

Witness Name: AILSA WIGHT

Statement No.: WITN4509001

Exhibits: WITN4509002-

WITN4509009

Dated: 2<sup>nd</sup> June 2022

INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF DR AILSA WIGHT

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## **Section 1: Introduction**

I, AILSA WIGHT, will say as follows: -

1. My name is Ailsa Wight. My address is known to the Inquiry. I was born in 1956. My professional qualifications relevant to the duties I discharged while working with the Department of Health are a medical degree MBBS, MSc, and FRCPath (Fellow of the Royal College of Pathologists).

I am providing this statement in response to a request under Rule 9(1) of the Inquiry Rules 2006 dated 29 March 2022.

### **The Process of Drawing up this Statement**

I have been asked by the Inquiry to set out my understanding of a number of issues related to infected blood and blood products and to the Inquiry's Terms of Reference. The Inquiry's Rule 9 Statement Request covers a wide span of time, as well as a range of different issues, and inevitably I have only a limited and usually very general recollection of events.

I have reviewed written material to assist with my answers. This statement is based on a review of the documents provided by the Inquiry, that is, the documents which the Inquiry refers me to in the Rule 9 Statement Request. My advisers also conducted a search for additional documents, but I have only referred to a small number of documents other than those referred to in the Rule 9 Statement Request, where these seemed particularly relevant.

My statement needs to be read subject to the caveats above as to the information on which it is based.

## **Employment and Career History**

2. My employment history is as follows:
  - i. Prior to joining the Department of Health (“**DH**”), I was working as a Senior Registrar at St Mary’s Hospital, London, in the Microbiology Department;
  - ii. I joined DH in June 1991 as a Senior Medical Officer (Grade 5). I took over responsibility for bovine spongiform encephalopathy (“**BSE**”) / Variant Creutzfeldt-Jakob disease (“**vCJD**”) as of September 1991. Until 1 April 1995 I was a Senior Medical Officer in the Health Aspects of the Environment and Food Medical Division, reporting to Roger Skinner;
  - iii. On 1 April 1995, the medical and administrative divisions merged to form a single Division, Health Aspects of the Environment and Food Division. I became head of an integrated Unit within this Division, covering aspects of vCJD. The division was headed by Dr Eileen Rubery. Dr Skinner remained my immediate line manager;
  - iv. The Food Standards Agency was set up in 2000, incorporating relevant staff from DH and the then Ministry of Agriculture, Fisheries and Food. However, at the request of senior DH officials I remained with DH, continuing my erstwhile Unit Head post covering aspects of food safety, together with vCJD, and taking on various infectious disease responsibilities, including bioterrorism in 2001. I reported to Elizabeth Smales and then Mary O’Mahoney;
  - v. In 2004, following a major reorganisation, I was appointed formally as Deputy Director of Infectious Diseases and Blood Policy. I reported to Gerard Hetherington as Director of Health Protection, and then to Elizabeth Woodeson who replaced him in 2006. Helen Shirley-Quirk became acting Director in 2009 and then she and Clara Swinson jointly carried out the role until Helen was formally appointed the sole Director in 2012. For this period, David Harper was Director General of Health Protection;
  - vi. In 2011 I took on responsibility for the Infected Blood payment schemes, including the establishment of the Caxton Foundation following publication

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of the Department's review of the infected Blood payment schemes in 2011. Felicity Harvey took over from David Harper as Director General in 2012, and Clara Swinson took over from her in 2015;

- vii. My role thereafter broadly continued the same, though with significant additions of policy responsibility, including radiological and environmental protection health and then screening and vaccination policy until I retired in September 2019.
3. I have set out in paragraph 2 above the positions that I held at DH. With regards to my role with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, I was the DH observer on the following groups: the Spongiform Encephalopathy Advisory Committee (SEAC) from late 1991; the Transmissible Spongiform Encephalopathies Working Group (SEWG) of the Advisory Committee on Dangerous Pathogens (ACDP) from 1991 – 1993; and the Medical Research Council (MRC) Epidemiology Sub-group of the TSE Co-ordinating Committee (the Allen Committee) from 1991 to 1995. From 2004 my team took on sponsorship responsibility for the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO) and for the main ACDP. I was never formally appointed to any of these committees; my policy role for the range of health protection issues included sponsorship of a range of relevant scientific advisory committees (including SEAC, SaBTO and ACDP), which provided independent advice to government. The nature of my team's work meant that there was very regular and frequent communication with a range of experts in academia, public health and surveillance bodies. From time to time we would set up ad hoc, informal and time-limited groups on specific issues with relevant experts, with whom we had ongoing dialogue.
4. I have been asked to explain how the Blood Policy Team and any other units I worked in relevant to the Inquiry's Terms of Reference fitted into the structure of DH. The Blood Policy Team and the vCJD Team were part of the overall infectious diseases and blood policy (subsequently health protection) branch within the Health Protection Division of the Public Health Group. I have set out above to whom I reported over this period. The Inquiry has referred me to [D MACF000023\_055], which is a letter written by me (in my role as Deputy Director of Health Protection) to Martin Harvey (Chief Executive, the Skipton

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Fund) and dated 30 September 2011. The letter summarises a number of changes to roles and responsibilities that were being made within the Health Protection Division on 3 October 2011, following the retirement of Jonathan Stopes-Roe. I explained that I would be taking over from Jonathan as Deputy Director responsible for sponsorship of the Macfarlane Trust, the Eileen Trust, Skipton Fund Ltd, MFET and the Caxton Foundation. Nannerl Herriot was to hand over sponsorship business to Rowena Jecock, to enable sponsorship and policy to be aligned within a single team. I explain in the letter that Ben Cole is the Senior Manager in Rowena's team, and he would be Martin's day to day contact for all aspects of business relating to the five bodies, with Michelle Haywood taking over from Glen Clarke in dealing with operational finance such as processing invoices for payment.

5. I have not been a member of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, other than those set out above, apart from the informal Infected Blood Reference Group.
6. I have not undertaken any work (whether paid or voluntary) relevant to the Inquiry's Terms of Reference outside of my work for the Department of Health.
7. I have previously provided the following witness statements, which I have included in my exhibit table:
  - i. Statement and supplementary statement for the BSE Inquiry (1998-99) [WITN4509002] [WITN4509003];
  - ii. Statement for the Secretary of State for Health in the case of R (Mary Moore) v Skipton Fund Limited and the Secretary of State for Health (28 January 2010) [WITN4509004]; and
  - iii. Statement in the litigation R (Alex Smith) v Secretary of State for Health (18 December 2017) [WITN4509005].

