Witness Name: William Vineall
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Dated: 29 April 2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF WILLIAM VINEALL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 August 2020.

I, William Vineall, will say as follows: -

Section 1: Introduction

1. My name is William Vineall. My professional address is 39 Victoria Street, Westminster, London SW1H 0EU. My date of birth is GRO-C 1967.

2. I have been Director of NHS Quality, Safety and Investigations at the Department of Health and Social Care ("the Department") since 2016. Part of my role includes oversight of on-going inquiries or investigations pertaining to the responsibilities of the Department, not just restricted to current NHS issues. I am duly authorised to

make this statement on behalf of the Department. The contents of the statement are true to the best of my knowledge, information and belief.

3. The team in the Department that provides evidence and information to the Infected Blood Inquiry has sat within my Directorate since late 2018. Since early 2019 the team responsible for policy and governance of the England Infected Blood Support Scheme ("EIBSS") has sat within my directorate and so, from then, came within my area of responsibility. As such, I was not in post when EIBSS was established or for the first approximately 15 months afterwards. The Departmental officials in my team who now work on EIBSS were also not in post for much of the period of time that I am asked about. To a limited degree, I have been able to rely on the recollections of some individuals who previously worked in this area. But, for more historical information, this statement has largely relied on documents. My evidence on more recent events is compiled from documents and from information provided to me by officials currently working on EIBSS.

4. Where this statement has relied on documents, the majority of these documents are part of the Department's electronic records. It is therefore reliant on document searches carried out across IWS, the electronic database currently used by the Department. For reasons associated with the design of IWS as well as the volume of documents at play, general document searches on IWS or searches for batches of documents are very challenging to deal with and not very useful. In addition, broadly defined search terms will return much material that is irrelevant to the Inquiry. Because of this document searches have focused on specific issues raised in the Rule 9 request. Should the Inquiry require more information on any particular issue, then I and my team are happy to assist. Equally, should future searches identify further information relevant to the questions I am asked, I will update the Inquiry.

Section 1A: Overview of relationship between the Department, the NHS Business Services Authority and EIBSS

5. Before I answer the specific questions posed by the Inquiry, I would like to provide some background on the relationship between the Department, the NHS Business

Services Authority ("NHSBSA") and EIBSS. As the Inquiry is aware, NHSBSA administers EIBSS on behalf of the Department.

6. NHSBSA is an Arm's Length Body ("ALB") and Special Health Authority of the Department. An ALB is a specific category of public body (classified by the Cabinet Office) that delivers a public service, but is not a ministerial government department. ALBs operate with varying degrees of operational independence, and are generally not under day-to-day ministerial control. Government departments rely on ALBs to carry out a range of functions.

7. NHSBSA was established by the NHS Business Services Authority (Awdurdod Gwasanaethau Busnes y GIG) (Establishment and Constitution) Order 2005 under powers contained in the National Health Service Act 1977. The general function of NHSBSA is to provide a range of critical central services and, in particular, payment processing services to NHS organisations, NHS contractors, patients and the public (paragraph 2.1 of the Framework Agreement, referred to below). Other examples of NHSBSA's functions are managing the NHS Pension Scheme in England and Wales, making payments to pharmacists in England for prescriptions dispensed in primary care settings and managing the NHS Injury Benefit Scheme in England and Wales. Within NHSBSA's functions, administering EIBSS is only one part of NHSBSA's work.

8. The Department's relationship with the ALBs, including NHSBSA, should reflect an assessment of each ALB's ability to manage its risks, including those relating to performance and financial management. The Department's monitoring of, and support for, an ALB should be proportionate to such risks. The governance arrangements are set out in a Framework Agreement between the Department and NHSBSA (Exhibit WITN4688004). There are various 'levels' to the accountability relationship which I do not describe in detail. However, as set out in paragraph 4.1 of the Framework Agreement, the Secretary of State for Health and Social Care (the "SoS") is accountable to Parliament for the health and social care system, including NHSBSA. In addition, NHSBSA is accountable to Parliament, through the SoS, for the performance of all its functions, including EIBSS. Further, the Department and NHSBSA have agreed a set of shared principles to support partnership working, namely (paragraph 6.2 of the Framework Agreement):

