

Witness Name: Jane Elizabeth Ellison
Statement No.: WITN3904009
Exhibits: [WITN3904010] – [WITN3904075]
Dated: [05.05.2022]

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF JANE ELIZABETH ELLISON

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I am providing this witness statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 November 2021.

I, Jane Elizabeth Ellison, will say as follows:-

Section 1: Introduction

Please set out your name, address, date of birth and any relevant professional qualifications relevant to the duties you discharged while Parliamentary Under-Secretary for Public Health.

1. My name is Jane Elizabeth Ellison, my address is known to the Inquiry. My date of birth is GRO-C 1964. I have a BA Honours degree but no professional qualifications relevant to the duties I discharged while Parliamentary Under Secretary of State for Health (Public Health) ('PUSSPH').

Please describe your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates.

2. From September 1986 to May 2010 I was employed by the John Lewis Partnership, joining the graduate training scheme, and subsequently undertaking a range of retail management roles, including in-store department management, direct marketing customer communications and, at the time I left the Partnership, manager of customer magazines. I was the Member of Parliament for Battersea from 7 May 2010 until 3 May 2017. During this period, I also held two ministerial roles; Parliamentary Under Secretary of State for Health (Public Health) from 7 October 2013 until 15 July 2016 and Financial Secretary to the Treasury from 15 July 2016 to 8 June 2017. From July to November 2017 I was a Special Advisor to the Chancellor of the Exchequer. In November I joined the World Health Organisation as Deputy

Director General, Corporate Operations and in March 2019 assumed my current role of Executive Director, External Relations and Governance.

Please set out the positions you have held at the Department of Health and give a narrative description of the roles you have undertaken at the Department of Health and your responsibilities in these roles. Please include any role you have had with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, and describe how you came to be appointed to those positions.

3. I was the PUSPH from 7 October 2013 until 15 July 2016. In addition to my ministerial responsibility for the areas germane to this Inquiry, my ministerial responsibilities during the period also included, but were not limited to, the following policy areas: antimicrobial resistance, blood transplants and organ donation, cancer, dementia, diabetes, fertility and embryology, health improvement (including addiction to medicines, alcohol, drugs, obesity, physical activity, tobacco), health protection (including emergency preparedness, vaccination, long-term conditions), prevention measures (including children's health and school nursing, fluoridation, health visiting, NHS health checks, preventing avoidable mortality) and sexual health. My portfolio also included sponsorship of: Public Health England, NHS Blood and Transplant (NHSBT), the Human Tissue Authority (HTA) and the Human Fertilisation and Embryology Authority (HFEA). In the course of discharging my responsibilities in these policy areas I would reply to correspondence, respond to written and oral Parliamentary questions, lead and respond to Parliamentary debates, undertake relevant visits and meet with ministerial colleagues, Members of Parliament, policy officials, experts, charities, individual members of the public and others.

Please identify the other Members of Parliament holding ministerial roles in the Department of Health between 2013 and 2016.

4. The other Members of Parliament holding ministerial roles in the Department of Health between October 2013 and July 2016 were Rt Hon Jeremy Hunt MP, Rt Hon Norman Lamb MP, Dr Daniel Poulter MP, Rt Hon Alistair Burt

MP, Rt Hon Ben Gummer MP and George Freeman MP (jointly with the Department for Business, Innovation and Skills). In addition, The Rt Hon the Earl Howe and The Lord Prior of Brampton held ministerial posts.

Please identify by name senior civil servant colleagues involved (during the times you worked at the Department of Health) in decisions about blood and blood products, and in relation to financial support for those infected with hepatitis C and HIV via NHS treatment, and who were involved with advising you as a minister.

5. The senior civil servant colleagues involved (during the time I worked at the Department of Health) in decisions about blood and blood products, and in relation to financial support for those infected with hepatitis C and HIV via NHS treatment, and who were involved with advising me as a minister included Dr Ailsa Wright, Dr Rowena Jecock, Donna McInnes and Kypros Menicou.

Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

6. I have no membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference.

The Inquiry understands that you ceased to be the Parliamentary Under Secretary of State for Public Health in July 2016. Have you undertaken any work (whether paid or voluntary) relevant to the Inquiry's Terms of Reference since then? If so, please describe it.

7. I have undertaken no work (paid or voluntary) relevant to the Inquiry's Terms of Reference since July 2016.

Please confirm whether you 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 ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports which you provided.

8. I have not provided evidence to, or been involved in, any other inquiries, investigations or criminal or civil litigation in relation to the conditions cited in question 8.

Section 2: The role as Parliamentary Under-Secretary of State for Public Health in relation to the AHOs

Please explain, in as much detail as you are able to, your role and responsibilities as Parliamentary Under Secretary of State for Public Health ("PUSSPH") insofar as both may have concerned matters to which the Inquiry relates?

9. I had ministerial responsibility for the policy areas germane to this Inquiry, including the structure and scope of the financial support schemes. The day-to-day responsibility for the administration of the schemes rested with the Alliance House Organisations ("AHOs"), which were operationally independent of the Department. In regard to matters to which the Inquiry relates, I would reply to correspondence, respond to written and oral Parliamentary questions, lead and respond to Parliamentary debates and undertake relevant meetings with ministerial colleagues, Members of Parliament, policy officials and others as relevant.

Please explain the involvement you had with the Alliance House Organisations ("AHO") in your role as PUSSPH.

10. I replied to correspondence about the work of the AHOs, responded to Parliamentary questions and debates in which their operations were referred

to and discussed their work with officials in relation to the working of the financial support schemes and the extent to which they were meeting the needs of beneficiaries. The Department provided their funding so I was also involved in discussions in the context of the Department's budget.

How frequently did you and the Minister of State for Health meet with the chair and trustees of the AHOs? How did such meetings come about? Were minutes kept? The Inquiry has been unable to locate minutes of some of these meetings (for example the meeting on 4 November 2014 between MFT and a Department of Health Minister). Do you have any information that may assist with locating them?