## **Section 2: My Role in the Department of Health with respect to AHOs**

8. I have been asked to explain my responsibility for and involvement with the Alliance House Organisations (“AHOs”) in my various roles at DH. Prior to 2011, I was only responsible for blood safety policy, and had no direct involvement with the AHOs. After Jonathan Stopes-Roe’s retirement in 2011 my team took on responsibility for the blood payment schemes. The main task of this was agreeing the annual allocations, and in 2011 the establishment of the Caxton Foundation.
9. I have been asked to describe the pattern of meetings between the AHOs and the Minister for Health, Secretary of State and Senior Department of Health Officials. As far as I recall, there were no regular meetings between AHOs and Ministers or the Secretary of State. The documents referred to show that in 2011, 2012, and 2014/15, there was an annual review meeting with the Macfarlane Trust. Rowena Jecock and I attended all of these meetings, and Ben Cole, Kypros Menicou, Naomi Balabanoff, Eleanor Gill and Harry Haralambous (the latter two from DH Finance) attended some of these meetings. Various matters were discussed, and the meeting notes appear quite detailed. I am also referred to three meetings with the Caxton Foundation in 2011-2012. Rowena Jecock, Julie Lucas and I attended the first two of these, and Rowena Jecock and Ben Cole attended the last meeting in 2012. Various matters were also discussed at these meetings, and the notes here appear quite detailed as well. In 2011 Caxton was a new body, and there was more contact initially as the arrangements were being established. Thereafter there were regular annual accountability reviews of all of the AHOs, which I usually chaired.
10. I have been asked whether I attended board meetings with any of the AHOs. As far as I can recall, I never attended board meetings with the AHOs. The Inquiry has referred me to a note of the annual review meeting of the MFET [DHSC5038269], rather than a board meeting.

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11. I have been asked to describe the working relationship between the AHOs and DH during my time there, in particular:
- a) Reporting obligations on the AHOs to DH: As I recall, there was an annual report from each of the AHOs to DH. This consisted of an accountability review and look back on the previous year, and a forward look to the coming year.
  - b) Whether DH considered the AHOs to be independent of the Government: The AHOs were independent of government, although funding was provided by DH and as such the bodies were accountable to DH for their expenditure. In general terms, this involved showing how monies were spent and discussing any bigger issues that could impact on funding. The AHOs were administered by their boards in line with each organisation's objectives.
  - c) Whether it was acceptable to DH for the AHOs to campaign/lobby for a change in government policy to benefit its beneficiaries: AHOs were free to do what they felt was appropriate in line with their board's decision-making powers and objectives, and for those that were charities, the Charity Commission.
  - d) Whether I agree or disagree with a description that the relationship between the Department of Health and the AHOs was too "cosy": I did not see the relationship as cosy or otherwise, I saw it as business-like.

### **Identifying beneficiaries of the AHOs**

12. I have been asked to describe DH's role in identifying beneficiaries for each of the AHOs. I had oversight of the Caxton Foundation from its establishment in 2011 and this is therefore the AHO about which I have more direct knowledge. The Beneficiaries for Caxton were those who had already applied to the Skipton Fund and/or could prove they were infected with hepatitis C as a result of receiving infected blood.
- a) The processes set out in the documents I am referred to predate my involvement with the Macfarlane or Eileen Trusts [EILN0000016\_001], [SCGV0000239\_016], [EILN0000016\_017], [MACF0000003\_064], [DHSC5255804] and [CAXT0000095\_006]. However, as I recall, experts



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were approached for advice when necessary when the eligibility criteria were difficult to assess.

- b) I have been asked to describe how this process changed over the years. As I recall, external experts were involved where necessary in helping to establish whether the eligibility criteria were met in particular cases. On a day-to-day basis, although it was my team that handled such issues, I was only consulted if there was a particular issue that they could not resolve. The document which I am referred to [DHSC6873798] is an email from Rowena Jecock in which she says that in assessing claimants for the Eileen Trust, it was the medical records of patients that would be taken into account. Rowena's email says that from July 2009 DH will no longer play any role in checking medical histories of the claimants, and "in the future, we intend that the [Eileen] Trust should liaise directly with the UKBS, as the most appropriate bodies to assess transfusion histories of potential claimants". It seems from this that the view was that it was most appropriate to go direct to the experts to advise on patient histories.

### **Contact with and knowledge of the beneficiary community**

13. I have been asked what contact I and others at the Blood Policy Team (in so far as I am aware) had with the beneficiaries of the AHOs. I do not recall having personal contact with beneficiaries of the AHOs.
14. I have been asked what my knowledge and understanding was of the needs of the beneficiaries of the AHOs. The Inquiry suggests that I was responsible for blood policy payment schemes from 2006, however I did not become responsible for the payment schemes until late 2011 when Jonathan Stopes-Roe retired. Prior to 2006, I was responsible for blood safety but not for the payment schemes; as part of blood safety, I had oversight of ensuring the evidence base was as robust as possible, using external expert advice (such as clinical/academic opinion, the Health Protection Agency and SaBTO). From 2011 my knowledge and understanding of the needs of the beneficiaries of the AHOs was as far as I can recall, through their correspondence to the department.

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15. I was aware of some tensions between the beneficiary community and the AHOs:
- a) I became aware of this because there was correspondence between some of the beneficiary community and Ministers. The beneficiaries also wrote to DH and as I recall submitted FOI requests.
  - b) As part of an increasing awareness of these tensions and the concerns of some beneficiaries, a review was conducted in late 2010. The “Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants” was published in January 2011<sup>1</sup> [WITN4509006] (I will refer to this as “**the 2011 Review**”). The aim of this review was to assess the support available to those who had been infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products including: the level of ex-gratia payments made; how such payments were made; the provision of insurance to those infected; and medical care. I was involved with this review and therefore would have been generally aware of the concerns raised by the beneficiaries. The 2011 Review made several recommendations regarding increasing the amount of money paid to individuals, and making such payments more regular, in particular in relation to hepatitis C, demonstrated by the establishment of the Caxton Foundation following the 2011 Review. A key aim was to try to create parity, fairness, and transparency across the HIV and hepatitis C bodies.

### **Funding of the AHOs**

16. I have been asked about the basis upon which the annual allocation for the MFT was set by DH. Allocations were agreed in consultation with MFT on the basis of information that MFT provided.
- a) I have been asked to what extent the needs of the beneficiary population were taken into account when setting the annual allocation. Because DH set the annual allocation based on information provided by MFT, the needs

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<sup>1</sup> PRSE0004024

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of the beneficiary community would be considered to the extent that MFT included these in the consultations with DH on annual allocation.

