 2003 – 6 May 2005	Secretary of State for Health
06 May 2005 – 5 May 2006	Secretary of State for Defence
05 May 2006 – 28 June 2007	Home Secretary

- 2.4. In May 2007 I resigned from the Cabinet and returned to the backbenches. I did not then stand for re-election in the 2010 general election.
- 2.5. On 16 July 2010 I became a life peer of the House of Lords.
- 2.6. This statement refers to the period when I was Secretary of State for Health, from 12 June 2003 – 6 May 2005.

Q3: Roles and Responsibilities as Secretary of State for Health

- 3.1. As Secretary of State, I was accountable to Parliament for the work of the Department of Health ('DH'). This included oversight of the National Health Service (the NHS) and responsibility for public health in England. The work of DH also included responsibility for social services, both adult and children, so extended well beyond the boundaries of the NHS.

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- 3.2. The challenges facing the NHS at the time were serious and extensive. My focus as Secretary of State was on its reform and its restructuring, to practical and effective ends. The challenges which I, together with other members of the Government, sought to address included, among many other things, very long waiting times for certain procedures; when I came into office, these could be as long as 3 years. I fought for, and was successful in introducing, a requirement that the maximum waiting times should be 18 weeks. We took a number of measures to shorten elective waiting times and waiting lists, including controversial measures such as using private sector capacity. We were able to appoint substantially more nurses and doctors, and significantly reduced deaths from cancer and cardiovascular-related illness. As part of the NHS Plan, we also extended patient choice and changed the system of 'block grant' payments to hospitals for their work, changing it to a system based on activity so that the funding followed patients' choices, including the choice of hospital.
- 3.3. Other specific areas of work that the Department was involved with during the period I was Secretary of State included, in 2003, the introduction of new contracts for GPs (introducing greater autonomy) and for hospital consultants, (with the aim of increasing their direct contact time with patients). This was followed later that same year by the standardisation of pay and conditions for NHS staff. New legislation, the Health and Social Care (Community Health and Standards) Act 2003, was enacted which provided for the establishment of NHS Foundation Trusts. In 2004, plans for the involvement of GPs in commissioning health care services were announced. This was then built on in 2005 with a report 'Commissioning a patient-led NHS'. In 2004 a White Paper 'Choosing 'Health' was published, which addressed issues such as obesity, nutrition, sexual health and smoke-free workplaces, restaurants and bars.
- 3.4. Additionally, I note from the Chief Medical Officer's Annual Reports in this period that DH had to consider issues such as the re-emergence of tuberculosis, MRSA and 'superbugs', concerns about a flu pandemic (bird flu) and the response to the Shipman Inquiry. I have already noted that the Department, in addition to its responsibility for the NHS, retained responsibility

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for managing the social care system at a national level, through the setting of framework legislation and objectives. This was a sector which, according to the Department of Health's website of the time, employed around 1 million staff.¹ The NHS itself employed, as of September 2003, a further 1,212,500 staff approximately.²

3.5. I mention these issues to demonstrate some of the realities of my task as Secretary of State and the breadth of the topics that occupied most of my time. Inevitably, I could not be involved in all aspects of the work of the Department. The large numbers of Junior Ministers (detailed below) reflected the volume of work in the Department, and were essential to support me and to oversee, in greater detail, decision-making in the Department. I retained the overall accountability to Parliament, but in practice would not have seen all the submissions or other forms of information being sent to the other members of the Ministerial team. I would have expected to have been consulted on major policy issues or matters of political prominence. I was also available if Ministers wished to raise any matters with me. Equally, Mr Hutton was an extremely experienced Minister who could be expected to provide assistance to the more junior or more recent members of the team, if required.

3.6. The matters referred to in this statement reflect that division of work and responsibility. For example, I can see that I had a reasonably active role in the initial decision to establish what became known as the Skipton Fund, fairly shortly after I took office. Looking back on it, I think that it is likely that I took charge of this both because I felt strongly that measures to provide financial support to those infected by Hepatitis C were needed, and also because making this happen meant reversing traditional policy, overcoming Treasury opposition (both to the principle of any support, and to the provision of funds), liaising with the Department for Work and Pensions ('DWP') regarding a social

¹

https://webarchive.nationalarchives.gov.uk/ukgwa/20050502232912/http://www.dh.gov.uk/AboutUs/DeliveringHealthAndSocialCare/TheHealthAndSocialCareSystem/HealthAndSocialCareSystemArticle/fs/en?CONTENT_ID=4105339&chk=v/eD0Q

² <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-hospital-and-community-health-services-medical-and-dental-staff/nhs-hospital-and-community-health-service-hchs-workforce-statistics-in-england-medical-and-dental-staff-2003-2013-as-at-30-september>

security payments disregard and negotiating with the devolved administrations and with Scottish Ministers in particular. After the decision to introduce a Scheme had been taken and announced, I had less active involvement in its details, whether matters relating to its administration or the details of the eligibility criteria.

Q4: Junior Ministers

4.1. Within DH, I was assisted by junior Ministers who had particular responsibilities. These were:

- a) John Hutton, Minister of State for Health (11 October 1999 – 6 May 2005);
- b) Rosie Winterton, Minister of State (Health Services), (13 June 2003 – 28 June 2007);
- c) Lord Warner, Parliamentary Under Secretary (Lords) (13 June 2003 - 10 May 2005);
- d) Melanie Johnson, Parliamentary Under Secretary (Public Health) (13 June 2003 - 5 May 2005);
- e) Dr Stephen Ladyman, Parliamentary Under Secretary of State for Health (Community Care) (13 June 2003 - 10 May 2005); his responsibility covered adult social services.
- f) Baroness Andrews, Spokesperson in the House of Lords. By convention, the Whip spoke for the Government in debates, etc, when the responsible Minister (i.e. Lord Warner) was not available.

4.2. The Minister with responsibility for blood and blood products was, throughout this time, the Parliamentary Under Secretary (Public Health), Ms Johnson. This is reflected in the documents discussed below.

Q5: Responsible Civil Servants

- 5.1. I have been asked to identify the senior civil servants involved during my time as Secretary of State for Health in decisions about blood and blood products, the risk of infection arising from blood and blood products, and the response to such risks and in providing advice to ministers in relation to such issues.
- 5.2. The most senior officials within DH at this time were:
- (1) Sir Nigel Crisp, the Permanent Secretary and NHS Chief Executive;
 - (2) Professor Sir Liam Donaldson, Chief Medical Officer ('CMO').
- 5.3. The CMO was heavily involved in issues relating to variant Creutzfeldt-Jakob Disease ('vCJD').
- 5.4. My Private Office contained the officials that I relied on most. My Principal Private Secretary was Mr Dominic Hardy. Ms Helena Feinstein was the Private Secretary who most often dealt with the subject matter of this statement.
- 5.5. I have noted from the papers that most submissions relating to the formation of the Skipton Fund came to me from Mr Gutowski, and some to Sammy Sinclair. I have less recollection of these names, perhaps because the former official was not a member of my private office, and the latter apparently served for a relatively short period after my appointment before being replaced by Helena Feinstein.

Q6: Committee Memberships

- 6.1. I have been asked to set out my membership, past or present, of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of my membership and the nature of my involvement.
- 6.2. I do not think that I have, or have had, any relevant memberships.

Q7: Other Inquiries or Investigations

- 7.1. I have been asked whether I have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ('HIV) and/or Hepatitis B virus and/or Hepatitis C virus infections and/or vCJD in blood and/or blood products.
- 7.2. I do not think that I have been involved in any relevant inquiries.

Section 2: The Establishment of the Skipton Fund

Q8: Announcement of 29 August 2003

General Introduction

- 8.1. The Inquiry has noted that on 29 August 2003, I announced that a financial assistance scheme for people infected with Hepatitis C from blood/blood products would be established. This was the fund that became known as the Skipton Fund. The announcement, which was made by way of a press release, is to be found at [NHBT0015207_002].
- 8.2. I have been asked to describe my involvement in the decision to establish such a scheme. I have been reminded by the papers seen for the purpose of this Statement that in January 2003, some months prior to my appointment, Mr Malcolm Chisholm, Minister for Health and Community Care in the Scottish government, announced his intention to set up a scheme of ex-gratia payments for those infected with Hepatitis C as a result of treatment in Scotland with NHS blood or blood products [DHSC0004421_127]. This was followed in March 2003 by the report of the Scottish Expert Group chaired by Lord Ross, which set out recommendations for the Scottish Executive on how such a scheme might work.
- 8.3. It will be apparent to the Inquiry that the intention to establish a UK-wide scheme was announced shortly after I took office as the Secretary of State for Health on 12 June 2003. I have been supplied with a copy of the briefing that I received on this subject within days of coming into office. I think it is apparent from the Private Office note commissioning the briefing [DHSC5541406] that

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this is the first briefing on the topic that I had received. The Note sent by Mr Gutowski in response of 17 June 2003 [DHSC5320518] summarised the background, and that advice from the Law Officers was awaited. Mr Gutowski's Note stated that *"Up to this point we have maintained a line to take and whilst awaiting Law Officers advice and we see no justification to move away from it."* It set out the previous DH "line", that financial assistance for people infected with Hepatitis C through blood was not thought to be justified, and that compensation or financial help was only paid when there had been fault on the part of the NHS. I was therefore informed, at an early stage, of the approach to these issues that had been taken in the past.