11. I do not believe I met with the chair and trustees of all the AHOs although I did meet with Chris Pond, Chair of the Caxton Foundation. I also met with Ann Lloyd and with the chairs of the Eileen and Macfarlane Trust as described in paragraph 22. I corresponded with others. Given I had no day-to-day operational responsibility for the support schemes, meetings were *ad hoc* and in relation to the proposed policy reform of the support schemes. The relationship was different than that for bodies listed in paragraph 3 for which I was a ministerial sponsor.

How would you describe the working relationship between the AHOs and the Department of Health during your time there? In particular:

12. The working relationship between the AHOs and the Department of Health seemed to me fairly business like, albeit quite familiar which did not surprise me given the length of time some officials had been in post and the nature of the financial relationship.

a. Did you consider the AHO's to be independent of the Government?

I did consider the AHOs to be operationally independent of the Government but clearly not financially independent.

b. Was it acceptable to the Department of Health for the AHOs to campaign/lobby for a change in government policy to benefit its beneficiaries?

I do not recall thinking it was either acceptable or unacceptable for the AHOs to campaign or lobby for a change in government policy to benefit its beneficiaries, but to the extent it was surprising it just reflected the complicated and unclear nature of their role and mandate.

c. Would you agree or disagree with the description in the APPG report dated January 2015, that the relationship between the AHOs and the Department of Health was cosy? ([RLIT0000031] p.80-92; [MACF0000045_002] p.9).

Based on my own experience, I would disagree with the description of the relationship between the AHOs and the Department of Health as 'cosy' because that evokes a degree of friendliness and warmth that I never perceived but I would characterise the relationship as familiar for the reasons I explain above. If the concern behind the description is of inappropriate closeness, this is not something I perceived.

Contact with and knowledge of the beneficiary community

What contact did you and others in ministerial positions at the Department of Health (in so far as you are aware) have with the beneficiaries of the AHO's? Please include any formal forums for contact between the Department of Health and those communities, and any ad hoc contact that you had. You may find [WITN1056138] helpful.

13. I met with some beneficiaries of the AHOs, both in my capacity as a minister and as a constituency MP. I believe the latter was true of other ministers who were also Members of Parliament. In addition, I corresponded with many beneficiaries and with their Members of Parliament. I know the Rt Hon Jeremy Hunt MP met beneficiaries, having been present at, at least, one meeting and I know the Rt Hon Alistair Burt MP met beneficiaries, again, having been present at, at least, one meeting (the meeting with the Prime Minister in

January 2016). I was aware from conversations with Alistair Burt that he had more extensive contact with beneficiaries as he had campaigned over an extended period of time on the issue. This might be true of other ministers, but I do not know. I did not meet with beneficiaries through any formal forum, although I did meet the Chair and other members of the APPG fairly regularly.

How regularly did beneficiaries copy you into correspondence with the AHOs? [CAXT0000101_011; WITN2050102].

14. My recollection is that beneficiaries copied me into correspondence with the AHOs from time to time but not frequently. Members of Parliament when writing to me about issues of concern would more often refer to correspondence between beneficiaries and the AHOs.

What action did you take after being copied into correspondence between beneficiaries and the AHOs? Did you ever escalate concerns raised by beneficiaries to colleagues or raise the issue with the AHOs?

15. If specific allegations of impropriety were made about the AHOs in correspondence I would have raised it with officials and asked for further information to inform any follow up action. My recollection is that most of the correspondence I was copied into referred to complaints about unsatisfactory interactions with senior leadership of some AHOs or general quality of service. I did escalate these concerns to the Secretary of State in the context of discussing the need we perceived for reform of the support schemes and raised them on at least one occasion with a chief executive of an AHO.

Did this type of correspondence leave you with an impression as to the effectiveness of the AHOs? Please explain your answer.

16. This type of correspondence left me with the impression that there was an inconsistent quality of effective support for beneficiaries, with some AHOs generating more negative comment than others. It is also fair to say, having been a retail customer communications manager for some years in my career

prior to entering Parliament, that I was aware that those satisfied with their experience tend not to correspond about it. Nevertheless, it was a concern.

Your predecessor, Anna Soubry MP, met with experts and campaigners to discuss the financial support schemes for those infected with hepatitis C, in November 2012 [HSOC0029810]. Did you set up and attend similar meetings when you assumed the role? Please provide details of meetings you attended relating to the Inquiry's Terms of Reference.

17. I did not set up and attend meetings similar to those attended by Anna Soubry MP in November 2012 when I assumed the role of PUSSPH.

During your time at the Department of Health, what was your knowledge and understanding of the needs of the beneficiaries of the AHOs? What were the sources of that knowledge and understanding? You may find [CABO0000165_003] of assistance.

18. During my time at the department my knowledge and understanding of the needs of the beneficiaries of the AHOs was informed by the extensive Parliamentary and other engagement described in paragraphs 9, 10 and 13. I read all incoming individual correspondence to which I subsequently replied as minister and also read many of the individual beneficiary replies to the Department of Health consultation on the reform to the financial support schemes. Insights provided by the staff members of the AHOs who dealt with beneficiaries, in some cases over many years, were also helpful.

Were you aware of any tensions between the beneficiary community and any of the AHO's? If so:

- a. How did you become aware of this?
- b. What if anything did you or to your knowledge, the Department do about it?
- c. How did you consider these tensions impacted on the ability of the AHOs to discharge their role?

19. I was aware of tensions between the beneficiary community and some of the AHOs from correspondence, both direct and with MPs, from Parliamentary debates and from conversations with MPs and the APPG. If a specific issue was raised that related to the senior management of the AHOs my recollection is that officials would raise it with the individual or Chair of Trustees. More generally the tensions contributed to the imperative, as I saw it, to try to reform the schemes, as clearly these tensions were bound to have an impact on the ability of the AHOs to discharge their role.

Effectiveness of the AHOs

When you assumed the role of PUSSPH, were you aware of the concerns your predecessor had about the Caxton Foundation? [HSOC0029810].

20. When I assumed the office of PUSSPH I was not aware of the concerns my predecessor had about the Caxton Foundation. In the course of answering correspondence and preparing for debates, I probably became aware of them.