a. Working together for patients, people who use services and the public, demonstrating commitment to the values of the NHS set out in its constitution;
b. Respecting the importance of autonomy throughout the system, and the freedom of individual organisations to exercise their functions in the way they consider most appropriate; and
c. Recognising that the SoS is ultimately accountable to Parliament and the public for the system overall. NHSBSA supports the Department in the discharge of its accountability duties, and the Department supports NHSBSA in the same way.

9. As the Inquiry is aware the system of providing financial and other support was the subject of public consultation in 2016 and 2017 (further details are contained in the draft witness statement of Donna McInnes. I understand that statement remains in draft and so references in this statement to Donna McInnes' statement relate to her draft statement. Should that draft need to be changed for any reason, this statement too may need to be updated). In this statement I will be referring to the following documents:
    a. "Infected blood: reform of financial and other support", published in January 2016 (the "2016 Consultation");
    b. "Infected blood: government response to consultation on reform of financial and other support", published in July 2016 (the "2016 Consultation Response");
    c. "Infected blood: consultation on Special Category Mechanism and financial and other support in England", published in March 2017 (the "2017 Consultation"); and
    d. "Government response to consultation on Special Category Mechanism and other support in England", published in October 2017 (the "2017 Consultation Response").

10. Under the NHS Business Services Authority (Awdurdod Gwasanaethau Busnes y GIG) (Infected Blood Payments Scheme) Directions 2017 (the "2017 Directions") (Exhibit EIBS0000028) the SoS directed NHSBSA to act as administrator of the new infected blood support scheme in England only, i.e. EIBSS, from 1 November

2017. Supporting the 2017 Directions are a Memorandum of Understanding ("MOU") and Service Specification between the SoS and NHSBSA in relation to EIBSS (Exhibits WITN4688005 and WITN4688006). These documents are not legally binding, but cover matters such as the service to be provided by EIBSS, roles and responsibilities, financial arrangements and performance levels. The Department and NHSBSA have similar documents in place in relation to other functions performed by NHSBSA.

11. Under the MOU NHSBSA is directed to administer EIBSS by providing certain services, as defined in the Service Specification, and NHSBSA agrees to provide these services in accordance with the terms of the MOU and Service Specification. The MOU and Service Specification that are currently in place were signed in mid-2018. Prior to this the parties worked in accordance with the terms of the draft documents. The current Service Specification is dated August 2018 and all subsequent references in this statement to the Service Specification are to that document, unless stated otherwise.

12. The purpose of the MOU is "to define and facilitate the relationship between the Department and NHSBSA in respect of the administration of the Scheme in England" (paragraph 2.1). The main components of the services NHSBSA is required to provide under the Service Specification are (paragraph 1.5):
    a. Assessing new applications for registration with EIBSS and the special category mechanism ("SCM") against eligibility criteria;
    b. Making decisions on whether applicants qualify for various payments and what payment they qualify for;
    c. Administering annual, lump sum and discretionary payments;
    d. Establishing and overseeing an independent appeals mechanism;
    e. Providing support and answering queries about entitlement to payments under the scheme, and signposting other services; and
    f. Establishing and maintaining adequate governance arrangements to deliver these services, and reporting to the Department as required by the MOU.