- 8.4. Fairly soon after my appointment I came to disagree with that position. Looking back on events now, what I can recall is that I developed a firm view that a scheme to provide financial assistance to those infected with Hepatitis C from NHS blood or blood products was the right thing to do, and that the Department's previous position was unsustainable. This was founded upon the fact that I came to understand that those who had been infected with HIV through these routes had received support, but those with Hepatitis C had not. In essence, I did not think that this distinction was justifiable, and I believed that this needed to be addressed by the Department. The documents that I have now seen indicate that I appeared to have come to that view within a couple of weeks of taking up office as Secretary of State. See the email from my Private Office quoted at paragraph 8.10 below.
- 8.5. The approach to be taken to these matters was, at its core, a matter of political judgement. But my own view was reinforced by the stance which, I was informed, had been taken by the Scottish Executive. Since I was also briefed on the initiative taken by Mr Chisholm, I saw the opportunity to address the issue on a UK-wide basis.
- 8.6. That said, I also knew that whatever could be done would have to be affordable. This was a reflection partly of the general constraints on government and DH spending, but also the fact that there was no provision in the DH spending settlement for such a scheme. In relation to the first, the general problem that the demands on the (finite) health budget are near

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infinite, and that funding one initiative will mean not funding another, will be known to the Inquiry. The fact that no funding had been provided for in previous DH settlements meant that this problem was yet more acute, not least as it was highly unlikely that the Treasury would have agreed to provide additional funds. The financial negotiations are addressed in a little more detail below in answer to Q11, but the broad point is that any Scheme needed to be affordable and it would have been necessary to consider carefully what we could, or could not, do.

History of Events, June – August 2003

- 8.7. As I have mentioned, the first document showing my involvement in this issue that I have been shown now is the briefing dated 17 June 2003 from Mr Gutowski. I have also been reminded that by 20 June 2003, the advice of the Law Officers (that is, the Attorney General and the Advocate General for Scotland) as to whether or not the establishment of a Scottish Scheme was within the powers devolved to the Scottish Executive, dated 19 June, had been received.
- 8.8. It appears that this advice had been commissioned by the DWP jointly with the Scottish Office on 30 January 2003, i.e. well before I became the Secretary of State. I have been shown a copy of the letter of advice sent in reply, in which the Law Officers advised that they had determined that the Scottish Executive's proposed scheme for payments to persons infected with Hepatitis C, as a result of treatment by the NHS in Scotland, would be within devolved competence. The proposed scheme was viewed, not as a scheme for social security purposes, but rather as having the purpose of addressing the fact that injury had been caused by an agency of the state (the NHS in Scotland) to particular individuals and of providing those persons with some level of compensation for harm caused.
- 8.9. At the moment, it seems that no copy of a submission or other document presenting this advice to me has been traced, but I would have been shown it or at least would have been made aware of its contents.

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- 8.10. This was followed by an initial steer from me, given for the reasons I have set out above, that I wanted to see progress towards a UK-wide Scheme for support for those infected with Hepatitis C from blood or blood products. Thus, I can see from an email of 23 June 2003 from my Private Office [WITN0793002] that I was due to speak to my counterpart at the DWP that day. But my Private Secretary recorded that I *“may then want a meeting with officials to discuss, although he [i.e., SofS] has said that given both the precedent with HIV and the likely Scottish decision to now go ahead, it looks as if we will on the basis of fairness have to go down the compensation (ex-gratia) route. If so, it is likely SofS will want to announce this at the same time as any Scottish announcement.”* This is consistent with my recollection that I quickly decided that the previous ‘line’ could not be supported, and that I was concerned by the contrast with the way that those with HIV had been supported.
- 8.11. I see from a further email of the same date [DHSC0042275_008] that I did speak to my counterpart at DWP (Mr Andrew Smith) on 23 June 2003 (or thereabouts). It is apparent from the note that legal advice from the Attorney-General had been received, and, as I have set out above, that the matter of a compensation or support scheme had been ruled to be a “health” matter, rather than one of social security. The DWP was stating, as a result, that this was not a matter for it to fund. A cross-Departmental meeting was proposed.
- 8.12. This discussion was duly followed [DHSC0042275_005] by a cross-Departmental meeting on 25 June 2003 which discussed these issues. The meeting was attended by Ministers from DH, DWP and the Treasury (‘HMT’), as well as the Scottish Office. The note of the meeting [DHSC0042275_005] records that Ministers agreed the following:
- (1) *The UK Government will introduce a scheme for Hepatitis C sufferers in England.*
 - (2) *This is a devolved matter in Scotland (and almost certainly in Wales and Northern Ireland also – an official was to check this) and so it is for the devolved administrations to make their own decisions on this issue.*

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(3) This decision should be communicated to the devolved administrations by John Reid personally when further issues have been worked through.

- 8.13. A “holding line” was to be circulated for agreement in case public comment was needed in advance of the further talks with the devolved administrations [DHSC0042275_003] but I would not have expected to be involved in that level of detail.
- 8.14. A further note of what was agreed at that meeting can be seen in an email from my private office of 25 June 2003 [WITN0793003]. This noted that I was to speak to Paul Murphy and Peter Hain to brief them on the issues with respect to Wales and Northern Ireland. It also noted how the Chief Secretary for the Treasury, Paul Boateng, was very non-committal about financing of the scheme in England. My Private Secretary also referred to the issue, as she understood it, that if HMT were to give money for the scheme in England, they would also have to find money for the scheme in Scotland, *‘which lets them off the hook and removes the disincentive for them devising yet more schemes’*. However, it does not appear from this note that such a rationale was actually discussed at the meeting; rather, it appears that this was an opinion of my Private Secretary to explain the non-committal stance of Mr Boateng. I do not now recall whether such a rationale was ever expressed directly to me.
- 8.15. [DHSC5094083] is the submission dated 1 July 2003, which followed that meeting. It was addressed to my Private Office and those of Alastair Darling (Secretary of State for Scotland), Mr Andrew Smith (Secretary of State at DWP) and Mr Paul Boateng (Chief Secretary to the Treasury).
- 8.16. The submission records that we had asked for a “joint submission” on the issues involved in setting up what was then described as a Compensation Scheme for Hepatitis C sufferers in England. Advice in respect of the position in Wales was also included.
- 8.17. The submission started by setting out the legal position with respect to Wales. It was thought that the power to set up a scheme had not been devolved to the Welsh Assembly. By contrast, Northern Ireland (like Scotland) had the power to set up its own scheme *“as both health and social security matters*

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are devolved.” The options for setting up the scheme were canvassed; the preferred option was thought to be extending the remit of the Macfarlane Trust, although further discussions would be needed as that was a UK-wide body. There were also concerns expressed about the use of s64 grants used to pay the Trust’s administrative costs.

- 8.18. There was a lengthy discussion of the financial implications. It was noted that the scheme under consideration by the Scottish Executive would cost up to £210m if a similar scheme was implemented in England, at least if all those infected made a claim. If the proposals of the Scottish Expert Group were accepted, then the cost would be up to £600m. Successful drug treatment might lower costs, by reducing the number of cases where the disease developed into cirrhosis. Officials noted that the proposed scheme made no provision for making payments to the dependants of people with Hepatitis C who had since died; if this was altered it would increase the costs substantially.
- 8.19. Law Officers had ruled that this was a “health issue” so the costs of the scheme in England would need to be borne by DH. HMT had said that no additional money would be forthcoming and the scheme would need to be funded from the funding agreed in the Settlement Review 2002. *“We will need to work with the Devolved Administrations to attempt to reduce and/or reprofile the costs”.*
- 8.20. The arguments for and against benefits disregards were canvassed; for example, that secondary legislation would be needed.
- 8.21. The submission asked Ministers to agree to communicating the decision to introduce a scheme, with a view to officials from all interested Departments then working over the summer to devise an appropriate Scheme.
- 8.22. I have not seen a formal record of the response to that submission, but it seems that there was agreement to proceed with work on a Scheme.
- 8.23. I have been supplied with a copy of a submission sent to my Private Office on 15 July 2003 from Mr Gutowski [DHSC5110388]. This attached a draft letter to Mr Chisholm. Mr Gutowski set out proposals to take the matter forward, including the formation of a small working group of officials, once the draft letter had been sent out. A final version of that draft letter was sent on 28 July

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2003 and, as per the draft included in Mr Gutowski's submission, set out the legal view, that the *"proposed scheme is accepted as within devolved competence."* It also proposed talks between England and Scotland in the first instance, with Wales and Northern Ireland to be invited to join in once a scheme had been devised [DHSC0028241].

- 8.24. The legal view set out was based on the Law Officers' Advice, received on or about 20 June 2003 as I have explained above.
- 8.25. In late July and August, therefore, officials from DH and Scotland were discussing proposals, with an expectation that I would be updated about progress in late August. But it is apparent from documents that the timing of the public announcement, in very general terms, of the UK scheme on 29 August 2003 was ultimately determined by the need for the Scottish Minister to update the Scottish Parliament. He was due to attend the Scottish Parliament's Health Committee on 9 September 2003 and needed to update it that a scheme was accepted to be within devolved competence in Scotland. I received a note to this effect on 26 August 2003 from Mr Gutowski [DHSC0004421_121]. This was despite the fact that the proposals remained tentative, and that key issues such as sourcing the additional £220m or so needed had not been resolved. Counsel's advice on the devolution issues in respect of Wales was also being sought. However, the scope for waiting was limited, given that the Scottish imperative referred to above. Following receipt of the submission and also a conversation with Mr Chisholm on the same day, 26 August [DHSC0014997_120], I agreed to the option of making an immediate announcement [DHSC5323728; DHSC5973078].
- 8.26. I have also been shown a copy of an undated Note that records answers to the questions that I had been asking at that point in time, including with regards to meeting the conditions set by HMT, which had indicated that any announcement would need to be cleared with HMT first [DHSC5323673], although exactly when it was shown to me is not clear. It is apparent that the Treasury was taking a very close interest in this matter due to the spending implications and wrote to me on 27 August 2003 setting out the conditions that

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it required to be met, if the announcement was to go ahead [DHSC0014997_116]. See further Q11 below, on the Treasury input.