Did you form an opinion about the effectiveness of the Caxton Foundation following your attendance at a Westminster Hall debate on 5 November 2013, whereby the Caxton Foundation was heavily criticised? [CAXT0000110_063]. What was the nature of the criticism levied against the MFT and CF?

21. The Westminster Hall debate on Hepatitis C (Haemophiliacs) on 29 October 2013 was less than a month after I assumed the office of PUSSPH and, given the criticism voiced during the debate, it did give me cause for concern about the effectiveness of the Caxton Foundation. However, I was also aware that I could not at that early stage have a fully informed view. The Skipton Fund and McFarlane Trust were also mentioned during the debate. The nature of the criticism largely related to complaints that the beneficiaries did not find organisations responsive to their individual needs.

Did you meet with Ann Lloyd following her letter of 12 May 2014 [AHOH0000053] to discuss the progress made by the Caxton Foundation to improve its effectiveness?

22. I cannot recall if I met with Ann Lloyd in the circumstances described. The letter the Inquiry has referred me to appears to be sent by way of an update and a meeting wasn't requested. I did meet with Ann Lloyd together with the chairs of the Eileen and Macfarlane Trusts on 4 November 2014 to discuss a plan for reforming contaminated blood payment schemes [WITN3904021].

Did you take any action or escalate the issue upon receiving a letter [WITN5594002] from MFT beneficiaries declaring no confidence in the Trust in 2014? If so, what action? If not, why not?

23. I cannot recall the specific action I took upon receiving the letter from MFT beneficiaries declaring no confidence in the Trust in 2014. However, based on my general approach as a minister I would have regarded such a matter as serious and would have asked my private office to ensure officials looked into the matter and report back to me. I was by this point in my tenure increasingly aware of the generally unsatisfactory nature of some of these relationships and so was sensitive to such complaints, reinforcing, as they did, my feeling that scheme reform was needed.

Did you take any action or escalate the issue upon receiving a letter [WITN1122048] from Elizabeth Boyd and Russell Mishcon raising concerns about the way the MFT was being administered by its chairman and chief executive? If so, what action? If not, why not?

24. I do remember receiving the letter from Elizabeth Boyd and Russell Mishcon raising concerns about the way the MFT was being administered by its chairman and chief executive. I did escalate the issue, raising it and discussing it with officials, but I cannot recall the specific action I took.

Did you discuss the contents of the letter from Elizabeth Boyd and Russell Mischon on 12 February 2014 [WITN1122048] with the Health Minister, Jeremy Hunt MP, or any other concerned parties? If so, what was the nature and outcome of the conversation, and if not, why not?

25. Given the serious nature of the contents, it is likely that I would have discussed the letter from Elizabeth Boyd and Russell Mischon with the Secretary of State during one of my regular meetings about issues within my portfolio, but I cannot be certain. This was an area in which the Secretary of State took a particular personal interest and more generally we discussed the issues raised about the AHOs and the dissatisfaction expressed through various channels. This contributed to the decision to make reform of the payment schemes a priority for the department.

How much oversight did the Department of Health have? Did it have the remit to intervene if concerns were raised about the effectiveness of the AHOs?

26. My view was that the Department of Health had strategic oversight but not day to day operational oversight. Given that the department set up and funded the schemes, and that ministers were held to account in Parliament for their operational or structural shortcomings, there had to be a remit to intervene if concerns were raised about the overall effectiveness of the AHOs.

How much oversight did the Department of Health have? Did it have the remit to intervene if concerns were raised about the effectiveness of the AHOs?

27. This question is repeated from 26.

Funding of the AHOs

Please set out the process by which the Department of Health provided funding to the AHOs and your role in that process (and whether your role changed over time).

28. The Department of Health allocated funding to the AHOs as part of the annual departmental budgeting process and I would discuss this with officials in the context of broader discussions about allocations to different priorities in my section of the budget. I would then make a recommendation to the Secretary

of State, who would review it and discuss anything he had queries about before agreeing it as part of the overall Department of Health package.

- a. Please explain the annual 'top-up' funding process.

I cannot recall the specifics of the annual top-up funding process.

- b. The Inquiry has heard evidence that the Department of Health was very slow to inform the AHO's of their annual allocation (see for example [MACF0000060_016]). What was the cause of this? What steps, if any, did you take to try and remedy this?

I cannot recall a specific reason that the department might have been slow to inform the AHOs of their annual allocation and I do not recall any steps I took to remedy it; it would have depended on whether I was aware and if the reasons for the delay were avoidable or not. I would note that agreeing budgets was generally challenging during this period, with many difficult choices.

Did the process by which the Department of Health allocated funding to the AHOs change over the time you were involved? If so, how? Were there problems with this process?

29. I cannot recall if the process changed whilst I was involved but from the time it was decided to try to reform the schemes, this was an additional factor in all considerations of the issue, as was the long pending Penrose report.

How did the Department of Health set the budget for the AHO's more generally? Did you have any input into this process?

30. My recollection is that the budget for the AHOs was set using actuarial considerations, recent budget history and having regard to any new factors. My involvement was towards the end of the process when I would look at the

figures in the context of the budget lines within my areas of responsibility, as described in paragraph 28.

The Inquiry has heard that the funding for the AHO's may have come out of a different pot of money to the NHS allocation. Is that correct? Please give details.

31. The funding for the AHOs came out of the part of the department's budget that was not the protected NHS allocation. The budget I oversaw was non-NHS covering the breadth of the public health portfolio.

During your tenure the Department of Health received several submissions from the AHO's (and in particular from the Macfarlane Trust) to increase their allocation. See for example:

- (a) The request made to increase the allocation for Macfarlane Trust for the year 2014/2015 from £2.2 million to £3.2 million (referred to in the draft letter from Roger Evans to Rowena Jecock at [MACF0000026_088] and the MFT annual report at [MACF0000026_058]. The response is at [MACF0000062_001].
- (b) A request was made by the Caxton Foundation to increase its allocation for the year 2014/15 [AHOH0000001] which was turned down by the Department of Health in February 2014 [CAXT0000110_089].
- (c) A request made for the year 2015/2016 [MACF0000061_067] to increase the allocation for the Macfarlane Trust in light of the shortfall of £800,000 per annum. You may also find [MACF0000061_066] of assistance.