- b) I do not recall this process changing over time. Over the period of my responsibility, it was the case that we were trying to balance the needs of the community against the funding restraints.
17. I have been asked to set out the process by which DH provided funding to the AHOs. This would have been within the remit of the DH Finance team.
- a) I have been asked to explain why funding changed from a three yearly cycle to an annual cycle in 2007. As outlined above, this predated my involvement with the blood payment schemes, so I am not able to provide an answer to this.
  - b) I cannot recall how the annual 'top-up' funding process worked, and I would need to defer to my financial colleagues.
  - c) I understand that the Inquiry has received evidence that DH was slow to inform the AHOs of their annual allocation. I have been referred to [MACF0000060\_016], which is an email to me from Roger Evans, dated 7 January 2013. Mr Evans expressed that he and the Board were anxious to receive information from the Department about their financial allocation for 2013/2014, that they had not been provided with a "financial principles document" as promised, and that the information was essential prior to the January board meeting in order to develop the financial strategy. From a policy point of view, as soon the allocation amount had been agreed we told the AHOs and we did not sit on this information. This was dependent on departmental allocations from Treasury, and then health Ministers and finance colleagues reaching a decision on funding available to all parts of the health system. This delay in timing was not an issue limited to the AHOs. I believe that DH Finance colleagues would be able to explain the overall process better. There is no additional relevant information in the second document the Inquiry has referred me to [CAXT0000110\_022], in which I provide the Caxton Foundation with their allocation for 2013/14.
18. I have been asked to explain my role in the funding process. My role in this specifically began in 2011/12. The Inquiry has referred me to three documents,

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which show that my role included informing AHOs of their annual funding allocation, and considering and raising with the AHOs questions as to their administrative and service costs in the context of sound financial accountability. I do not recall any further details.

19. I have been asked to explain why DH set operating balances for the three charities given that they were set up to be independent of the Government. As I understood it, this process was in line with wider government spending policy of ensuring that government knew how funds would be spent.
20. I have been asked to explain why DH released the Caxton Foundation's allocation as it was spent during the year, rather than in an annual payment. I believe this may have just been part of responsible financing, however I would defer to finance colleagues on this.
21. The Inquiry has indicated that Christopher Fitzgerald, the former Chair of the Macfarlane Trust, said that the funding for the AHOs may have come out of a different pot of money to the NHS. As far as I recall this is correct, as I believe it came out of the central departmental allocation, distinct from NHS monies. However again I would defer to finance colleagues who I believe would be able to provide the most accurate answer.
22. I am referred to submissions from the AHOs during my tenure to increase their allocation, and to two refusals for such requests. [CAXT0000110\_089] is a letter from me to the Chair of the Caxton Foundation in February 2014. It explains that Ministers had decided not to agree to the increase in allocation request, and that following the Westminster Hall debate of 29 October 2013, Ministers were continuing to consider how best to address a range of issues about the system of support available for those affected by contaminated blood. I explain that the reason for this was the continuing downward pressure on government spending, which had been discussed with the Caxton Foundation on a number of occasions. This was a very difficult message, but I believe one that would have been widespread across government at that time.
23. I have been asked how the submissions referred to above were received by the Blood Policy Team at DH, and in particular:

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- a) Which of these submissions for increased funding were escalated to the Minister of Health, and what the criteria were for escalation: I cannot recall if all the submissions referred to above were escalated to the responsible Minister (usually MS(PH) or PS(PH)), but as the reference at paragraph 22 above suggests, there was escalation. As to the criteria for escalating to the Minister, as I recall if the increase was for a significant amount and well evidenced it would certainly have gone to Ministers.
  - b) Whether DH took account of the representations made by AHOs, and the process by which this was done: Yes, I recall DH did take these into account. The Blood Policy Team would discuss their requests with finance (among others Ed Jewell was one person in finance who we discussed this with) and come to a collective view based on evidence and balancing this with affordability. The final decision would have been made by Ministers.
  - c) Whether there was anything more the AHOs could have done to persuade DH to increase their allocation: In the financial climate at the time, I believe it was unlikely there is anything more the AHOs could have done. DH and wider government budgets were consistently under significant pressure during this period.
24. I have explained why the Caxton Foundation business case was turned down in February 2014, as evidenced in my letter [CAXT0000110\_089], at paragraph 22 above. I do not believe I can add any further insights.
25. I am asked why DH refused to increase the budget of the Caxton Foundation in 2015 in light of the sudden increase in beneficiary numbers by 50%. The document I am referred to is the annual report of the Caxton Foundation of 2014/15, and does not shed any light on why the budget was not increased. I do not have any recollection of the reasons.
26. I am informed that the Inquiry has heard evidence from both the Macfarlane Trust and Caxton Foundation Trustees that, in their view, both charities were underfunded. I do not recall when I first became aware that this was the view of the Trustees. The annual report of 2013/14 and 14/15 clearly suggest that more funding was requested, but the document referenced here does not provide evidence as to why it was turned down, and I cannot recall. Whenever

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AHOs requested more finance, we would ask for a business case and discuss that with DH finance.

27. I am asked whether I agree that the Macfarlane Trust and the Caxton Foundation were underfunded. As far as I can now recall, I had no view on whether the Macfarlane Trust and Caxton Foundation were underfunded. However, as DH officials, we took all of their requests for funding seriously, taking into account the evidence provided, and discussing with finance and with Ministers.
28. I have been asked what impact the level of Macfarlane Trust reserves had on the decisions made by DH about grant allocation, and in particular:
- a) Whether DH considered that the Macfarlane Trust should be funding its annual grants programme from its reserves: Yes, it was considered that reserves could be used, because of the financial constraints with taxpayer's money. As seen in Ben Cole's email of 9 December 2011 at document DHSC5015927, it was understood by DH that the Macfarlane Trust had "quite large reserves" which were held in investment accounts. Eleanor Gill, Finance Business Partner, also says in her email of 28 November 2011 [DHSC5280215] "if the charitable need is indeed as great at the business case suggests arguably MfT would have already used a substantial proportional of their reserved to meet this need". Legal advice had also been obtained on this position, as seen in the submission from Ben Cole to the Secretary of State of 6 December 2012 under paragraph 12 'Legal View':
- "The Charity Commission requires Charities to have a reserves policy, but there is no strict requirement for charities to actually maintain a reserve. It is therefore possible, provided its financial circumstances make it appropriate, for a charity to operate lawfully without a reserve. DH has no powers to instruct MfT about whether it should have a reserve, or what size it should be, but as sole funder, DH can refuse to fund a reserve and withhold or reduce annual allocations until the reserves are paid down"* [DHSC5007810].
- b) Why DH required the Macfarlane Trust to provide a business case for the spending of its reserves, given that the Macfarlane Trust was an

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independent charity: As at 28(a) above, given DH was making annual allocations, and as part of accountability for taxpayer's money DH needed to ensure that all of the money was being spent appropriately. The Macfarlane Trust needed to show how they would spend their reserves before the government could give them more money, as taxpayers would expect accountability. The submission from Ben Cole to the Secretary of State of 6 December 2012 (paragraph 11) also shows that there were "broader concerns about MfT's internal governance" within MfT and so "requiring MfT to submit a plan explaining how it intends to assess charitable needs as a condition of spending its reserves should help re-focus the Board on MfT's purpose" [DHSC5007810].