- 8.27. The decision to make an announcement within a matter of days meant that Wales and Northern Ireland had to be consulted and their agreement obtained as a matter of urgency. I received a Note on 27 August 2003 [DHSC5324678] which recorded Counsel's Advice, which was to the effect that the proposed Scheme would fall within the competence of the Welsh Assembly. This meant that (i) the Welsh Assembly could refuse to join the scheme; (ii) it would need to fund Scheme payments itself; and (iii) Assembly Ministers would have to sign up to the Scheme before an announcement could be made. Officials were to contact officials in the Welsh Assembly to see if this could be achieved.
- 8.28. An update was sent to me in the evening of 27 August 2003 by Mr Michael Clarke, setting out the advice on how to make the announcement at that point [DHSC5323860 and WITN0793004]
- 8.29. [DHSC0014997_115] indicates that agreement was reached, with both Wales and Northern Ireland issuing Press Notices on Friday 29 August (in addition to Scotland).

Views of Mr Milburn

- 8.30. The Inquiry has asked whether I took a different view from my predecessor as Secretary of State for Health (Mr Milburn) on the merits of such a scheme, and, if so, on what basis.
- 8.31. It is my recollection, borne out by the documents I have seen, that I did take a different view from the Departmental position that had pertained hitherto under all of my predecessors (and which was set out in the briefing Note I received on 17 June). As far as I can recall, I did not speak to any of them at the time about this issue, so I cannot comment on their personal views. I have explained above (paragraph 8.4) that I fairly quickly formed a view on what should be done, and I set out to achieve it shortly after being appointed Secretary of State.

Wording of the Press Release

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- 8.32. The Inquiry has noted that the press release on the topic reported me as saying: *“After becoming Secretary of State, I looked at the history of this issue and decided on compassionate grounds that this is the right thing to do in this situation”*. I have been asked what aspects of “the history of this issue” led to my decision.
- 8.33. As far as I can remember, I was not involved in the detail of settling the terms of the press release. I believe that the final version of the statement would have been sent to me for my approval. In all likelihood I would have discussed these matters with my Private Office, Officials and/or Special advisors, but at this distance I cannot recall details.
- 8.34. In relation to the Inquiry’s question about the reference to the “history of this issue”, I believe that the “history” that I was primarily influenced by was the fact that not only had infections been the product of NHS treatment, but that those who had been infected with HIV through the same route had received at least some government support. The distinction did not seem to me to be justifiable, when both groups had strong compassionate claims for support. Paragraphs 8.1 – 8.11 above describe how the issue was first brought to my attention, and the documentation sent to me. There would also have been, in all probability, discussion and questioning around these involving officials and advisors, but at this distance I cannot remember the specific details of these.

Scottish Influence on Decision-Making

- 8.35. I have been asked to what extent my decision was influenced by the announcement of Mr Chisholm, in January 2003, that there would be an ex-gratia payment scheme in Scotland.
- 8.36. I have already noted that in January 2003, prior to me becoming Secretary of State for Health, Mr Chisholm announced his intention to set up a scheme of ex-gratia payments for those infected with Hepatitis C as a result of treatment in Scotland with NHS blood or blood products. This was part of the context on which the issue of a Scheme was discussed shortly after I came into office, but I cannot speak to its influence on thinking about these issues up to that point. However, it is apparent from the documents that at this point, the

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Department's 'historic' position remained opposed to a financial support scheme, despite the Scottish developments.

8.37. I have also already referred (paragraph 8.3) to the fact that officials appear to have been prompted by an anticipated discussion with the Scottish Executive Ministers to raise the matter with me very soon after my taking office. The Scottish Executive decision was, therefore, a catalyst in addressing the matter at that immediate point in time.

8.38. Some time afterwards, and after I had indicated my own direction of travel, the matter was put thus in a submission to me in August [DHSC5323673]:

"The Chief Secretary [of the Treasury] is concerned that this should not set a precedent for English spending decisions being driven by Scottish priorities and policies. There must be a clear value for money case for introducing a scheme in England independent of Scottish considerations. The Chief Secretary notes that it is inevitable that Scotland will sometimes follow their own policies different from England e.g. on free care for the elderly and foundation hospitals and we should not feel obliged to replicate Scottish priorities in England."

8.39. This submission obviously sets out HMT's perspective (see for example the references to "value for money"). But it makes the point that a scheme could not be introduced merely for the sake of consistency with Scotland.

8.40. My own view was – and has always been - that there is room for divergence between the two nations – an inevitable consequence of Devolution, of which I have been a life-long supporter. Neither Government should feel compelled to adopt the other's policies. But neither should they feel compelled to differ. Each question has to be judged on its merits. The examples of such divergences given in the minute were of Scottish (opposition to) Foundation Trust hospitals, and its provision of free care for the elderly. Neither of these approaches were replicated in England, for what I believe to be sound political, practical and financial reasons. Another example, not mentioned in the Treasury minute but being discussed when I was Secretary of State for Health (although I think implemented in Scotland after I left the DH) was that of universal free prescriptions in Scotland. On this, for instance, I did not agree

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that prescription charges should be abolished for everyone since I thought that it was better to concentrate financial relief from such charges where it was most needed, on the poorest, and not on everyone, irrespective of their wealth or income.

- 8.41. These examples demonstrate that there was scope for divergence of health policies – including ones relating to the financing of support or treatment – between the two nations. The important point is that on this question of infected blood financial assistance, it is my recollection that I believed the initiative taken in Scotland was the right one – and one that should be available to those affected in England, indeed, preferably throughout the UK. And I believe the documentation speaks to that.
- 8.42. The Scottish initiative did have an impact on the timetabling of the English decision (see the events of late August). It provided impetus (though even after we had embarked on the UK-wide scheme I still tried to expedite its implementation (see for example [DHSC0016672 and DHSC5325079])). It provided a ready-made template for England and the other devolved institutions. It may also have added leverage to my own case for change, against resistance from, e.g., HMT. I have no hesitation in giving credit to the Scottish Executive for their initiative. Nevertheless, the decision to introduce an English scheme was a positive one, taken primarily because I considered that it was the appropriate thing to do. I would not have pursued it simply to achieve unity of policy with Scotland.
- 8.43. The Inquiry has suggested that it might be said (see, e.g., the concern expressed in [DHSC0004421_127]) that the DH was forced into accepting a scheme, because Scotland had decided to do so. I have set out my comments on this issue above; I do not think that it is a complete, accurate or fair representation of the reasons for the actions that I took.

The Involvement of the Devolved Administrations

- 8.44. I have been asked to set out the discussions that were held, in advance of my announcement on 29 August, with representatives of the health departments/devolved assemblies in Scotland, Wales and Northern Ireland. I have been asked why, as at 30 July 2003, discussions had taken place with

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Scotland only, with Wales and Northern Ireland being unaware of developments (see [DHSC0004421_141]).

- 8.45. The fact that discussions were initially held with Scottish officials only can be seen from my letter to Mr Chisholm, 28 July, in which I stated that I would prefer to restrict decisions to Scots-English officials and *“once we have a scheme worked out we can invite Wales and Northern Ireland to join in”*. Further, in an email from my private secretary to Mr Gutowski, I was noted to have indicated that officials in England and Scotland should work together over the summer with a view to providing an update to me by 26 August 2003 and thereafter I was to speak to the Welsh Office/Assembly and Northern Ireland in late August about their own approach to a compensation scheme [WITN0793005]. The reasons for this approach were speed, simplicity and coherence of handling of what was an extremely complex issue and the speed and effectiveness of implementation.
- 8.46. In addition, the legal position with respect to the devolution settlement in Wales was initially not clear and advice from Counsel was sought (see the Note at [DHSC5323673]). The situation in Northern Ireland was regarded as being clearer but this had not been confirmed.
- 8.47. The decision that there was little alternative but to announce a UK scheme in late August has been described at paragraphs 8.24 - 8.29 above. The result was that Wales and Northern Ireland were informed of the proposals shortly before the announcement (see the Note dated 27 August 2003 [DHSC5324678]). They agreed the decision that a scheme should be implemented.

Q9: Ongoing Involvement after August 2003

- 9.1. I have been asked to describe my ongoing involvement, after 29 August 2003, in decisions regarding the parameters and details of the scheme. As mentioned above (paragraph 3.6), after the scheme was decided in principle and its establishment underway I was less involved in the operational details of the scheme, other than in main outline issues (beneficiaries, payment levels

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etc.) than I had been in originating the policy, liaising with the Scottish Executive and steering it internally and through other Government departments. As the relevant Minister responsible, Melanie Johnson thus became more involved in the detail though I retained oversight of progress.

- 9.2. On 1 September 2003, I was sent a letter from the Haemophilia Society [DHSC6701725]. This welcomed the announcement that had been made and expressed the hope that the Society's own Expert Group's report (recommending a scheme based on the Canadian model) and the recommendations of the Scottish Expert Group, would be a useful basis for discussion of the scheme. My reply on 22 September thanked the Society and noted the meetings that had been set up with officials and also with Ms Johnson MP, the Parliamentary Under-Secretary with the primary responsibility for leading progress on this matter [HSOC0003580].
- 9.3. On 12 September 2003, I received an update from Mr Gutowski which outlined the details of Mr Chisholm's appearance before the Scottish Health Committee [DHSC5325041]. The submission noted that Mr Chisholm had reconfirmed that payments would be as announced by him in January (i.e. £20,000 + £25,000). *"He also confirmed that there would be no payments to dependants which again is a position which we adopt although we have not made any public statements to this effect"*. The Minister confirmed that the start date for eligibility would be when the UK announcement was made (29 August 2003) and rejected calls for a public inquiry by stating that no new evidence had come to light to warrant one. The Note recorded that DH officials had met with those from the Devolved Administrations and that good progress was being made. Groups like the Haemophilia Society were to contribute to and comment on the various aspects of the Scheme where they had a particular expertise or interest.
- 9.4. A note [DHSC5325079] records that I was broadly content with the strategy set out in the Note but keen to press the matter forward as expeditiously as possible. I asked for details of the proposed timetable.
- 9.5. I can see, from the papers now provided to me, that Lord Morris asked a question on progress on 16 September 2003; the answer was given by

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Baroness Andrews on the Government's behalf [DHSC5187538]. She referred to ongoing discussions on the scheme.