How were these submissions received? In particular:

- (i) Which of these submissions for increased funding were escalated to you or the Secretary of State for Health? What was the criteria for escalation?
- (ii) Did the Department of Health take account of the representations made by the relevant AHO? If so, what was the process by which this was done?
- (iii) The AHOs had very limited success in increasing their allocation. In your view was there anything the AHOs failed to show when persuading the Department of Health to increase their allocation?
- (iv) Were the AHOs' failures to ensure an increased allocation related to budgetary constraints at the time?

- (v) Who had the final say on whether or not to increase the allocation?

32. I do not recall which of the specific submissions from the AHOs concerning an increase in their allocation were escalated to me or to the Secretary of State, but I do recall being made aware of important correspondence on the subject, and indeed discussions during regular policy meetings with officials on this issue. Decisions at that time not to make significant changes to the existing financial support schemes were influenced by two overriding factors; firstly, the fact that given the feedback from the infected and affected and from their Members of Parliament, we had decided to look in detail at the options for reform of the financial support schemes. This tended to make us cautious when considering the case for any substantive change to the existing individual schemes. Secondly, the pending Penrose report which loomed large over all our deliberations. As I told the House of Commons in January 2015, when I came into office, I was advised that the original date for publication of the Penrose report would be June 2014. The publication of the final report was then delayed and, in the end, only published in March 2015, on one of the last sitting days of the 2010-15 Parliament. Our understanding was that Lord Penrose would examine any adverse consequences for infected patients and their families and identify lessons and implications for the future. Given that the events under discussion took place before devolution, though frustrating, it therefore seemed important to wait and have regard to the report, and any recommendations it might make, in developing policy on reforming the ex-gratia financial assistance schemes. This was a view also expressed by Members of Parliament and shadow ministers at various points.

Why was the Caxton Foundation business case turned down in February 2014, [CAXT0000110_089]? Were the concerns raised by Russell Mishcon and Elizabeth Boyd in [WITN1122048] about the Department of Health's ambition to achieve parity between the CF and MFT considered in the decision to turn down the Caxton Foundation's business case?

33. The two overriding considerations described in paragraph 32 above are relevant here and the consideration of the case for substantive change to any of the existing individual schemes should be seen in this context. Concerns raised about any of the AHOs, from any perspective, rather reinforced the case for looking closely at reform options.

Why did the Department of Health refuse to increase the budget of the Caxton Foundation in 2015 in light of the sudden increase in beneficiary numbers by 50%? You may find [CAXT0000035_078] of assistance.

34. At that time, together with officials, I was likely to have weighed in the balance whether any money available for the financial support schemes would be better directed into a reformed scheme. One policy option being looked at actively, and supported by the APPG report for example, was to reduce the fragmentation of the schemes and therefore the overheads and administration costs. In principle, any additional budget would be of greater benefit to more beneficiaries in these circumstances. There was never any question that new beneficiaries would not be covered by a financial support scheme.

The Inquiry has heard evidence from both Macfarlane Trust and Caxton Foundation witnesses, that in their view, both charities were underfunded. When did you first become aware that this was the view of the trustees? You may find [MACF0000061_053] and [MACF0000045_004] of assistance.

35. In broad terms, I was aware that both the Macfarlane Trust and the Caxton Foundation thought they were underfunded but I cannot be certain when I became aware this was the view of the Trustees.

Do you agree that the MFT and the CF were underfunded? If not, why not? If so, why was this?

36. If underfunded in this context means that the MFT and CF were unable to fulfil their financial responsibilities for regular payments to beneficiaries, I did not hold the view that they were underfunded. With regard to increasing the

amount available for discretionary payments or for scheme reforms mooted by AHOs, as stated above, from the time early in my tenure when it was decided to look at wider reform of the financial support schemes, my general approach as a minister was cautious. All funds would come from the public purse, and we were in a financially constrained situation, but I was also conscious that any meaningful reform was likely to need additional resource.

What did you understand the £25 million announced by David Cameron on 25 March 2015 to be for? In particular was it the intention of the Government that it would be spent in 2015-2016? Was it in fact spent then? If not, why not? When was it allocated and to what?

37. On 25 March 2015, David Cameron announced an additional one-off amount from the Department of Health 2015-16 budget of up to £25 million to support any transition to a different system of financial assistance. The announcement was intended to provide an assurance for those who have been affected that we had heard their concerns and were making provision to reform the system. The Department of Health identified £100 million from its budget for the proposals in the scheme reform consultation, announced when the consultation was launched. That was in addition to the current spending on the schemes and the £25 million announced in March 2015.

Section 3: Reform of the Payment Schemes

How much input did you have in the ministerial response to the Penrose Inquiry? You may find [CABO0000163_003] of assistance

38. As the responsible minister I would have been closely involved in reviewing a draft of the interim ministerial response to the Penrose Inquiry for consideration by the Secretary of State.

Please refer to pages 26 - 30 of [WITN1369023]. Why did the Government not make a formal, full response to the Penrose Inquiry, after indicating in March 2015 that it intended to do so?

39. With no time to consider the Penrose report, as it was released in the last few sitting days of that Parliament, the interim response had to be given before the very long report could be considered in detail. My recollection is that there was genuine surprise amongst officials, ministers and indeed shadow ministers that the Penrose report made only one recommendation. There was a new Government after the 2015 General Election - although some like me, retained the same post. Given there was only one Penrose recommendation, which ministers confirmed to Parliament they had responded to, I recall, on a personal level, feeling that I would rather focus on trying to make up for the previous delays by moving forward the consultation on scheme reform. I wanted to see meaningful, short-term change for the beneficiaries of the support schemes.