29. I have been asked what the rationale was for DH setting off any Caxton Foundation underspend in one financial year against the allocation in the following financial year, given that the Caxton Foundation was an independent charity. The same arguments apply as in my response above with regards to the Macfarlane Trust reserves. The Caxton Foundation's funding came exclusively from the government, so we had accountability to taxpayers. If the Caxton Foundation had underspend, then DH required them to provide a business case for requiring additional funding from the government. I have been asked to refer to my allocation letter to Jan Barlow of 26 April 2017 [CAXT0000003\_107], however the date of this letter is 2016 and it does not provide any relevant further information.
30. I have been asked why there was there a delay in providing the allocation for Caxton for 2016/17. I do not recall why there was a delay, however I assume that the delay was caused as a result of waiting for central DH allocations to be finalised by the finance team. As soon as the Blood Policy Team were informed of the allocations for our sectors, we informed the AHOs. It was outside of my control how long this process took. I am referred to a letter from myself to Jan Barlow (Chief Executive of the Macfarlane Trust), dated 26 April 2016, informing the Trust that in 2016/17 funding of up to £2,200,000 will be available to the contaminated blood scheme [CAXT0000003\_107]. I note that this document says that the money will be allocated once MFT provided a

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breakdown of their service delivery costs, which may have also been a reason for the delay, but I cannot add anything further.

31. I have been asked what the basis was for DH setting the level of reserves appropriate for the Caxton Foundation, given that it was an independent charity. I would like to refer back to my response at paragraph 28(a) above with regards to the legal advice received on this same matter with regards to the Macfarlane Trust. As funders, DH were accountable for government money, and needed to consider wider pressures on the departmental budget. Money held by the Caxton Foundation was money that was meant to be paid out to beneficiaries, so there was no need for this body to have a large reserve.
32. I have been asked what the basis was for DH setting the level of reserves appropriate for the Eileen Trust. I would like to refer back to my responses at paragraphs 28(a) and 31 above. DH was involved with the question of reserves because of the responsibility to manage public money, which was being used to fund these Trusts. My letter to Peter Stevens from the Eileen Trust of 26 March 2013 says “from 1 April 2013, ET will no longer receive funding via MFET Ltd, but should invoice DH directly for the funds it requires” [DHSC6795900]. Given that this funding was coming directly from DH, DH had an obligation to assess the amount of money required by the Eileen Trust.
33. I have been asked to explain the circumstances in which funding for any of the AHOs was sought from the devolved administrations, and how the level of their contribution was set. I am referred to a letter I sent to David Worthington, Head of Health Protection Division in the Welsh Assembly, of 7 September 2011 [DHSC5001745]. This letter describes the additional arrangements that were being set up to support those who had been infected, and addresses the additional costs that this would result in. In this letter I wrote “Officials in Wales have sought HM Treasury (HMT) assistance in facilitating an agreement for DH to meet the additional costs of providing increased support in Wales”. In this instance the response from HMT was that DH should not pay for devolved spending. As I recall, for any contribution that was made the level was set on the basis of the Barnett formula.



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34. I have been asked what the arrangements were as between England, Northern Ireland, Scotland and Wales for funding the new hepatitis C and HIV payments announced in January 2011 by DH and March 2011 by the devolved administrations. As I have provided at paragraph 33 above, the view from HMT was that DH should not pay for devolved spending. The same message was delivered by myself to the Scottish government by a letter sent on the same day as the letter to the Welsh government [DHSC5105390]. I am referred to a letter from David Worthington, Head of Health Protection Division in the Welsh Assembly to me dated 27 September 2011, in which he agrees that “the costs of providing increased financial support to those infected by contaminated blood in Wales will be met by the Welsh Government. I am therefore writing to you to provide formal confirmation that the Welsh Government will meet the costs incurred by the Skipton Fund and the Caxton Foundation in respect of claimants in Wales” [DHSC5683895]. Similarly, I am referred to a document shows that the Scottish government also agreed to meet the Skipton and Caxton Foundation costs [DHSC5683949].
35. With regards to the £25 million announced by David Cameron on 25 March 2015 I have been asked:
- a) What I understood this money to be for; in particular whether it was the intention of the Government that it would be spent in 2015-2016: I understood that the money was intended for the purpose which David Cameron provided in the House of Commons on 25 March 2015: “I can confirm today that the Government will provide up to £25 million in 2015-16 to support any transitional arrangements to a better payments system.”<sup>2</sup> [WITN4509007] This announcement was immediately followed by a general election, which delayed further consideration and progression of this commitment.
  - b) Whether it was spent for its intended purpose: The money was spent to support the beneficiaries.
  - c) When it was allocated and to what: It was not spent initially, as in January 2016 DH undertook a public consultation called “Infected blood: reform of

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<sup>2</sup> DHNI0000703

financial and other support”<sup>3</sup> [WITN4509008] and I believe we held off on spending to see the outcome of this review to ensure that the money was used as effectively as possible in reflecting the most current needs of the beneficiaries. This money rolled forward to be part of the implementation of that review in financial year 2016/17, when it was allocated together with additional funds of £100 million. The consultation paper of January 2016 says “In March 2015, the Prime Minister announced £25 million to ease transition to the reformed scheme. Following the Spending Review, the Department of Health has identified up to an additional £100 million, during this Spending Review period, for the proposals in this document”. The government response to this consultation in July 2016<sup>4</sup> [WITN4509008] sets out in ‘Chapter Four: Transition to a reformed scheme’ what this money was to be allocated to.

### **Skipton Fund**

36. I have been asked what involvement I had in setting up the Skipton Fund. I became involved with the blood payment schemes in 2011, so was not involved with the setting up of the Skipton Fund in 2004. I am referred to several document which I believe evidence my strategic oversight over Skipton from 2011 but also show that I was not involved with the detail of these discussions [DHSC6698821], [DHSC5126209], [DHSC5142875], [DHSC5162072], [DHSC5164390], [DHSC5219548], [DHSC5659424], [DHSC5680861] and [DHSC5111022]. I would defer to other colleagues as to the original practical arrangements of setting up the Skipton Fund.
37. I have been asked about the extent of my involvement in the development of the criteria for Stage 1 and 2 payments for the Skipton Fund recipients. I was aware that there were questions around eligibility criteria, as evidenced in the documents to which I am referred. These were often very complex matters to decide, especially if the evidence trail was lacking, so we used clinical experts to give us their best view based on balance of probabilities, to be as fair as possible.