- 9.6. On 3 October 2003, I was sent a submission by Mr Gutowski noting my wish for the announcement on the parameters of the scheme to be made quickly and seeking my agreement to the various elements of the Scheme [DHSC0016672]. It recorded meetings with colleagues from the Devolved Administrations and that agreement had been reached that payments should be identical to those announced in Scotland. Draft eligibility criteria were set out at Annex A, including the variations and exceptions to the basic criteria (including, for example, that those who had received payments from the MacFarlane Trust for HIV would not be eligible for Stage 1 payments, and a commitment not to take legal action against the NHS, although this latter requirement was later dropped; see paragraph 9.16 below). The submission suggested that at this stage, the proposal remained to administer the Scheme via the Macfarlane Trust, which was in principle willing to do this *“subject to the condition that the scheme was in the interest of their registrants and knowing the exact details”*. Mr Gutowski was to take this forward.
- 9.7. Mr Gutowski noted that the level of payments envisaged and the fact that there would be no payments to dependants would generate an adverse reaction. He suggested that the Haemophilia Society would be opposed and that it should be invited to a proposed meeting with the Trust, to enable discussions with the Society; he hoped that this involvement would prevent some criticism when the announcement was finally made. I was asked to agree the criteria for the Scheme, the proposed meeting and the timetable for progress, as well as the need to write to my counterparts Andrew Smith (for social security benefits disregards) and Dawn Primarolo (for the proposed disregard on income and tax credits).
- 9.8. I approved the strategy set out in the submission on 8 October 2003 [DHSC5326827]. I note that the proposed disregards were subsequently agreed to by my counterparts at DWP and HM Revenue and Customs ('HMRC') (see the announcement on 23 January 2004, below). The proposed disregard did not increase social security expenditure, but it meant that

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savings of £5 million / year were not sought (that being the sum that would have been saved by taking the payments into account [DHSC5328320]). The same principle applied to the income tax credits disregards. I also note, from the final announcement made by Ms Johnson on 3 June 2004, that legislation relating not only to benefits but also residential care charging had to be amended to ensure that people receiving payments from the Scheme were not penalised [DHSC5066754].

- 9.9. Announcement of the Scheme led to representations and lobbying about those elements of it which were not regarded as sufficiently generous by groups representing the interests of those affected.
- 9.10. I received a Note [DHSC5977636] and a Submission on 3 December 2003 [DHSC5080604] from Ms Johnson, recommending revisions to the eligibility criteria. I have addressed her recommendations and the changes made as a result at paragraphs 10 and 12 below.
- 9.11. On 9 December 2003, I confirmed approval of the Parliamentary Under-Secretary's proposals for these recommended revisions [DHSC5977779].
- 9.12. Again, I can see now that further questions were asked by Lord Morris in a debate in the House of Lords on 11 December 2003. The response was given by Lord Warner [DHSC5187538].
- 9.13. An update was sent to me on 6 January 2004 by Mr Gutowski [DHSC0004555_132]. This was in preparation for a formal announcement of the Scheme's details and the eligibility criteria. It noted the issues that still remained to be resolved (namely, the process of enabling social security and tax disregards, the details of the "medical trigger" for Stage 2 payments, the administration of the scheme and formal funding agreement from all the four devolved administrations). The document that I have been shown includes my handwritten approval of the proposals.
- 9.14. On the same day, a letter was sent to me by Mr Connarty MP, the Chair of the All-Party Parliamentary Group [WITN0793006]. He expressed disappointment that a letter about the Hepatitis C Scheme had been sent by Ms Johnson, rather than myself, and pressed for a meeting with me in order to make the Group's points about the limitations of the Scheme. Some points (the issue

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of payments to the co-infected and the payments to those who had cleared the virus) had already been addressed by Ms Johnson's December proposals, but other issues remained, including the concern that dependants would not receive payments (Mr Connarty and the Group would not have known which issues had been addressed as the details of the Scheme had not yet been published). The handwritten comments at the top of the letter suggest that I responded by meeting with the Group on 12 January 2004. At that meeting I listened to their concerns but made no commitment [DHSC5255001] in anticipation of the final preparations for the formal announcement to be made 11 days later.

- 9.15. The public announcement was made by a press release on 23 January 2004 [WITN0793007]. This was followed by a Written Ministerial Statement from me on 26 January [WITN0793007].

Further Change to Eligibility Criteria and Set-Up, 2004

- 9.16. From the papers that I have been shown for the purpose of this statement, it does not appear that I was directly involved in Scheme developments through the remainder of 2004. It was agreed by all four Devolved Administrations that previous compensation payments would not be set off against the Skipton awards. I have been shown a copy of a Ministerial Submission dated 5 March 2004 to Ms Johnson about this [DHSC0004425_029] (a document not copied to my Office), which sought agreement that payments made via court awards, etc would not be deducted. In addition, it appears that shortly thereafter, there was agreement that no undertaking to waive rights to take legal action against DH or NHS would be required (see [DHSC0004425_017] under "policy considerations"). But I do not appear to have been involved in the details of this.

- 9.17. I can see from the documentation that the start of operations for the Fund was announced by Ms Johnson on 3 June 2004 [DHSC5066754]. Applications would be processed from 5 July 2004.

Update on Progress, March 2005

- 9.18. I have been supplied with papers showing that I received updates on the progress made with setting up the Fund, in late March 2005. I can see that I

remained concerned to ensure that progress was not delayed [DHSC5363189 and DHSC5123255] and so asked for an update, which is at [DHSC5123255].

Q10: Setting the levels of Stage 1 and Stage 2 Payments

- 10.1. The Inquiry has asked about the basis upon which the level of stage 1 and stage 2 payments were set.
- 10.2. The submissions that I have seen and summarised above set out a proposal that the payments be funded at the level already proposed in Scotland, i.e., £20,000 for Stage 1 and £25,000 as a further Stage 2 payment. It is apparent that there were concerns about finding the money for a Scheme, even on that basis; although in addition, there would not have been any desire to step out of line with Scotland by proposing a more or less generous scheme than had been proposed there.
- 10.3. I have referred below (Q11) to the resistance of the Treasury even to our own proposed scheme and the conditions they placed upon acceptance. The possibility of finding yet further sums was not, therefore, discussed or analysed in any great detail in the submissions that were sent to me. I note that in the initial submission of 1 July 2003 [DHSC5094083], under the heading of “Financial Implications”, there was brief reference to the proposals of the Scottish Experts Group: if these were to be accepted *“then the costs would be up to £600m.”* (References to the Scottish Experts Group are to the Group chaired by Lord Ross). Paragraph 21 also noted that:

“The proposed scheme makes no provision for making payments to the dependants of people with Hepatitis C who have since died. The scheme proposed by the Scottish Expert Group did propose payments for dependants and it is possible that we will come under pressure to extend the scheme in such a way. This would increase the cost substantially. It is also possible that we will come under pressure to increase the value of the scheme towards that proposed by the Scottish Experts Group. Again, this could increase costs significantly. If the scheme is administered by the MacFarlane Trust which pays dependants of HIV sufferers it would be difficult not argue [sic] against similar provisions for Hepatitis C sufferers.”

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- 10.4. Further in a submission of 30 June 2003 from Richard Douglas, the Director of Finance and Investment in DH at the time, to me and copied to the Permanent Secretary and CMO amongst others, the issue of the costs of the scheme was again discussed. In particular it was noted that it was unlikely that the Treasury would provide additional funds. It also noted the increased estimate of costs to £600 million should the Scottish Expert Group proposals be accepted. Further, funding the lower estimated cost of £200 million for the scheme, a figure based on the Scottish Executive's proposal for the amount of payments (£20,000 to those living with the virus and a further £25,000 to those who develop cirrhosis), was noted to require "some tough decisions and leave us very vulnerable for the rest of the year" [DHSC0042275_010].
- 10.5. It can be seen from that above that although officials had considered the Scottish Experts Group report, the advice to Ministers was being given on the basis that the proposals would significantly increase expenditure and were not regarded as a sustainable or an appropriate way forward as a result.

Consideration to the Report from Lord Ross

- 10.6. I have been asked what consideration was given by me to the recommendations made by the Scottish Experts Group Report about the level of payments. I have been supplied with a copy of the Report, which is dated March 2003 [HSOC0020367] for the purpose of this Statement. (I have also been sent a copy of the Preliminary Report dated September 2002 [HSOC0003349], but since this is even more remote in time from the point at which I was in office at DH, I have not reviewed it).
- 10.7. As for the Report of March 2003, I have explained above what reference was made to it in submissions received by me. I cannot recall having received a copy of the Report at the time and I would have relied on officials and/or Ms Johnson for more detailed consideration of the options and recommendations.

Haemophilia Society's Expert Group (2002)

- 10.8. I have further been asked what consideration was given by me to the conclusions of the Haemophilia Society's working group which had previously been provided to DH in June 2002. I have been referred to [HSOC0005927], which is the Report of June 2002.