Please refer to your comment from 22 January 2016, on page 29 of [WITN1369023]. If the Penrose Inquiry had been sufficiently thorough as to negate the need for an inquiry in England, why did the Government in England not make a formal, full response to the Penrose Inquiry? (See also [WITN1056153]).

40. I cannot recall having any specific conversations about whether or not the new Government should or should not make a formal, full response to the Penrose Inquiry. I do not believe the Scottish Government made a response to the Inquiry they initiated which is also likely to have shaped our thinking.

What led to the announcement of the public consultation on the reform plans on 16 December 2015?

41. My view as the lead minister was that there was a strong case for reform and all the correspondence with the infected and affected, the Parliamentary debates and questions, and meetings with the colleagues and the APPG over the previous two years had reinforced this view. We had now had sight of the

Penrose report; the new funding announced before the Election was still available to support any transition to a different system of financial assistance; and the new government's policy remained consistent with the previous government. Therefore, the department could move ahead with its intended plan to prepare and announce a public consultation on the reform plans.

What if any input did you have into the Department's consultation on the AHOs?
[WITN3904006].

42. The consultation on the proposals on the scheme reform was a priority for me and as such I had regular discussions with policy officials and engaged actively on the design of the consultation itself.

How were the devolved administrations involved in the production of the consultation document?

43. I cannot recall any details regarding how the devolved administrations were involved in the production of the consultation document. Officials reported that they had regular meetings with the devolved administrations in relation to the working of the financial support schemes and I probably thought at the time that this would be the channel through which the devolved administrations would be engaged, as appropriate, on the consultation.

Please refer to pages 45 - 50 of [WITN1369023], concerning criticism made by TaintedBlood about the consultation.

a. Why was no reference made to the Scottish proposals on financial scheme reform within the consultation?

44. At the time the Department of Health published the consultation some proposals had been put forward by a reference group set up by the Scottish government, but the Scottish government had not yet responded to them, so they were not formal government proposals.

- b. Do you consider that enough was done to involve campaigners and infected/affected individuals in the consultation? [WITN1056150]
- c. Do you think enough was done to raise awareness about the consultation and include members of the infected/affected community about its creation, wording and points of focus? [WITN1056153]

I do consider that a great deal was done to involve the infected/affected individuals in the consultation and indeed every aspect of the consultation was informed by every letter, email, debate, urgent question and relevant conversation of the preceding two years. The consultation was, however, clear with regards to its scope being limited to the potential reform of the financial support schemes and this meant it inevitably disappointed those campaigning for a more far-reaching response covering, for example, compensation and the call for an inquiry.

- d. Why was the Reference Group meeting on 5 October 2015 ([WITN1369023], page 46) [WITN3904006] not attended by a Department of Health official?

We appointed an independent facilitator to chair a meeting with representatives from some of the main campaign groups. This took place on 5 October 2015. The purpose of the meeting was to hear the views of some of those affected in preparation for the formal consultation process. The Haemophilia Society, Tainted Blood and the Contaminated Blood Campaign were each invited to nominate five delegates in order to provide an opinion on seven different affected categories. As I recall, the feeling was that the use of an independent facilitator might help to focus the conversation on the specific subject of this consultation; the presence of officials would be more likely to stimulate a wider conversation.

- e. Do you have figures relating to the “considerable difference” between what was identified as being necessary by the attendees of the Reference Group meeting, and what was deemed affordable within the proposed new scheme, as set out in the preamble to the consultation? [WITN3904006].

Regarding the affordability of the new scheme, at that time as a junior minister I knew the following: the money would come from the Department of Health budget, we had identified an additional £100 million over the spending review period, this was in addition to the £25 million announced in March 2015. The projected future spend at that time was £570 million. The report of the meeting of the reference group referred, for example, to requests to compensate those infected/affected for lost earnings over a lifetime and to paying off mortgages, as well as referring to compensation. I cannot recall if these proposals were costed (similar proposals had been costed in the past I believe) but they are self-evidently major costs and set alongside the groups' desire to see the continuation of the financial support schemes, they would be additional costs. I therefore think the observation made in the preamble was reasonable.

- f. Why was the consultation questionnaire open to anyone to complete, instead of targeted at the small number of people personally infected or affected by NHS blood products?

The consultation was targeted at the small number of people personally infected or affected by NHS blood products; however, had it been limited only to those known to one of the AHOs it would have excluded those infected or affected in that category who for whatever reason were not registered or had never made themselves known to a campaign group. We knew there were people in this category as most months new beneficiaries came forward for the first time. The question was raised as to why MPs, for example, could complete the survey. Many colleagues had deep insight into, and interest in, the issue, and were also speaking out on behalf of people who did not feel able to raise their own voice. There was no reason to think large numbers of people with no interest in this matter would take part in the consultation, and experience bore this out.

- g. Was any form of weighting employed in the analysis of the questionnaire responses to reflect the views of those directly affected by the new proposals?

The overwhelming majority of respondents to the consultation were those directly affected by the new proposals; but had, unexpectedly, there been a large number of respondents who were not relevant to the consultation more regard would certainly have been given to the views of those directly affected.

h. Do you think the consultation adequately considered the special circumstances of haemophiliacs, as raised by TaintedBlood ([WITN1369023], p.48) and the former trustees of the MFT? [WITN1122048].

I was aware when I launched the consultation, that there might be circumstances which we had not made allowance for and this was the purpose of the open questions in the document. I never thought that we would be able to anticipate all the different personal circumstances of those infected and affected. We expected that the consultation would reveal any unintended consequences of the proposed reforms and would provide an opportunity for these to be addressed before the scheme was finalised. In my interactions with Parliamentarians representing their constituents I stressed the open nature of the consultation and the need to respond to the exercise with a level of detail that would allow amendments to be considered and effected. The consultation was genuine, as evidenced by the fact that changes were made to the initial proposals.

Do you hold a copy of the letter sent to you on 19 February 2016 by TaintedBlood (mentioned in [WITN1369023], p.50) setting out their concerns about the consultation? If so, please provide it to the Inquiry.