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<sup>3</sup> WITN3953052

<sup>4</sup> WITN4496006

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38. I have been asked what I understood to be the rationale for excluding certain categories of beneficiary from eligibility for the Skipton Fund (for example, natural clearers). Such issues were discussed with the experts and kept under review with the relevant advisory committees, and the understanding was that natural clearers recovered within 6 months. I would like to refer to my witness statement of 28 January 2010 in the claim of Moore v Skipton Fund Limited and the Secretary of State [WITN4509004]. This discusses the question of natural clearers at paragraph 18:

*"In October 2004 officials consulted Professor Howard Thomas, Professor of Medicine, Imperial College School of Medicine, and Consultant Physician/Hepatologist, St Mary's Hospital, London and then Chair of the Advisory Group on Hepatitis to seek further guidance from the Department of Health on how to apply the criteria to these cases, and to future applicants who had spontaneously cleared the virus. The advice which emerged from this exchange in November 2004 was that patients who clear the virus in the acute phase would have experienced few symptoms, and that any they did experience would have been short lived because of the transient nature of the infection".*

In this case the judge dismissed the application for judicial review against the Secretary of State for Health.

a) I have been asked why the position changed in February 2012. I cannot recall exactly what was behind this, however it was most likely a pragmatic decision based on emerging evidence that reinfection could occur. I am referred to a letter which I wrote to the Skipton Fund on 22 February 2011, in which I explain that:

*"In a very small proportion of cases, it is possible that viral clearance occurs spontaneously during the chronic phase of infection. If there is clinical evidence that this occurred (i.e. clearance of all strains/genotypes of the virus) and the individual was subsequently re-infected before September 1991 through further NHS treatment with blood or blood products, also resulting in chronic infection, Skipton may make a further Stage 1 payment. A decision to make such a payment must be based on*

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*evidence that is sufficient to distinguish a new and separate infection from possible reactivation of a prior infection” [DHSC6658866].*

39. I have been asked what steps I and/or to my knowledge, others at DH took to publicise the Skipton Fund to potential beneficiaries, particularly after changes were made to the eligibility criteria. I would like to refer to a draft submission from Rowena Jecock to PS (PH) dated February 2011, which I cleared [DHSC5111022]. This explains the progress with changes to the support available following the 2011 Review, and says at paragraph 2 “the new measures have now been widely publicised. A further press release will be issued soon, as a reminder”. As I recall, efforts were also made to publicise this information through various related organisations, and this same submission says at paragraph 3 “the Hepatitis C Trust has been supportive and has publicised the new measures on its website”.
40. I have been asked about my input in the decision to (i) extend the Skipton Fund to include those who died before 29 August 2003 and (ii) to accept applications from the estates of such individuals where those applications were received after the 31 March 2011 deadline. This was a result of the 2011 Review. I can't recall what input I had with regards to both decisions, however I believe that I felt at the time that the extension to those who died before 2003 was reasonable. I am referred to a draft submission from March 2011 (a specific date is not provided) from Ben Cole to PS(PH) and cleared by me, which says (although I don't recall the details) that “we recommend that you publicly maintain the 31 March 2011 deadline in order to encourage the maximum number of people to come forward in this financial year, and that you provide a steer on handling claims received after that deadline” [DHSC5284065].

### **Caxton Foundation**

41. I have been asked what my understanding was of why DH decided to provide monies to the Caxton Foundation, a charity – for the benefit of Skipton Fund beneficiaries, rather than providing financial relief directly themselves. The Skipton Fund and Caxton Foundation were both set up to support hepatitis C beneficiaries. Skipton was structured as a company, rather than a charity, therefore it could not make discretionary payments, and we wanted a body that

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could make discretionary payments to those with hepatitis C in the same way that the discretionary payments for HIV were made by the Macfarlane and Eileen Trusts. So Caxton was set up to ensure consistency of approach across the schemes as far as possible. We wanted Caxton to provide a good model of how charitable funding could work, which I believe it did. The aims were to be as transparent and as fair as possible. I have been asked in particular:

- a) What my view was as to how well the charitable model (as experienced by the Macfarlane Trust and the Eileen Trust) had worked: I did not have a view on the effectiveness of the charitable model itself.
  - b) Whether I or anyone else at DH was concerned about beneficiary dissatisfaction with the Macfarlane Trust replicating itself with the Caxton Foundation, and what steps were taken to avoid this. I do not recall specifically. However, I do recall that our aim in setting up the Caxton Foundation was to improve accountability in meeting beneficiaries' needs and for the approach to be mirrored as far as possible across the other historical AHO charities.
  - c) I have been asked whether there was any consideration given to providing access to additional financial support to Skipton Fund beneficiaries via a non-charitable vehicle so as to avoid beneficiaries having to show charitable need in order to access financial support. However, I believe the 2011 reforms (following the announcement by the Secretary of State, in January 2011) did provide access to additional finance to Skipton Fund beneficiaries via a non-charitable vehicle. These reforms created increased payments via the Skipton Fund: stage 2 beneficiaries were to receive an increase in their lump sum payments and there would be annual payments for Skipton stage 2 sufferers. This 2011 announcement separately included the establishment of the Caxton Foundation, a charitable model to support those affected by hepatitis C.
42. I have been asked about why I understood it was a ministerial objective to achieve 'read across' between the three charities, and why was it important to DH to align "the Trusts more closely". This was about fairness, equity and transparency, recognising that the other two charities (the Macfarlane Trust

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and Eileen Trust) had been established for a long time. We did not want to dismantle arrangements, but rather make them more consistent and overt. I am referred to minutes of a meeting between DH and the Trusts on 18 February 2011 in which Debby Webb from DH says “to avoid the risk of creating new anomalies, it would be important for the functions of the new charity not to be too different from MFT and ET” [HPCT0000210\_015]. As far as I can recall, this aligned with my understanding at the time.