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- 10.9. I do not believe that the Haemophilia Society's report was referenced in the initial submissions sent to me in June – August 2003, and I do not think that I would have been given a copy at this time.
- 10.10. I have explained above (paragraph 9.2) that on 1 September 2003, I was sent a letter from the Haemophilia Society [DHSC6701725] which referred to the Expert Group. My reply of 22 September [DHSC0016672] noted that meetings that had been set up with officials and also with Ms Johnson MP, reflecting the identity of those with primary responsibility for leading progress on this matter.
- 10.11. The announcement of the Scheme, in general terms, in August 2003 was followed by representations on its contents, and meetings or lobbying on the same. Thus, I can see from [DHSC5328495] that Ms Johnson, sought information on extending the scheme to further categories, including dependants, following a meeting with the Chairman of the All-Party Parliamentary Group on Haemophilia and the Haemophilia Society held on 29 October 2003. The attendees had received some information about the terms of the proposed Scheme, on a confidential basis, as a result of the discussions held with the MacFarlane Trust to see whether the Trust would run the Scheme. In response to her request, Ms Johnson received a briefing on the topic on 10 November 2003 [DHSC5328495]. Officials recommended that the eligibility criteria for the Scheme be widened to enable:
- (1) The initial £20,000 payment to be made available to those co-infected with HIV (the initial criteria proposed their exclusion, on the basis of the HIV payments made);
 - (2) The initial £20,000 payment to be made available to those who cleared the virus following successful drug therapy (again, these individuals were initially excluded).
- 10.12. However, further calls, both in respect of increasing the size of the awards and for their extension to dependants, were seen as unaffordable.
- 10.13. This was not a submission sent to me, but on 3 December 2003, I was sent a Note and an accompanying Submission by the Parliamentary Under-Secretary for Public Health, Ms Johnson [DHSC5977636 and

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DHSC5080604]. She set out the response to the Scheme as a result of the October meeting with the two groups, referred to above. She summarised the issues:

“Leaving aside the size of the proposed payment which they claim are too low, the main stumbling blocks are:

- a) No payments to dependants of those who have died prior to the announcement of the scheme;*
- b) No payments to those co-infected with HIV;*
- c) No payments to those who cleared the hepatitis C virus (HCV) following treatment.”*

10.14. The submission thus did not engage with the argument that the proposed payments were simply too low, no doubt because of the affordability issues. Ms Johnson noted that DH Finance had earmarked £150m in the 2002/3 accounts to finance the Scheme. There was no reference to the 2002 Haemophilia Society Report.

10.15. I agreed to the proposed widening of the eligibility criteria on 9 December 2003 [DHSC5977779]. That is, I agreed that, as set out at paragraph 10.11 above:

- (1) The initial £20,000 payment would be made available to those co-infected with HIV; and
- (2) The initial £20,000 payment would be made available to those who cleared the virus following successful drug therapy.

10.16. I have been referred by the Inquiry to [HSOC0003259], which is a letter to me dated 4 November 2003, from Mr Hodgson, writing as the recently retired Chair of the Haemophilia Society. In this, he argued that the payments under the proposed scheme would be inadequate. He referred to the payments recommended by the Society’s own expert Working Group, which had recommended payments of £140,000 per person (on average). He made additional points about other potential scheme beneficiaries, such as dependants.

10.17. I cannot recall ever having seen this letter. It is likely that it would have been handled by Ms. Johnson without my involvement, as she was generally

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responding to letters from the Haemophilia Society and the All-Party Parliamentary Group on Haemophilia.

Summary.

- 10.18. I have been shown a briefing prepared for a Parliamentary Debate in the Lords on 5 February 2004 [DHSC5331990]. Lord Morris asked a number of questions about the proposed scale and scope of the Scheme. The briefing included the following:

“Although the reports by the Haemophilia Society and Lord Ross were considered during our deliberations, unfortunately it has not been possible to meet their recommendations on the payment structure of the scheme. These recommendations were made without prior knowledge of the pressures on the health budget and we have had to weigh the issue of making payments against all the other demands on the budget.”

- 10.19. The briefing also noted that the proposed payments were broadly in line with the initial one-off payments made by the Macfarlane and Eileen Trusts and recommended by Lord Ross – although they did not then reproduce the ongoing monthly support then provided by both Trusts and recommended by Lord Ross. It continued: *“The Haemophilia Society’s Working Group recommended far higher payment levels, as would be expected from an independent patient organisation. However, their recommendation to stagger payments according to the claimants’ needs has been taken on board and is reflected in the addition of a second payment on reaching a medically defined trigger point.”*

- 10.20. This is not a briefing that was prepared for me, but I have no reason to doubt its contents, or the statement that both reports were considered when proposals were considered and helped to shape the proposals, but that the ‘packages’ were judged to be unaffordable. This is what was conveyed to me, even if I did not personally see the two Reports.

Q11: Treasury Input

- 11.1. I have been asked whether the conditions imposed by Paul Boateng, Chief Secretary to the Treasury in a letter to me dated 27 August 2003 [DHSC0014997_116] had any bearing on the level at which the payments were set for the Skipton Fund.
- 11.2. The letter stated that the agreement of the Treasury to the announcement to be made about the Scheme was given “*reluctantly*” and subject to the following conditions:
- a) DH must agree to meet the full costs of the scheme from its current settlement, and that I agreed not to make a claim on the reserve to meet these costs, or seek additional funds to cover them in the forthcoming spending review;
 - b) That I should discuss the proposals with Wales and Northern Ireland, and (in essence) reach similar agreements that their introduction of similar arrangements for Hepatitis C sufferers would be on the same basis. Costs would either have to be met by these administrations from their existing funds or, failing that, DH would have to meet the costs;
 - c) That I further agreed, and secured a similar agreement with the devolved administrations, “*that the Department of Health and devolved administrations will meet in full any future costs incurred should there be a legal obligation put in place [to make] comparable payment arrangements arising from any compensation awarded as a direct result of the precedent set by the establishment of this scheme.*”
- 11.3. I have been asked what impact these conditions had on the level of payments set for the Skipton Fund.
- 11.4. First, I should highlight that, as is clear from the Treasury’s letter of 27 August, the Treasury’s concerns were not wholly financial but were linked to Mr Boateng’s concerns about the principle of making ex-gratia payments when there was no legal liability. He referred at paragraphs 2 and 4 to the precedent that he was concerned might be set, saying that: “*.. the precedent for other cases where there is no formal liability [is] profoundly unhelpful.*” Part of the

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discussion concerned the need to satisfy the Treasury that there would be no unintended consequences as a result of the scheme, or that if there were, they would be absorbed by DH.

- 11.5. A short submission to me dated 28 August 2003 from Martin Campbell, who I understand was the acting Branch Head of Resource Planning and Acquisition in the Finance Directorate of DH at the time, replied to these concerns. Mr Campbell advised that he did not consider it likely that a precedent would be created by the setting up of a “compensation scheme for Hepatitis C sufferers” as it would be an ex-gratia system with no admission of liability and that two such similar schemes were already in operation, the Macmillan (which I take was an erroneous reference to Macfarlane) and Eileen Trusts. Further that the requirement to absorb the costs of the scheme within DH budgets would be easier if accounted for in the 2002/3 budget and the costs of the scheme for the Welsh and Northern Irish administrations would not be covered by the DH. [DHSC0004421_079].
- 11.6. Thus, as to the financial conditions set by the Treasury, DH found the sum of £150m to fund the Skipton payments, from the existing 2002/2003 settlement. It was not realistic to add to it. The Treasury had required not only that no bid be made for Central Reserves, but that DH would not bid for additional funding in forthcoming expenditure rounds, as a result of this policy initiative. This was one of the factors in the background to the resistance to pressures to widen the eligibility criteria or increase the size of payments.
- 11.7. The Inquiry has further asked what were “*the pressures upon the government in England and Wales*” to which, according to this letter, I had referred during a conversation with Mr Boateng on 27 August. Doing the best that I can now, it seems to me that this is a reference to: (i) the fact that in my view, a refusal to offer assistance to those infected with Hepatitis C was indefensible, for the reasons I explained at the outset of this Statement; and an unsustainable position in the long run; (ii) there were strong Parliamentary and campaigning pressures for action; and (iii) Scotland had announced its intention to introduce a support scheme and had the legal authority to do so. These were all pressures, but they were also factors that gave me leverage with the Treasury,

to persuade it to agree to a Scheme despite the concerns not only about the financial but the precedent effects.

Q12: Spouses and Dependants

- 12.1. I have been asked why spouses and other dependents of those who had died were excluded as beneficiaries of the Skipton Fund.
- 12.2. The proposal to exclude the dependants of those who had died by the time the Scheme was introduced was included in the initial submission of 1 July 2003: see the quotation from paragraph 21 at paragraph 10.3 above. It had formed a part of the proposals developed in Scotland.
- 12.3. I have already noted [DHSC5328495] and paragraph 10.11 above] that the Minister for Public Health, Ms Johnson, sought information on extending the scheme to further categories, including dependants, following a meeting with the Chairman of the All-Party Parliamentary Group on Haemophilia and the Haemophilia Society held on 29 October 2003. She received a briefing on 10 November 2003 [DHSC5328495]. This addressed the call to add dependants to the scheme but stated (paragraph 10):
- “The cost of extending the scheme to dependants (>£154m) would at least double the cost of the scheme and remains unaffordable within the existing budgets of all the four Health Departments.”*
- 12.4. See also paragraph 15, which referred to affordability. I have already set out at paragraph 10.13 above, how she subsequently wrote to me on 3 December 2003 (after the proposed ‘stocktake’ referred to in the Submission of 10 November was cancelled). She proposed two changes to the eligibility criteria, but no changes to the exclusion of dependants of those who had died before the inception of the Scheme. The submission stated that the additional costs, now put at an estimated minimum of £144.7m, would be unaffordable, as set out above. She proposed meeting more limited requests that could be accommodated within the “scored funds” currently available.
- 12.5. Whilst I was aware that the exclusion of these categories was controversial (not least as a result of the parallels with the HV schemes which provided support to dependants) and the subject of repeated representations, I do not

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think that I ever received a proposal from officials or junior Ministers that they should be included, as a result of the costs implications. I have already discussed the conditions upon which the Treasury was prepared to accept the Scheme and the DH budgetary limits.

- 12.6. I have been shown a briefing prepared for a Parliamentary Debate in the Lords on 5 February 2004 [DHSC5331990]. Lord Morris asked (amongst other questions) why the “widows of those who died are excluded from help”. The suggested answers included the following:

“The underlying principle behind the ex-gratia payments is to help alleviate the suffering of people living with inadvertent hepatitis C infection. That is where the money available has been concentrated. These payments are not compensation for bereavement, although we recognise the pain and hardship suffered by widows.”.