45. I hold no correspondence or other documents relevant to the matters to which the Inquiry relates.

Please refer to [MACF0000022_091].

a. What steps were taken to inform the Macfarlane Trust of the purpose of the review, and the Government's perception of the viable options which could follow the consultation process?

46. I cannot recall the steps taken to inform the Macfarlane Trust of the purpose of the review, it is likely that officials took the lead on this activity.

b. Do you think trustees and employees of the financial schemes could have been engaged in the process at an earlier stage? If not, why?

It might have been possible to engage trustees and employees of the financial schemes at an earlier stage but there were difficult judgments to be made at the time, not least because of the complex and sometimes contentious relationships between the AHOs and beneficiaries.

c. Was the APPG involved in formulating the questions asked in the consultation?

I do not think the APPG was involved in formulating the questions asked in the consultation although, clearly, the views of the MPs involved in the APPG, expressed directly to me and in debates helped inform the Department's perspective.

Please refer to [WITN3953052]. To what extent were the consultation responses used to inform the development of the reformed payment schemes?

47. The consultation responses were very much used to inform the development of the reformed payment schemes. A specific team in the Department was established to ensure that every response was read in full and captured in the analysis. I believe that I read a good many responses myself in addition to reading the summaries prepared by officials.

Do you hold a copy of the response you sent to Diana Johnson MP's letter to you on 3 February 2016? [WITN1056152]. The Inquiry has been unable to locate it. If so, please provide it to the Inquiry.

48. I do not hold a copy of such a response to Diana Johnson MP's letter to me on 3 February 2016. I hold no correspondence or other documents relevant to the matters to which the Inquiry relates.

Please refer to [CABO0000165_003]. Was your suggestion to focus payments on those infected and focus lump sum payments on bereaved relatives so that they exit the scheme, consulted on by the beneficiary community and AHOs? How were the amount of lump sum payments to bereaved relatives to be determined?

49. The proposal to focus ongoing payments on the infected and offer lump sum payments to bereaved relatives was consulted on as part of the department's consultation. Considering the criticism of the discretionary nature of funds available to bereaved relatives - which resulted in a very wide range of payment amounts - we wanted to explore if the certainty of a lump sum was considered preferable and more equitable by relatives. The consultation was very open on this point however, asking respondents whether they preferred to retain access to discretionary funds or accept a lump sum, or indeed have the choice between the two.

Given the additional resources identified to support the reform of the payment schemes, we needed to make difficult but rational choices; my recollection is that the amount of the lump sums was closely related to the payments that the infected individual had been receiving as income. We had to balance what could be made available to bereaved relatives against what we could offer to those who were infected; our priority was to focus available resources on supporting those who were infected, and we had to work within the budget we were given [WITN3904061 - WITN3904063]. The options considered were largely dependent on the budget available [WITN3904010]. It is perhaps also worth noting that the intention was that these payments would not be means tested and would be in addition to any other financial benefits available to individuals through the social security system.

The response to your suggestion in the previous question was considered by beneficiaries in the consultation ([WITN3953052], p.13), whereby the overwhelming majority of respondents wanted a choice between ongoing payments and a lump sum payment for bereaved partners. Was this response adequately reflected by the Government in the development of the reformed schemes?

50. The principle of choice was an important one guiding the consultation. Much of the correspondence I had received from beneficiaries had stressed how demeaning it was for them to have no choices. We made a number of changes to our initial proposals after the feedback received in the consultation.

On 17 April 2015, a UK Health Departments Infected Blood Payments Scheme Reform meeting took place [WITN4688017] at which the Health Departments stated their desire for parity between the administrations in respect of any reformed scheme. Was this what the departments were working towards by the time your tenure as PUSSPH ended, or had they already moved away from this as a principle?

51. It was clearly desirable to strive for parity between the administrations, mainly because it was fairer to the beneficiaries. However, the administrations were all financially responsible for the beneficiaries who lived in their jurisdiction, and as such the department in England could not impose the principle of parity. As I recall Scotland preferred to make different choices on scheme reform and not be bound to England's direction of travel; this led to regular questioning of me in Parliament as to the respective merits of the schemes.

What measures were taken to work towards parity between the devolved administrations at the consultation stage? [DHNI0001460].

52. In relation to measures taken to work towards parity between the devolved administrations at the consultation state, officials would have discussed this with the devolved administrations at this time. However, I cannot recall what, if any, measures were taken. There was correspondence between myself and

ministers in the devolved administrations at various junctures as we did want to work together on it.

Please refer to [WITN4066020]. Why were the health departments in Scotland, Wales and Northern Ireland not made aware of the details of the reformed scheme prior to the publication of the response document [WITN3953052] in July 2016?

53. If it is the case that the health departments in Scotland, Wales and Northern Ireland were not made aware of the details of the reformed scheme prior to the publication of the response document in July 2016, I do not know why this was. Generally speaking, I recall a high level of awareness in this area of policy of the need to engage the devolved administrations.

Please refer to [CGRA0000792]. Did you personally raise the issue of the balance of spending between Government Departments, and exceptional spending made by the Treasury with the Prime Minister on occasions before or after Diana Johnson's letter on 28 September 2015?

54. I did not raise this personally, in any formal way with the Prime Minister, this would have been a matter for the Secretary of State to raise in the context of other discussions of the department's budget etc. As a junior minister my regular contacts were with policy staff and advisers to the Prime Minister and we did discuss funding of the schemes fairly regularly.

Please refer to [WITN4066020]. After the Prime Minister announced £25 million to ease transition to the proposed reformed scheme in March 2015, why wasn't any information provided to the devolved administrations about how this money was intended to be used?