43. As to my input with setting up the Caxton Foundation, I was involved in this process, and the evidence shows that I met with the nascent organisation at various times around its inception.
44. I have been asked if I met with the Trustees of the Caxton Foundation regularly. I do not recall meeting with the Trustees regularly. I do recall meeting with the Chair regularly (at least annually).
45. I have been asked whether I was concerned about Mr Evans' decision not to appoint a user Trustee to the Caxton Foundation. I do not recall if I was concerned or not. The Board would have been best placed to decide whether a user Trustee should be appointed.
46. I have been asked what steps DH took to publicise the Caxton Foundation to the Skipton Fund beneficiaries. I do not recall the details. But I am fairly sure all Skipton Fund beneficiaries were written to, to say that Caxton had been established. I am referred to Minutes of a meeting between the Department of Health and trusts on Caxton on 18 February 2011 [HPCT0000210\_015], in which Debby Webb said “a future press notice was planned for early March and it may be prudent to use that opportunity to emphasise that existing stage 2 recipients (or their representatives) would have proactively apply for the additional payments”. In an email from Ben Cole to a policy official in the Department for Work and Pensions, dated 23 November 2011 [DHSC5265812], he says:

*“Thus far there have been relatively few applications to the [Caxton] Foundation, which makes us wonder whether all potential applicants have heard of the Foundation, particularly widows of infected individuals, who may not have heard about it [via] NHS networks...It has been*

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*suggested that there may be opportunities for publicising the existence of the Foundation through DWP communications or networks. Would you be able to let me know whether DWP issues any routine communications that might be useful for our purposes?"*

To this the DWP policy official responded "we don't have a regular communication for claimants but we do have an external publication called Touchbase - <https://www.gov.uk/adviser/touchbase-magazine/>. This is a monthly on-line publication that external advisers and other professionals can subscribe to. If you want to include anything here the contact is Paula Blythe". I cannot recall if this was actioned.

47. I have been asked why it took until August 2014 for DH to instruct the Skipton Fund to make direct contact with beneficiaries of the Skipton Fund who had received a stage one payment but had not registered with the Caxton Foundation, to inform them about the Caxton Foundation. I do not recall the reason for the timing, but it may have been as a result of feedback from Caxton that they were not getting many applications, despite the Skipton beneficiaries having been written to when Caxton was set up. Thus instructing the Skipton Fund to make direct contact was a follow up, and not the only, notification action.
48. I do not recall expressing concerns regarding the Caxton Foundation to its Trustees or DH. The Caxton Foundation was committed to its terms of reference, and acted in accordance with fairness and transparency.

### **Appointment of Trustees/Directors**

49. I have been asked what I knew about the appointment process for the AHOs during my time at the Department of Health. I am referred to a submission relating to the appointment of a trustee to the Caxton Foundation, dated 4 December 2012 [DHSC5017308], which explains that "under the terms of the Caxton Foundation's Trust deed, it is for the Trustees to decide who to appoint a Chair. However, the Chair must be a Trustee, and the approval of Ministers is required for the appointment of new Trustees". This submission says that an open competition was run for this appointment.

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50. I do not recall having any direct involvement in this appointment process for each of the AHOs during my tenure at DH.
51. I have been asked how DH selected the candidates to put forward as trustees of the AHOs. I am referred to the Macfarlane Trust Appointments Protocol, which says that of the nine Trustees, three can be appointed on the nomination of DH [MACF0000008\_003].
- a) As to the qualities that DH were looking for in trustees which they put forward for the AHOs, I do not recall being involved with such discussions, so I cannot comment.
  - b) As to whether the AHO trustee positions were advertised, the submission relating to the appointment of a trustee to the Caxton Foundation, dated 4 December 2012 says: "The Trustees ran an open competition to identify a new Trustee who would also take the role of Chair. An executive search agency was used, and advertisements were placed in the national media" [DHSC5017308].
52. I have been asked what I understood to be the purpose of DH having a hand in the selection of trustees/directors of the Macfarlane Trust, the Eileen Trust and the Caxton Foundation, given their status as independent charities, and whether I had any concerns about this. To my recollection I never got involved in the selection of trustees and directors therefore I do not feel able to answer this.
53. I have been asked whether DH had a veto over all Caxton Foundation trustees. I am referred to the Caxton Foundation Trust Deed which says at in Schedule 2, paragraph 6, that the Secretary of State for DH "may refuse to give consent" to the appointment of a trustee. However:
- a) I do not recall a 'veto' ever being exercised; and
  - b) As to whether DH *would* have exercised a veto *had* there been a proposal to appoint a campaigner to the position of trustee: I am not aware of whether this ever occurred, and do not feel able to comment on what DH's position might have been in such circumstances.



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54. I do not recall any difficulties during my time at DH with the appointment of new trustees or directors at the AHOs.
55. I have been asked whether DH had a view during my tenure about user trustees. I do not recall DH having a particular view. I believe Caxton may have had a hepatitis C patient as a trustee. As I have said at paragraph 45 above, the Board of the AHO in question would have been best placed to decide whether a user Trustee should be appointed.

### **Department of Health input into AHO Policy and decision making**

56. I have been asked whether DH had a view on what 'charitable need' meant. As far as I was aware, 'charitable need' was defined by the Charity Commission. We would have discussed the interpretation of this with the organisations for the purposes of transparency and equity. It was not that we were making a judgement call on individual cases, but rather trying to get a consistent approach across the organisations.
57. I have been asked to explain if funds were held by the AHOs for children until they reached maturity, and whether the AHOs or Department of Health receive any advice on this. I do not recall.
58. I have been asked about the Macfarlane Trust's policy of using loans and advances rather than grants. This was before my time, and I do not feel that I have sufficient knowledge of this to be able to comment.

### Section 3: Reform of the AHOs

59. I have been referred to a memo drafted by Dr Rowena Jecock, dated 24 February 2009, in which Dr Jecock sets out a number of issues that DH needed to investigate in order to come to a conclusion on the recommendations made by Lord Archer [DHSC0006755]. In particular Dr Jecock stated that on the recommendations regarding insurance, DH would seek the view of the Association of British Insurers (“**ABI**”). I have been asked if this took place. I recall that there was some discussions with the ABI, which I believe were led by Debby Webb. I recall that the Blood Policy Team followed up any actions from these discussions, but I cannot recall the outcome.
60. I have been asked what input I had to the Ministerial response to the Archer report. I am referred to a submission written by Dr Rowena Jecock which I approved, dated 26 February 2009. In this submission it is suggested that Minister of State for Public Health may want to consider in particular: (i) drafting a statement “expressing this Government’s regret at the events that occurred and the consequences for those affected” and (ii) following Lord Archer’s report, addressing the anomalies between the schemes set up to provide financial relief to those infected and affected at an early stage, ahead of the Government’s substantive response to the Archer report. The team and I would have worked with Private Office and the communications team to develop the ongoing response to the Archer report.
61. I have been asked what part I played in the Government’s decision not to implement the recommendation made by Lord Archer that there should be parity with the Republic of Ireland. I am referred to a submission from Debby Webb to PS (PH) dated 11 August 2010, which I cleared [DHSC0006649]. This submission followed a judicial review against the decision by government not to implement the recommendation of parity with RoI (please see response to paragraph 62 below). The recommendation in this submission, is that PS(PH) reject the recommendation on parity with the compensation scheme with ROI because of “(i) the factual difference between the RoI & UK; and (ii) affordability”. I cannot recall any further details.