- 12.7. This was not a briefing prepared for me or that I would have seen at the time. Nevertheless, it seems to me to reflect the judgements on concentrating available resources that were taken.

- 12.8. I have been asked whether I think, looking back now, that this decision was correct. Of course, I accept that it would have been desirable to have included dependants, if possible and I do understand the disappointment and upset voiced. However, I have explained the financial constraints that applied. In addition, when I tackled the issue of a Scheme in summer 2003, I wanted to see rapid progress across all four nations. It seemed to me that a relatively simple scheme, following the model already proposed in Scotland, offered the best prospect of rapid sign-up by all the administrations, and reasonably rapid implementation. Both of these objectives were achieved; considering what needed to be done, the start date of July 2004 was a relatively quick one by Departmental standards. Even looking back, the scheme that was set up seems to me to have represented the best that could actually have been achieved, at the time. It may not have been ideal, or perfect, and I understand that further support has been agreed over the years. But it did make a substantial start to addressing the plight of those infected with Hepatitis C.

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12.9. The Inquiry has referred me to the following documents in connection with this question:

- a) [DHSC0004555_252]: this is the Note from Ms Johnson dated 3 December 2003, to which I have already referred at paragraphs 10.13 and 12.4 above.
- b) [DHSC0004030_193]: this is a letter from Mr Adrian Sanders MP to me dated 12 November 2003 and is an example of the lobbying or representations that followed the announcement of the Scheme and to which Ms Johnson responded in her proposals for widening the criteria in December 2003.
- c) [LDOW0000150] is a letter addressed to me, probably from a member of the public (details are redacted) dated 7 February 2004. This set out detailed arguments why the proposed Scheme was not generous enough and threatened judicial review.
- d) [HSOC0012578_007]: this is a letter from Lord Morris to Lord Warner, following the latter's Written Reply of 23 February 2005, to a question asked by Lord Morris. Lord Morris wrote that the widows of those infected by Hepatitis C were "deeply upset" by the reply, and set out the argument that the differences in treatment between those widowed as a result of HIV infection and those widowed as a result of Hepatitis C.

12.10. I fully understand the sincerity and passion with which these various feelings were represented to the Government, and did so at the time. However, I hope that a balanced view might set, alongside any criticisms of the inadequacies of the scheme, at least a degree of credit for the fact the Government tackled the issue at this time, or did what it considered possible under the prevailing circumstances.

Q13: Arms-Length Administration

13.1. The Inquiry has asked why it was decided that the scheme should be administered independently and why it was that the Government should be "*distanced from the disbursement process*". This is a reference to the note of

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the meeting of officials held on 30 July 2003 [DHSC0004421_141], where it was stated that *“the scheme should be administered independently and that Government should be distanced from the disbursement process”*.

13.2. I was not present at the meeting at which this discussion took place and I do not think that the notes were sent to me as an attachment to any submissions, etc. I can only assume that this followed the precedent of the Macfarlane and Eileen Trusts.

13.3. The original submissions sent to me reflected a planning assumption that the Scheme should be administered by a charitable trust, although a company was eventually established (see Q14 below). I have not seen any detailed consideration of the mechanics of the Scheme’s administration. I have been shown a copy of a letter from Ms Johnson dated 14 July 2004 to Lord Morris [DHSC0004197_133]. This stated:

“Because the Skipton Fund is a UK wide scheme with each administration having equal responsibility for it, officials decided at an early stage that it should be administered by a body separate from the four health departments. It was also decided at the time that because of their expertise and experience in administering funds in similar circumstances, the MacFarlane Trust would be invited to take on this role ...

.. Regarding the appointment of the Skipton Fund Directors, we were advised at an early stage that in the development of the scheme that the Fund could not be a charity. Instead, lawyers advised that that Fund would need to be a Limited Company”

Q14: The Establishment of a Company

14.1. The Inquiry has noted that the Skipton Fund was established as a company and not a charitable trust, unlike the organisations that had previously been set up (the Macfarlane Trust and the Eileen Trust).

14.2. I can see that by the time of my announcement of the Scheme in January 2004, the decision had been taken that it would be administered by a new *“independent operation”* which would be called the Skipton Fund. Its

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management would “associated” with that of the Macfarlane and Eileen Trusts, but it would not be directly run by them.

- 14.3. I have also been referred to a minute from Mr Gutowski of 2 April 2004 to Ms Johnson, which noted that lawyers advised that the Skipton Fund could not be a Charitable Trust because of the nature of the one-off payments, that is because they ‘were not to help alleviate on-going hardship.’ Consequently, the fund was registered as a limited company. The minute also noted the need for the fund to have a legal identity for the purposes of being referenced in Department of Work and Pensions Regulations which would permit the social security disregard [WITN0793008]. Whilst it appears this minute was copied to my Private Office it is unlikely that I would have seen it or dealt with the detail of this particular issue.
- 14.4. The letter that I have set out from Ms Johnson indicated that it was legal advice that led to the establishment of a company rather than a charitable trust. A little more information is contained in the update that I was sent on 29 March 2005 [DHSC5123255], which notes that the scheme was “not a charitable activity” [See Annex A of DHSC5123255].
- 14.5. I do not think that I can add much further information. But, while my memory of this is imperfect, I think I may have assumed at the time that the legal advice was consequent upon the complexities of a fund administering the policies and operations of four distinct governmental entities (whereas both the MacFarland and Eileen Trusts were established before the devolved institutions were established). This my vague recollection, though it is not supported by any documentation I have seen. In any case. I was informed that this was on the basis of legal advice, as mentioned above.

Q15: Publicity for the Fund

- 15.1. I have been asked what steps the Government took to publicise the Skipton Fund.
- 15.2. This is not a matter in which I would have had any direct involvement. I would suggest that officials or PS(PH) may be better able to address this.

Section 3: Other Issues

Q16, 17: Calls for a Public Inquiry

- 16.1. The Inquiry has asked what consideration I gave, during my time in office, to calls for a public inquiry.
- 16.2. I have been referred to my letter to Mr Andrew Kerr MSP of 4 April 2005 **DHSC6264733** in which I referred to the demands for a public Inquiry but wrote: *"However, as previously stated, the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified. Donor screening for Hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time."*
- 16.3. The wording of that letter was based on briefing to me from officials, see [DHSC5123255], which also added that *"despite the decision to make ex gratia payments, the position with regards to accepting liability has not changed."*
- 17.1. The reasons why a public inquiry was not thought to be necessary were set out in the note from officials above.
- 17.2. As far as I can recollect, my own views were based on two matters. First, I was never provided with information or evidence that suggested, as a minimum, a *prima facie* case that there had been a history of fault or culpability – whether consisting of fraud, negligence, cover-up or similar. This was what I would have been looking for, to consider a public inquiry, but I was not provided with evidence to that effect by officials. Second, and particularly in the absence of such a case, my focus was on providing practical help, and help that could be put into place relatively quickly.
- 17.3. Of course, I accept that this present Inquiry, after its far more detailed investigation, will reach its own decisions on any issue of failure or failings. I have also recognised, in Section 4 below (vCJD), that I had understood, at the time, that there was a perception, fair or otherwise, of a 'cover-up' concerning the handling of Hepatitis C infections amongst at least some sections of the public. But I would have wanted to see evidence that at least began to support

such a case, before considering, in more detail, setting up a public inquiry. I have described what I saw (or did not see) at the time at paragraph 17.2 above.

Q18: Letter of 4 April 2005

- 18.1. With regards to the letter from me dated 4 April 2005 (see above) in which I stated that *"We ...have considered the call for an inquiry very carefully" and that "the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified"*, I have been asked to describe what investigation, analysis or enquiries were undertaken in order to reach the view that no "wrongful practices" were employed.
- 18.2. I have already explained that, from my point of view, no evidence of "wrongful practices" had been presented to me. I cannot remember what I may have known about what investigations had been carried out.
- 18.3. But, looking back on the matter now, with the benefit of the documents provided, it appears that (a) an internal review of self-sufficiency documents had already been commissioned within the Department (see Q21 below). A draft may have been available by the time I left my office at the DH, but it was not published until afterwards; and (b) in Scotland too, there had been some investigation of the events surrounding the infection of haemophiliacs with HIV/Hepatitis C. As I say, I do not remember being briefed about these, but what mattered to me was the absence of any evidence of 'wrongful practices' before me.

Q19: Inquiries Abroad

- 19.1. I have been asked what part the establishment and findings of inquiries in other countries such as Canada, France and Ireland, played in the Government's decision not to hold a full public inquiry during my time in office.
- 19.2. I have no recollection of these inquiries affecting the decision not to hold a public inquiry.

Q20: View of Others

- 20.1. The Inquiry states that it has heard evidence from campaigners and from the former Secretary of State for Health, Lord Norman Fowler [INQY1000144 & INQY1000145] that the Government should have established a UK-wide public inquiry before now. I have been asked to set out my present view on this observation.
- 20.2. First, I note that the Inquiry's evidence from Lord Fowler was to the effect that he considered that a public inquiry should have been set up to consider the "*whole area of health education*", an inquiry which would have considered the handling of the AIDS Pandemic, and that he had advocated for this in 1991 (see p129 – 130 of the transcript of the evidence that Lord Fowler gave to the Inquiry on 22 September 2021). Whilst this would no doubt have comprehended many aspects of the current Inquiry's Terms of Reference, it would not have been the same inquiry. In any case, to the best of my knowledge and recollection, I had no knowledge of Lord Fowler's position on this issue some 12 years before I took office. Otherwise, I have no comment to make on Lord Fowler's comments.
- 20.3. I have no view on events since I left office. As regards my time in office, I cannot recall that at any stage I saw, or had put to me, reasonable evidence of the need for a Public Inquiry. As set out above, the view of officials, who had been considering this issue for much longer than myself, were that there were no grounds for a public Inquiry (see for example the briefing note of 29 March 2005 [DHSC5123255], or the briefing for the debate [DHSC5331990] to the same effect).