55. If it is the case that no information was provided to the devolved administrations about how the £25 million was intended to be used, I do not know why. The Prime Minister, and the Secretary of State in a Statement on 25 March 2015 were quite clear however that the money was to ease transition to the proposed reformed scheme. I also understand that

departmental officials kept officials at each of the devolved administrations up to date on the reform generally. In respect of the £25 million, as of June 2015, the precise way in which this would be used had not yet been decided and this was confirmed by departmental officials at a meeting held between the four UK health departments on 10 June 2015 [WITN3904027]. On 17 July 2015, correspondence was circulated by my office to the health departments in Scotland, Wales and Northern Ireland explaining that there would be a delay to the consultation on scheme reform. This also enclosed a copy of a Written Ministerial Statement which suggested that in relation to the £25 million to be allocated to ease transition 'no decisions have yet been made on how this money will be spent' and 'it will be used appropriately to support any transitional arrangements once we have consulted on how a new scheme might be structured' [WITN3904034 - WITN3904038]. As set out below in my response to question 57, the department sought to keep the devolved administrations updated on the progress of the consultation and proposed reform.

When the Department of Health announced a further £100 million from its budget for the proposals in the consultation for beneficiaries in England, why were the health departments in the devolved administrations not given prior notice about the funding announcement? [DHNI0001449].

56. I announced the further £100 million during my statement to the House of Commons on 21 January 2016, as part of the launch of the consultation. As I stated in Parliament, we offered the opportunity of a call with other ministers that morning and I spoke with the Scottish minister Shona Robison that morning; a senior official from the Welsh health department was on the call too. I cannot recall the detail of the call but I have seen a briefing note which suggests that the intention was for me to speak about the commitment of £100m for this spending review period on top of the current budget. [WITN3904059 and WITN3904060].

How was a resolution found to the issues set out in [DHNI0000682] concerning devolution and the competencies of the Secretary of State to set up and pay for payment schemes outside of England?

57. I cannot recall the detail of this issue but I have seen documentation which suggests that the Department of Health was advised in 2014 that the setting up of schemes to make ex-gratia payments to people infected with HIV is a function which had been devolved. Therefore, the advice was that it was up to each of the devolved administrations to decide how to approach this issue as the Secretary of State did not have the power to set up schemes or make such payments in relation to those infected outside of England (see submission at [WITN3904015 and WITN3904016]).

The advice given was that if we wished for schemes to progress on a UK-wide basis, then the department could administer these on behalf of the devolved administrations, but we would need agreement from the devolved administrations. I duly wrote to each of the devolved administrations in June 2014 indicating that we intended to consider reform and expressing a desire to work together [WITN3904011 - WITN3904014]. This suggestion was met positively by each of the devolved administrations, who in principle agreed to a UK-wide consultation [WITN3904022 - WITN3904026].

This advice further indicated that the responsibility for funding any new schemes would lie with each of the devolved administrations. It was acknowledged that this would result in a change from the existing schemes whereby England funded the HIV schemes as they had been set up prior to devolution. The hepatitis C schemes were at the time funded by the department, but the costs recouped from each of the devolved administrations [WITN3904064].

With regards to the increase in winter fuel payment suggested to you by Shona Robinson, how was parity between the devolved administrations, and equality between the Skipton Fund and Caxton Foundation, and MFET registrants achieved? [DHNI0000770; DHNI0000682].

58. With regard to the issue of the increase in winter fuel payments, I cannot recall the detail of this issue but there is some documentation relating to this. After I received Shona Robison's letter, I requested more information about how much additional funding would be needed [WITN3904042 - WITN3904046]. My office also asked for consideration to be given to payments to beneficiaries of the other payment schemes in addition to the Caxton Foundation [WITN3904039 - WITN3904041]. I can see that I expressed support for a one-off payment of £500.00 to all scheme beneficiaries in England in recognition of the delay in scheme reform [WITN3904052 - WITN3904056]. I was again advised that as these payments related to a devolved issue, the Secretary of State could only make decisions in respect of England. Agreement therefore needed to be sought from the devolved administrations to ensure parity across each of the countries [WITN3904047 - WITN3904051]. I can see that departmental officials liaised with the devolved administrations on this topic. Welsh and Irish officials were written to in November 2015 and asked what their position would be in respect of these payments [WITN3904057 and WITN3904058] and a meeting was held on 16 November 2015. [WITN3904057 and WITN3904058].

Do you consider that there was sufficient communication between the health departments of the four UK nations in regards to the issues of reform of the financial schemes, parity and funding? [WITN4066020].

59. In relation to communication between the health departments of the four nations regarding financial schemes, parity and funding, I understood there to be regular communications at official level between the health departments, which seemed to function well in the period of policy development. I understand that the idea was for there to be weekly meetings between departmental officials and officials of the devolved administrations to discuss scheme reform [WITN3904017 - WITN3904020]. I'm not sure if these meetings were in fact that regular, but there is various correspondence suggesting that there were frequent meetings about this. I also wrote to my counterparts at key times during the process of reform.

My initial desire was for all nations to work together to bring about UK-wide reform [WITN3904011 - WITN3904014]. However, as this was a devolved issue the department could not make the devolved nations take the same approach as England. Scotland decided that they did not want to participate in the consultation and they would undertake their own review [WITN3904028 - WITN3904033]. I expressed disappointment about this, and a desire to continue to work with Wales and Northern Ireland so that the consultation could be issued on a three-country basis [WITN3904011 - WITN3904014].

On 17 July 2015, correspondence was circulated by my office to various interested parties, including the devolved administrations, confirming a delay to the consultation on scheme reform [WITN3904034]. However, Department of Health officials continued to work with their counterparts in the devolved administration in respect of reform. In my experience, not just on this issue, the tight deadlines associated with preparing and then getting clearance for a Ministerial statement, especially if sensitive, did result in courtesies that should have been extended to colleagues in other administrations (or sometimes other departments) being occasionally overlooked. I wrote to apologise for this on at least one occasion when the government response to the consultation on scheme reform had been published. I also offered to discuss the details of the reform and noted that 'I know our officials have been working together over the past few months, so I presume you were made aware of the direction of travel as the new scheme was developed' [WITN3904072 - WITN3904075].

Scotland ultimately decided to embark on its own system of reform which was announced in March 2016. It seems that as of July 2016, Wales and Northern Ireland were yet to confirm whether they would adopt the same reforms as England, but departmental officials continued to work closely with their counterparts in the devolved administrations to try to ensure that beneficiaries in all countries be treated fairly [WITN3904065 - WITN3904071]).