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62. I have been asked what input I had into the Government's response to the judicial review of its response to the Archer report. I am referred to a submission from Debby Webb to PS (PH) dated 26 May 2010 and cleared by Clara Swinson [DHSC0003623\_004]. As explained in this document, a judicial review claim was brought against the government's decision that "ex-gratia payments made by the Government to individuals who had contracted HIV from blood/blood products would not be comparable to much higher levels of compensation paid in the Republic of Ireland" and that the judgement in this claim was "in favour of the claimant and against the SofS for Health". The submission also provides at paragraph 17 that "the Judgement does not require Ministers to necessarily change the decision...or to make extra funding available. The Court made it clear that matters relating to the allocation of resources were not under challenge in this litigation, and that it would be legitimate for the Government to take account of whether it had been at fault or would be vulnerable to a civil claim". The submission recommends not challenging this decision. However, at the same time the decision was taken to conduct a short review of the provision and support in England for those affected with HIV and/or hepatitis C via contaminated blood – as evidenced in the later submission which I am referred to of 7 October 2010, written by Rowena Jecock and cleared by Clara Swinson. As Deputy Director of Infectious Diseases and Blood Policy, I was aware of the existence of the judicial review claim, but I cannot recall having any significant input. The email chain I am referred to at DHSC0003623\_028 dated October 2010 indicates that Debby Webb and Clara Swinson were leading on this particular matter, so I would defer to them for a more detailed explanation.

63. I have been asked what input I had in Lord Andrew Lansley's announcement on 10 January 2011 that that Skipton Fund Stage 2 beneficiaries were to receive an increase in their lump sum payments from £25,000 to £50,000 and that there would be annual payments of £12,800 for Skipton stage 2 sufferers. My team and I, and other colleagues across the department prepared the 2011 Review report in a very tight timeframe between October and December 2010, and I was closely involved in the review conclusions and recommendations announced by Lord Lansley. The aim, as the submission which I am referred

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to from Rowena Jecock of 7 December 2010 [DHSC0003814\_090] makes clear, was to enhance the payment arrangements for those with hepatitis C and work towards greater parity between hepatitis C and HIV arrangements.

64. I have been asked about my input into DH's consultation on the AHOs, which was carried out in 2016. As with the 2011 Review, my team led on the 2016 Review and I was closely involved. My involvement was mainly on strategic aims, rather than the detail of the consultation.
65. I am informed that I attended a UK Health Departments Infected Blood Payments Scheme Reform meeting on 17 April 2015 [WITN4688017], in which the Health Departments stated their desire for parity between the administrations in respect of any reformed scheme, and whether this was a new aim in so far as I was aware. I do not recall specifically if this was a new aim.
66. I have been asked what input I had to the Infected Blood Reference Group. As I recall, this was an ad hoc group to provide evidence for and to sense check the 2016 Review findings; I believe external experts were key to this process. If I recall correctly, the group was set up by my team and I, with Helen Shirley-Quirk. The first meeting of the Group was held on 17 May 2016 [WITN4509009], with Kypros Menicou and I attending on behalf of DH. The meeting was chaired by Chris Pond, who informed the group that "the purpose of the Reference Group is to act a critical friend to the Blood Reforms Transition Board". I recall attending some of these meetings, but I may not have attended all of them.
67. I have been asked what view DH took during my tenure about whether the details of beneficiaries could be passed from the AHOs to the proposed new schemes. I am referred to [DHNI0000632], which is an email chain from November 2016. I am not copied into this email chain, and cannot recall any details, so others would be best placed to answer this.
68. I have been asked whether I considered the AHOs to be well run. Overall, I had no definitive view; it varied depending on feedback from the AHOs and beneficiaries to my team at any particular time.

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69. I have been asked whether I considered the AHOs to be well supported by DH. I had no particular view at the time. As I recall, we did what seemed reasonable at the time. From 2011 (when I became responsible for the blood payment schemes) our main objective was transparency and fairness in a very tight fiscal climate. Given the history, we implemented changes to the schemes incrementally because there were existing structures in place, and we did not consider it to be efficient or helpful to start from scratch. As the records show, there was frequent and regular engagement between my blood policy team and the AHOs.

## Section 4: vCJD

70. I have been asked to explain my role and responsibilities for vCJD during my tenure at DH. Following the BSE Inquiry, I continued to be responsible for vCJD until I left in 2019 as part of my wider infectious disease responsibilities which I have set out in my response at paragraph 2.

71. With regards to a screening test for vCJD, I have been asked:

- a) What role DH had in either funding or developing work on a screening test: I am referred to a submission from Rowena Jecock to the Minister of State for Public Health, dated 27 November 2006 [DHSC0007172]. This says at paragraph 6 “the development of an accurate and sensitive test for pre-clinical or sub-clinical vCJD is crucial to protect the blood supply, and prevent transmission of vCJD”. A test for vCJD was a very important goal and was a key priority in the overall DH funded research programme which the research and development team were responsible for.
- b) What I understand the reasons to be why no screening test was developed and/or adopted for use by the blood services: The position was guided by the expert scientific committees, blood services, and legal advice. I am referred to a memo by Libby Gunn, solicitor in the DH legal team, to Peter Bennett, copying myself and others, dated 29 May 2007 [DHSC0023605, page 1551 IBI bundle]. Libby’s advice explains the unreliability of the new tests at paragraph 3:

*“the scientific experts suggest that there will be many more false positives than true positives, and even true positives will not necessarily reflect the number of people who will go on to develop the disease, as opposed to simply “carry” it.” The advice on the use of these tests is summarised at paragraph 20 of the memo: “It is possible to lawfully not use vCJD tests to screen all donor blood. The UK could prohibit the use of the tests for screening of donor as a transitional measure under Article 13 of the IVD Directive. I understand the grounds on which such measures would be based to be a predicted critical reduction of donor blood supplies as a*

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*result of community fear as well as the higher number of false positives requiring deferral of donors. In my opinion the likelihood of the Commission finding that such measures are justified is high, assuming that there is sufficient evidence to support the prediction. Alternatively...the NBS could choose not to purchase the tests (assuming that the tests do not meet the specificity requirements). It is arguable that such a choice does not question the CE mark as a mark of safety and efficacy; rather the choice would be based on the fact that the CE mark does not attest to an appropriate specificity for the particular purpose of mass blood screening”.*

I recall that during the time of my tenure finding a suitable screening and/or diagnostic test for vCJD was very difficult.

72. With regards to the surveillance of vCJD in donor and patient populations, I have been asked:

- a) What role (in broad terms) DH had in this: DH funded the Creutzfeldt-Jakob Disease Surveillance Unit (CJDSU) and the Health Protection Agency (HPA, which became Public Health England). With the CJDSU we funded a study involving the blood services aimed at identifying donors and/or recipients who developed vCJD. This was called the Transfusion Medicine Epidemiology Review (TMER).
- b) What role I played: I was instrumental in supporting the Director of the CJDSU to ensure that the TMER study went ahead. My role was to work with the CJDSU and to justify the need for the study to DH.