Q21. Letter from Lord Owen

- 21.1. The Inquiry has referred to a letter to me dated 7 October 2003 [LDOW0000142] from Lord Owen. In this, Lord Owen referred to an internal investigation undertaken by DH. He had been told by the former Minister, Hazel Blears, on July 2002, that DH "*had set in train a study of its records going back over the history of the Department's original commitment to self-*

sufficiency". It was expected to take several months. Lord Owen asked for an update about its findings.

- 21.2. I have been asked, first, whether I saw the record or report of the internal investigation which Lord Owen referred to. I have no recollection of ever seeing such a record or report. I understand from the letter from Ms Johnson referred to that a draft was available by 17 March 2004, but that the report was not published until some time later, by which time I had left the Health Department.
- 21.3. I have further been asked what part that investigation or its findings played in my decision to announce an *ex-gratia* payment scheme for those infected with Hepatitis C. The answer is that to the best of my recollection it did not play any part.
- 21.4. I have also been asked what part that investigation or its findings played in the Government's decision not to hold a public inquiry. I cannot speak for others, but for my part it played no part that I can recall.
- 21.5. The Inquiry further notes that on 17 March 2004, five months after Lord Owen's letter to me, Ms Melanie Johnson sent a response [See HSOC001069]. I have also been supplied with an annotated draft response from Mr Hutton [WITN0793009].
- 21.6. I have been asked about the extent of my involvement in the drafting process of the response to Lord Owen.
- 21.7. That the response came from the Parliamentary Under-Secretary for Public Health reflects the fact that matters relating to this issue were handled by her, with Mr Hutton probably involved in periods when she was unavailable. To the best of my knowledge and recollection I was not involved and I do not think that I can add to her explanation of the work that had been undertaken, or explain why the Report had taken so long to be finalised and sent out.

Q22: Parliamentary Contributions

- 22.1. I have been asked to provide a chronological list of all statements, speeches or interventions made by me in Parliament during my tenure as Secretary of State for Health, insofar as relevant to the Inquiry's Terms of Reference.

17/12/2003	Statement on developments in vCJD
26/01/2004	Written Ministerial Statement on ex-gratia payment scheme for people infected with Hepatitis C from NHS blood or blood products
16/03/2004	Statement on further developments in vCJD
22/07/2004	Written Ministerial Statement on blood donations and vCJD
09/09/2004	Written Ministerial Statement on vCJD

Q23: Other Comments

- 23.1. I have been asked if I have any further comment that I wish to provide about matters of relevance to the Inquiry's Terms of Reference.
- 23.2. I do not think that I can provide any further useful comments.

Section 4: vCJD

Q24: Notification Exercise of September 2004

- 24.1. I have been asked what knowledge and involvement I had in decisions as to whether or not to notify patients of possible exposure to vCJD in 2003 and 2004.
- 24.2. I do not recall what specific knowledge and involvement I had in the notification of patients and have relied on the documentation that has been provided to me for the purpose of this statement.
- 24.3. That said, generally I recall at the time feeling there was a perception, however fair or unfair, of a 'cover-up' concerning the handling of Hepatitis C infections. As a result, when the risk of vCJD infection crystallised, my response was to be as open and transparent as I could, and to act as quickly as possible. I wanted to avoid the perception that the government was keeping information from patients or the public. However, as I noted in my speech of 17 December 2003, the desire to be as open as possible had to be balanced against the risk

of terrifying people unnecessarily about the chance of their having potentially contracted vCJD.

- 24.4. By way of background to the issue, a 'Q&A' document of 30 August 2004 [DHSC0006494_078] sets out some background explanation as to how the issue of notification to patients had developed and the actions of the DH as follows (see p4 of the briefing):

*"Following identification of vCJD, the risk of transmission of vCJD via blood was not known, even though it was considered theoretically possible. A research study called the Transfusion Medicine Epidemiology Review (TMER) was set up in 1997 to investigate the possibility of a link between CJD and blood transfusion. The study involved looking at data from blood donors and blood recipients with CJD (all types) and control donors and recipients. The study was purposely set up to try and avoid the possibility of inadvertently revealing the status of the donor to the hospital staff, as this could put those staff in a difficult situation. Ethical approval for this study was granted on the basis that recipients **should not** be informed in light of the lack of knowledge of the probability of vCJD being transmitted through blood transfusion at that time. [emphasis in original].*

...

When the CJD Clinical Incident Panel was set up by the Department of Health in 2000, the Blood Services asked for advice on the recipients of blood components donated by individuals who later developed vCJD. This advice was requested on a "generic" basis without any indication of the personal details of those recipients. A risk assessment was commissioned and advice prepared by the Panel, which indicated that these individuals should be notified of the situation with respect to their blood transfusion. Certain other matters were to be addressed; in particular the mechanism for notification and the provision for support for these individuals. That work was progressing when the TMER, for the first time in Autumn 2003, demonstrated a link between a donor and recipient in the study, both of whom had developed vCJD.

When were patients first notified that they had received blood or components from donors who subsequently developed vCJD?

The announcement was made by the Secretary of State in December 2003, following confirmation of the link between donor and recipient, indicating the other recipients identified as recipients of donations donated by individuals who later developed vCJD would be notified (as per the Clinical Incident Panel's advice). This has happened now."

- 24.5. As I explained in an oral statement to Parliament on 17 December 2003 [DHSC5977779], in Autumn 2003 a recipient of a blood donation died from vCJD. The donor themselves had died from vCJD in 1999. I was first alerted to the situation on 12 December 2003. As I explained to the House (see the Statement), I was then briefed by the CMO on 15 and 16 December 2003 and addressed Parliament on 17 December 2003.
- 24.6. I stated to Parliament that it was possible that in this case vCJD had been transmitted from the donor to the recipient by blood transfusion, but that it was not a proven causal connection because it was also possible that both individuals developed vCJD from eating bovine spongiform encephalopathy-infected meat or meat products. This conclusion, as I explained in that statement, was that of the CMO and experts who reported to me.
- 24.7. In that statement, I also noted that the Health Protection Agency ('HPA'), working with the National Blood Service, was in the process of tracing 15 people who received donations of blood from donors who subsequently developed vCJD. *"All will be told about the circumstances of their case and have the opportunity to discuss the risks with an expert counsellor."* Further, I set out how the UK-wide CJD Incidents Panel ('CJDIP') considered the risk for patients, including haemophiliacs, who received plasma (prior to the phasing out of UK sourced plasma that was completed by the end of 1999) to be lower than those who received whole blood. I noted that it was very difficult to trace all individual recipients of such products, but that the panel would be advising on a case-by-case basis which recipients would need to be contacted as the necessary information became available.

- 24.8. Additionally, in response to a question from Mr Paul Burstow MP, I highlighted that at that time we could not prove that a person might be infected by receiving blood from a donor who subsequently died from CJD and that the matter I was referring to was the first of its kind. I also explained, with regard to the 15 identified recipients of blood, the need to balance the risk factors involved in contacting them. Whilst I acknowledged that some of those cases had been known for a considerable time, I explained that experts had considered that the state of knowledge was such that a more detailed assessment of risk was needed before contact was made, which could *“cause undue distress in the absence of that work. ... had those people been contacted earlier they would have been given a degree of reassurance that we should now have had to qualify – perhaps causing them more distress.”* It was only in light of this new case that an immediate contact process had been put in place.
- 24.9. As I explained in response to the question of Mr Paul Burstow MP, who noted the short time between my learning of the situation and making a statement to Parliament, I had decided that provided the reports of this new case were accurately reflected and not over-dramatised, it would be better to bring them to public attention, by my statement, as soon as possible.
- 24.10. In my statement I also noted that the risk assessment for patients who might have received plasma, whilst not complete, was nearing completion. The UK wide CJD panel had recommended in October 2003 that following completion of that assessment a package of action should be designed, with the HPA, to communicate the level of risk faced to individual patients. My statement in December was the first step in that process. The further progress of that assessment by the HPA is considered below.

Q25: Timing of the 2004 Notification Exercise

- 25.1. I have been asked what input I had into the decisions about the timing of the notification exercise in 2004.
- 25.2. Following my speech of 17 December 2003, which I referred to as the first step in the process of notification, the proposed notification process involved contacting the 15 people who had received blood donation from donors who

subsequently developed vCJD. After that it was intended that further assessment of risk would be undertaken on a case-by-case basis for those who received blood products.

- 25.3. However, as set out below, by 12 July 2004 there was a proposed change in approach, whereby there would be notification of all patients with clotting disorders. That notification appears to have originally been intended to begin in August 2004, but was delayed until September to ensure that recipients of this information would have good support available to them from clinicians (who may otherwise have been away over the summer break period). Again, I cannot now recall what specific knowledge and involvement I had on the timing of these notifications. However, I can say that I would have acted on the advice and information provided to me by clinicians, the CMO and other experts and would have followed their advice as to the balance of risk between notification and not and the timing of the same.
- 25.4. In a submission dated 22 January 2004 I was updated by Dr Harper that 14 of the 15 recipients of blood from donors who subsequently developed vCJD in England and Wales (one of whom had died, but not from any association with a neurological disease), had been contacted. He also noted that one of the two recipients identified in Scotland had also been notified by that time. Further, that since my statement in December 2003 an additional donor who had developed vCJD had been identified and so far, four recipients in England had been identified. With respect to plasma derivative recipients the HPA were noted to be continuing to carry out risk assessments on a case by case basis [DHSC0004555_129].
- 25.5. I have been referred to a minute of 11 February 2004 to my Private Secretary, Helena Feinstein, from Dr Rowena Jecock [DHSC0003556_010]. The minute noted that by that time all the living recipients of blood from donors who had subsequently developed vCJD referred to in my December Statement had been traced and contacted. Dr Jecock also noted that on 15 January 2004, Dr Harper (Chief Scientist and Director, Health Protection, International Health and Scientific Development) had informed me that we had become aware of an additional donor who subsequently developed vCJD (this appears to be a

reference to the submission of 22 January 2004 which I mention above, though the date of the submission is clearly at odds with Dr Jecock's reference). The National Blood Service had been working to identify the recipients and one was identified as a German national who received a unit of blood in 1993 before being discharged back to his referring physician in Germany. The minute noted how the head of the German CJD surveillance system had been notified and provided the case details and that the British Embassy in Berlin had been informed.