What were the justifications for combining the financial schemes into one single scheme? [EILN0000002_032].

60. As described earlier in my statement, there were regular complaints from individuals, campaigners and Members of Parliament about the fragmentation of the schemes, the associated complexity of navigation experienced by some beneficiaries, the heightened possibility of a potential beneficiary not being correctly signposted to a scheme, the variable quality of service provided and the characterisation of some of the support as charitable. The schemes had grown *ad hoc*, and for all these reasons the time seemed right to seek to simplify and streamline the financial support schemes. It was also felt that if, through a reorganisation to a single scheme, we could reduce overheads then more money became available for disbursement to beneficiaries.

What if any input did you have in the Infected Blood Reference Group?

61. Regarding the Reference Group on Infected Blood, I agreed to the appointment of an independent facilitator to chair a meeting with representatives from some of the main campaign groups. This took place on 5 October 2015. The purpose of the meeting was to hear the views of some of those affected in preparation for the formal consultation process. The Haemophilia Society, Tainted Blood and the Contaminated Blood Campaign were each invited to nominate five delegates in order to provide an opinion on seven different affected categories. I read the subsequent report and considered this as part of the decision-making process at that time.

What view did the Department of Health take during your tenure as to whether the details of beneficiaries could be passed from the AHOs to the proposed new schemes? You may find [DHNI0000632] of assistance.

62. In relation to whether the details of beneficiaries could be passed from the AHOs to the proposed new schemes during my tenure, I do not recall the details of all the legal advice we received but the issue was carefully considered.

Section 4: Other

Did you consider the AHO's to be well run? Please give details.

63. As to whether not the AHOs were well run, I formed the impression that this was variable; some AHOs were better run than others, based on the feedback I received from individuals, campaigners and Members of Parliament.

Please provide any other information and or views you may have that is relevant to our Terms of Reference.

64. I was committed to consulting on the proposals for reform. I was always conscious that I wanted to ensure that the views of all of the affected individuals were taken into account and everyone would have the chance to meaningfully participate in the consultation. I met with members of the All-Party Parliamentary Group for Haemophilia and Contaminated blood on 5 November 2015 to update MPs on the consultation process. We also held a one-off meeting with staff from the payment schemes on 9 November 2015. I facilitated the meeting and its purpose was to obtain initial views from the staff involved in running the schemes in preparation for the formal consultation.

65. As I have said earlier in my statement, I did not have a meeting with representatives from the main campaign groups during my time as a minister. On reflection, I would now make a different judgment. In my first debate on the subject (Westminster Hall, 29 October 2013) specific reference was made to unsatisfactory previous ministerial meetings with campaigners and the APPG. It was suggested by some speakers that as a minister I should have such a meeting when I had something substantive to say about support for the infected and affected. Therefore, I judged that I should wait, and, in addition, be able to consider the recommendations of the Penrose Inquiry. When it became obvious that Penrose was significantly delayed, it would have been better to go ahead to meet directly with the campaign groups. Given my familiarity with some of their main campaign objectives, I did not have the ministerial authority to satisfy these. Nonetheless it would have been an

opportunity to hear their concerns in person and try to reassure with regard to those issues that were in my authority, such as the fact that the outcome of any consultation on scheme reform was not pre-determined by ministers.

66. Indeed, at the heart of the consultation was a genuine desire to address the differing individual needs of those infected and affected by infected blood. I was personally interested in hearing from those who were 'quiet' – not activists but nevertheless people who were financially stretched. I was also conscious that any financial support scheme would impact people differently, depending on their circumstances. I was particularly interested in how, through this reform of the scheme, we could increase access to the very effective new treatments for hepatitis becoming available through the NHS. I was disappointed that the NHS could not prioritise the victims of this tragedy but route of infection was not allowed to be taken into consideration.

67. In designing the revision of the support scheme which was consulted on for some months, those involved, including myself, sought to balance a number of complex factors. One in particular was how to weight support: some of the infected and affected might prefer larger shorter-term lump sums, others the security of smaller annual sums but guaranteed across a lifetime. The department wanted to provide, over a longer period of time, more money, in order to provide the infected and affected with a predictable income.

68. I never thought that we would be able to anticipate all the different personal circumstances of those infected and affected. We expected that the consultation would reveal any unintended consequences of the proposed reforms and would provide an opportunity for these to be addressed before the scheme was finalised.

69. In my interactions with Parliamentarians representing their constituents I stressed the open nature of the consultation and the need to respond to the exercise with a level of detail that would allow amendments to be considered and effected. In my capacity as a constituency MP I too had received representations from affected individuals.

70. The consultation was genuine, as evidenced by the fact that changes were made to the initial proposals. The final reforms are contained in the document entitled "Infected blood: Government Response to Consultation on Reform of Financial and Other Support", dated July 2016 [WITN3904006]. The document provides an explanation of how we ran the consultation exercise. In addition to the events that were held, we received 69 letters from individuals in relation to the consultation which we took into consideration.
71. We wrote to all 3,482 registrants of the existing schemes to make them aware of the consultation. We also wrote to the Members of Parliament who had raised the issue on behalf of their constituents over the year prior to the consultation. When the consultation closed on 15 April 2016, we had received 1,557 consultation responses to the 11 questions that set out our proposals. The questions and the responses are contained within [WITN3904006].
72. We considered the consultation responses carefully and analysed the pre-consultation evidence that had been collated before arriving at the package of reforms. We made a number of changes to our initial proposals. Annex A to Exhibit 6 is a flow chart that identifies 8 differing individual circumstances for beneficiaries under the scheme. It shows that in relation to each, the reformed scheme differs from the consultation proposal.
73. I note that the financial support scheme in operation today is close in nature to what was consulted on in 2016.
74. Notwithstanding the understandable frustration of campaigners, throughout my time in this ministerial role I endeavoured to improve the situation of those infected and affected, principally through reform to the financial support schemes, in the context and circumstances as described in this statement.

Statement of Truth

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

Signed

GRO-C

Dated

5.5.22