73. I have been asked to set out my role in decisions made about importing plasma for transfusion. I am referred to a submission from Mark Noterman and cleared by me to the Chief Medical Office and PS(PH), dated 14 January 2011 [DHSC5655177]. This explains that SaBTO made a recommendations “to stop sourcing fresh frozen plasma (FFP) from UK donors and replace with imported FFP, as a further measure to reduce the potential risk of vCJD”. However, the submission shows that a departmental impact assessment did not support implementation on wider cost effectiveness grounds. The impact assessment was a standalone document which I did not input to. The submission

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recommends that, on the basis of the impact assessment “you do not accept SaBTO’s advice and agree that the current risk reduction measures to reduce the risk from plasma are retained and no additional measures are introduced”. The submission also makes a recommendation at paragraph 31 to “agree that SaBTO is asked to work with others to ensure that best practice for transfusion consent and use of blood and blood products is followed by service providers and is considered for inclusion with safety standards considered by CQC or their equivalents”.

74. With regards to notifying patients of their ‘at risk for public health’ status of vCJD, I endorsed the need for this exercise based on the emerging evidence. This is evidenced in a letter from Sir Liam Donaldson to Dr Martin Goram, Chief Executive of the National Blood Service, dated December 2003 [DHSC0020839\_020] In this letter Sir Donaldson explains the “recommendation that recipients of labile blood components from donors who [went] on to develop vCJD should be contacted and informed of their potential exposure and its implications”. There is a hand written note at the top of this letter which says “Agreed with Ailsa Wight 15/12/03”. As the evidence shows, the process was very much led by the science, and implemented by the experts at the Health Protection Agency. I have been asked in particular:

a) What, if any, advice DH took on the legal and ethical arguments for and against such notification. A submission from Rowena Jecock to the Minister of State for Public Health, copying myself and others, dated 27 November 2006 [DHSC0007172]. This says under the section titled ‘Ethical considerations’:

*“11. ...currently there is no proven treatment for vCJD and it is unknown if infection in an individual will necessarily lead to a disease. Given the long incubation period of the disease, there is concern about telling people they are infected when there is nothing they can do about it.*

*12. The Health Protection Agency, at our request, began a public consultation on this issue in October 2006. A report, which will inform policy, is expected in spring 2007”.*



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A subsequent submission from Rowena Jecock, dated 5 March 2007, sets out the legal advice obtain on this issue [DHSC0024074]. This explained the risk of liability under the Consumer Protection Act 1987 where the public had not been warned as to the safety of the blood. The submission shows that further advice was sought from solicitors, including “whether it would be useful to delay the use of a screening protocol until the tests have been properly evaluated”.

- b) What, if any, psychological support was made available to the notified patients. As I recall, DH asked NHS Direct to set up a helpline and asked the vCJD support network to get involved, as well as haemophilia clinicians.
- c) I have been asked to describe my role in any exercises notifying *donors* of their ‘at risk for public health’ status of vCJD: I do not recall being directly involved with this at the time. This process would have been led by the Health Protection Agency and the UK Blood Services, working closely with DH.

75. With regards to the process of de-notifying individuals of their ‘at risk for public health’ status of vCJD:

- a) I do not recall what if any involvement I had with the de-notification process. However, it would have been based on expert advice on the science and advice from the blood services.
- b) I do not recall what, if any, advice DH took on the legal and ethical arguments for and against such de-notification.
- c) I do not recall what support was made available to de-notified patients.

76. I have been asked what role DH had in approving sums paid out by the vCJD Trust to beneficiaries. I am referred to a letter dated 13 January 2012, sent to me from Field Fisher Waterhouse and titled ‘vCJD Compensation Scheme – Trustees Proposals to Increase Basic Sum and Invest’. This says “it is a requirement under the Trust Deed that the Trustees obtain the consent of the Secretary of State to vary the award paid to beneficiaries” [DHSC6664566]. I am referred to a submission from Naomi Balabanoff, cleared by me, to the Secretary of State, dated 15 March 2012 [DHSC5029294]. This submission asks approval by the Secretary of State “to annual increases in the basic sum paid out by the...vCJD Trust”. As far as I recall, this was approved. The sums

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paid out to beneficiaries was a matter for the Trustees to decide, and as I recall DH would have supported their views. The CJD Trust was set up with its board to decide what constituted appropriate payments. I was not involved in its establishment or any decisions about funding.

## **Section 5: Record Keeping**

77. I am informed that Inquiry has received evidence from Peter Stevens [WITN3070003] that DH did not have a copy of the Eileen Trust founding documents. I do not recall whether that is correct, and the Eileen Trust establishment predated my time.

## Section 6: Other

78. I would like to provide the further information:

- a) The history of the infected blood issue is a long and sad one. In terms of my involvement with the blood payment schemes, I was building on a fairly extensive historical legacy. The aim was to try and make processes as fair and transparent as possible based on evidence, whilst needing to have regard to public finances. It is important that the infected and affected are able through this inquiry process to be fully heard, and hopefully find closure.
- b) When as Deputy Director within Health Protection Division, with a range of infectious disease responsibilities, I took on in 2005/6 responsibility for blood safety and supply, I was fortunate to have a team leader with her own staff directly responsible for the day-to-day handling of blood safety and supply issues. I was mainly involved in overall management of the range of infectious disease issues I was responsible for, each led by a team leader of which blood safety was one. This necessarily meant that I spent significant amount of time on other issues apart from infected blood. In discussion with the Director of Health Protection, I tended to be more directly involved with the handling of the more strategic issues. As such, in relation to blood policy issues, my first real direct involvement was following publication of Lord Archer's report. I was subsequently similarly directly involved in the 2016-2017 reviews of the infected blood funding arrangements.
- c) Responsibility for the AHO payment schemes came to me in 2011, after the publication of the 2011 Review and the retirement of Jonathan Stokes-Roe. My main aim then was to ensure the schemes were as far as possible fair, transparent, consistent, and provided value for money. Caxton was a good example of this – colleagues and I identified a gap that needed filling in respect of hepatitis C and we tried to ensure that Caxton acted as a model of good practice for the future.
- d) Alongside this, we were very mindful of the need to balance taxpayer's money in the wider context of austerity and financial constraints, while

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paying attention to the scientific evidence base for these diseases (HIV, hepatitis C and vCJD). I do recall direct engagement with a number of Ministers over the period from 2010, all of whom were keen to make sure that we were providing the most appropriate and effective support for beneficiaries in the fiscal climate.

**Statement of Truth**

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

Signed..... GRO-C

Dated..... *20 June 2012*