- 25.6. On 16 March 2004, I made a further Written Ministerial Statement updating Parliament on the actions the Government had taken concerning vCJD. I confirmed that all surviving individuals who had received transfusions from donors who had gone on to develop vCJD had been contacted. Further, that following a meeting of experts on 22 January 2004, it had been decided that people who had previously received transfusions of whole blood since January 1980 should be excluded from further transfusions [DHSC5016322].
- 25.7. On 14 June 2004 Dr Wight provided me with an update regarding a new case of a person who developed vCJD having received blood from a donor who had also had vCJD. The update noted how as a consequence of the case it would be difficult to describe the risk of transmission of vCJD as theoretical. It also noted the intention for the notification of haemophiliacs and other recipients of plasma products to commence shortly [WITN0793010].
- 25.8. In a submission of 21 June 2004 Dr Wight provided a further update to me and the CMO on the notification of patients who received potentially contaminated blood and plasma derivatives. She noted the CJDIP had undertaken the preliminary risk assessments of patients developing vCJD and that haemophiliacs and patients with primary immunodeficiency were identified as key groups. She noted that a meeting of experts considered it appropriate that all patients with clotting disorders be informed that they were at increased risk of vCJD. She also noted that communication strategies were being developed by the HPA [DHSC6710413].
- 25.9. By 28 June 2004, emails between officials, one of which refers to a submission being made to me, noted the need for NHS Trust Medical Directors to make

every effort to trace patients who may have received implicated blood products. The emails noted how the work was being co-ordinated by the HPA [DHSC0032258_041].

- 25.10. A detailed submission to the Parliamentary Under Secretary (Public Health), Melanie Johnson MP, was sent by Dr Ailsa Wight dated 21 July 2004 [DHSC5024957]. She recommended a change in approach as to the notification of risk with respect to certain groups and that a notification exercise should begin in August 2004, with information sent to clinicians. The copy list is not included in this document, and it is not apparent whether it was sent to my Office.
- 25.11. The later submission of 10 August (see paragraph 25.17 below) records that PS(PH) was content with this advice.
- 25.12. Dr Wight's submission noted a shift from the initial consensus held by representatives of the CJDIP, HPA, Haemophiliacs and Primary Immunodeficiency doctors, Blood Products Limited (BPL) and the National Blood Service. These groups had favoured awaiting the outcomes of individual risk assessments. But the views of the haemophilia patients and doctors' groups were now clearly in favour of all patients with clotting disorders being informed that they were at an increased risk from vCJD. The classification of all haemophiliacs as 'at risk' was recommended.
- 25.13. By contrast, Primary Immunodeficiency patients were considered unlikely to have received sufficient product to put them at risk and so the public health risk would continue to be managed on an individual risk assessment. A group of other patients who had received blood products were likewise to be managed on an individual risk assessment basis. The submission noted the need for a staged process of communication, with clinicians responsible for various patient groups being contacted first; they would then be in a position to provide information packs for their patients. It also noted the need for the NHS to act to identify other patients. It recommended that DH should develop strategies with the HPA to achieve this and recorded the need to ensure information was placed in the public domain, such as by a written statement to Parliament or press statement.

- 25.14. A note from officials [WITN0793011] suggests that I was being kept informed of developments as I had apparently provided a “steer” on a written Ministerial Statement, which was being drafted.
- 25.15. On 22 July 2004, I informed Parliament of a second case of possible transmission of vCJD via blood transfusion [Hansard extract WITN0793012]. The ‘Q&A’ document of 30 August 2004 [DHSC0006494_078] noted the reason for the delay in announcing the case was due to scientific investigations being underway, the need to obtain expert advice on additional potential public health issues and legal issues with respect to disclosure and confidentiality. The Q&A noted the family of the individual involved had been informed. I also announced further exclusionary measures, adding two further groups to those excluded from giving blood.
- 25.16. A letter to me from the Haemophilia Society and Primary Immuno-deficiency Association of 4 August 2004 with respect to the vCJD notifications commented on the timing of the proposed notification exercise [DHSC5344200]. It raised concerns about the proposal to notify patients who were at additional theoretical risk of developing vCJD in the week of 23 August. The concern was that the date of notification, which fell in a period of high holiday absence, may mean that those notified would find their treatment centres under-resourced as a result of staff leave. The letter therefore suggested a two-week deferment for the notifications to the week of 6 September 2004.
- 25.17. This issue of a short delay was then taken up in a submission of 10 August 2004 from Gerard Hetherington to the Minister of State (Health), Mr John Hutton [DHSC5144240]. This referred back to the submission of 21 July to Ms Johnson, but recommended that letters to professionals should be sent on 18 August 2004, with information to patient groups to follow from 7 September. A Q&A and draft Ministerial comment would be prepared in case the release of information to clinicians resulted in information becoming public earlier than planned. The minute also recorded that the exercise of notification had been planned with the HPA.

- 25.18. It appears that the delay advocated was agreed, since in a Submission of 1 September 2004 from Michael Clarke (COMMS) to the CMO, PS(PH) and myself, I was informed that the process of notification for patients at risk of developing vCJD was to commence on 6 September 2004, with direct patient notifications occurring on 21 September [DHSC0006491_003]. The minute set out that clinicians would be notified of plasma products that needed to be traced to patients and that subsequently the HPA would undertake risk assessments for those patients if required. Mr Clarke noted that the groups of patients affected were haemophiliacs, who were expected to be easily identifiable by their specialist doctors; people with immunodeficiency who again were expected to be easily identifiable; and lastly, people who would have received sufficient quantities of particular blood products, such as those suffering severe burns, whose numbers were hard to estimate and whose traceability was dependent on the adequacy of NHS records. Clinicians treating those groups of patients were to be notified in the week of 6 September 2004. Doctors for haemophiliacs and primary immunodeficiency specialists would then be asked to write to their patients on 20 September 2004. Trust Medical Directors would also be asked to consider how far they could trace patients who fell into the third category. A press briefing, notice and Written Ministerial Statement was planned for the morning 22 September 2004.
- 25.19. In a further submission of 7 September 2004 from Michael Clarke to myself [DHSC5031954], the media and Parliamentary handling of the notification was discussed, and it was noted that I wanted a Written Ministerial Statement to be laid before Parliament at the same time as clinicians were to be written to. The proposal was that my statement would be made on 9 September 2004 a draft press release was attached. An email of 7 September 2004 from Helena Feinstein, one of my Private Secretaries, to Michael Clarke and Gerard Hetherington noted that I was content with the plan to make a written ministerial statement and for the CMO to do a press briefing on 21 September [DHSC5346644]. However, an email from Nikki Connor and Noel Gill of the HPA, of 7 September 2004 refers to a meeting I had with DH colleagues where there was a discussion of the detail proposed in patient notification

arrangements. I have no recollection now of that meeting. The email noted that I was satisfied with the arrangements and that the various appropriate contingencies were in place, but that I had requested that the dissemination of materials within the health service be delayed by one day. The email does note that there would be no change to the date on which notification to patients was to occur [DHSC5346653]. I do not now recall why I sought this delay, but it may have been to enable time for a Parliamentary statement to be made.

- 25.20. In my Written Ministerial Statement of 9 September 2004 [HCDO0000660], I noted that in June 2004 the HPA had reported on a risk assessment associated with each batch of product and advised DH on the patients that needed to be assessed and possibly subsequently contacted. In light of those assessments, the HPA had initiated a process to notify the patients of these developments, the HPA sending out information to clinicians and the clinicians then notifying the patients.
- 25.21. In a draft letter to Andrew Lansley and Paul Burstow, from myself, I repeated this information and highlighted that DH continued to follow a highly precautionary approach [DHSC0004570_027].
- 25.22. In a draft submission of 14 September 2004 to me and Ms Johnson, Ed Davis of the General Health Protection Branch, set out details on the notification of individuals. Communications were planned to commence on 20 September. He noted clinicians had been contacted on 9 September. In the week of 20 September letters were to be sent to 6,000 people with haemophilia and other bleeding disorders in addition to other patients. A press briefing was proposed to be made on 21 September which would be chaired by the CMO [WITN0793013].
- 25.23. A submission dated 20 June 2005 [DHSC0041306_069] notes that some 4,000 patients had been informed of their potentially increased risk as a result of this process, the majority being haemophilia patients. It noted that further precautions were proposed as a result of questions asked by the CMO, but this time they related to the donors themselves, not the potentially infected recipients.

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25.24. **In summary**, the Notification Exercise of Autumn 2004 was informed by the risk assessment completed by the HPA in June 2004 and by consultation of expert clinicians and other groups (see paragraphs 7, 11 of the Submission of 21 July 2004 to PS(PH) [DHSC5024957]). The expert view, as a result of that exercise, was that all patients with clotting disorders should be informed as soon as possible that they were at increased risk of vCJD if they received UK-sourced factor VIII, factor IX or anti-thrombin between 1980 and 1981. The recommendation was that the risk to other groups should continue to be managed on an individual risk assessment basis, by the HPA. As a result of this, Ministers agreed to a notification exercise in the late summer / autumn of 2004.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed:

GRO: C

Dated: 20 May 2022