13. The MOU and Service Specification set out reporting, governance and accountability arrangements between NHSBSA and the Department. These are described in more detail at paragraphs 147 to 157, but the broad framework is:

a. Annual senior level performance management meeting to review the performance of NHSBSA generally, across all of its functions (paragraph 12.1, MOU);
b. Quarterly accountability meetings between the Department and NHSBSA to monitor performance, spending and funding (paragraph 12.4, MOU). This is supplemented by the Service Specification, which provides for quarterly and monthly meetings between the Department and NHSBSA (paragraph 9.7 and 9.8, Service Specification);
c. Annual, quarterly and, where appropriate, monthly reporting by NHSBSA (paragraphs 12.2 and 12.4, MOU);
d. Key Performance Indicators ("KPIs"), used to measure performance, are agreed and should be met by NHSBSA (paragraph 13.2, MOU);
e. NHSBSA is responsible for handling complaints, which should be done in accordance with the Service Specification (paragraph 14.1, Service Specification);
f. NHSBSA should work collaboratively with the Department and other stakeholders to improve the EIBSS application process and information provision (paragraph 15.1, MOU); and
g. NHSBSA should share insight with the Department in order to assist with continuous service improvement (paragraph 15.3, MOU).

14. The Service Specification is presently being revised. As a result of the Government's announcement in relation to parity on 25 March 2021 (see below) substantial revisions to the Service Specification are needed. A copy will be provided to the Inquiry once it is revised.

15. I am informed, and the documents demonstrate, that during the transition from the Alliance House Organisations ("AHOs") to EIBSS, the establishment and operation of EIBSS through NHSBSA was overseen and directed by the Department's infected blood policy team. As explained above, I was not responsible for EIBSS at that time. In this transitional stage the Department had a more intensive role than has subsequently been the case. It worked with NHSBSA to assist with delivery of the new scheme in the initial stages, in accordance with the Department's policy decisions. During that early period, NHSBSA reported to the

Department on a regular basis and consulted with it on some operational issues that arose, such as delays incurred in making the initial payments under EIBSS due to technical problems with the system involved. This is demonstrated by the minutes of regular meetings taking place at the time, which I refer to at paragraph 151 below. As the Inquiry will gather from my responses below, the relationship has developed and changed since then. NHSBSA is responsible for the administration of EIBSS. The Department plays a policy-setting and governance role, and its involvement is through ongoing governance arrangements, including when NHSBSA informs it about operational issues which the Department needs to be aware of. This shift in the nature of the relationship following the establishment and bedding-in of the new scheme is to be expected. The Cabinet Office Code of Good Practice[1] on sponsorship of ALBs emphasises the need to:

a. Move the focus of relationships away from compliance and control towards a proportionate, risk-based partnership model, with departments/ALBs working together more effectively to accomplish common goals;
b. Focus on maximising the value from the relationship – using a department's and ALB's experience and skills;
c. Put greater emphasis on high level strategic relationships between a department and ALB senior leaders; and
d. Work together with openness, honesty and trust.

16. In May 2019, following transfer of the financial support scheme(s) to NHSBSA, the Government Internal Audit Agency ("GIAA") published an audit of the governance and assurance processes related to delivery of EIBSS (Exhibit WITN4688007). This audit was broadly positive and found that the Department and NHSBSA enjoyed a strong and collaborative working relationship and that shifting from multiple delivery partners to administration through a single entity made oversight more easily achieved. The GIAA concluded that "[t]he strong working relationship that has been established [between the Department and NHSBSA] ensures that any issues that arise in terms of policy delivery can be shared with the NHSBSA and potential operational impacts can be understood" and that "it provides a good opportunity for operational issues to influence policy decisions and ministerial

[1] Partnerships between departments and arm's length bodies: code of good practice, February 2017.

advice" (page 4). The GIAA recommended this process could be further strengthened by the introduction of a joint risk register. There is now an EIBSS risk register. I exhibit the most recent version at Exhibit WITN4688008.

Section 2: Transitional arrangements

17. I am asked why, when the financial support schemes operated by the AHOs were replaced with EIBSS (which took effect on 1 November 2017, with preparatory work for around two years before this), NHSBSA and the Department agreed on a strategy of not automatically sharing beneficiary data between the AHOs and EIBSS. As NHSBSA explains in its response to question 5(b) of its first rule 9 request, the AHOs would not transfer any beneficiary data without written consent from the beneficiary. This decision was taken by the AHOs, and I would not characterise it as a strategy agreed between or with the Department and NHSBSA. Indeed, I have been informed that the Department did not agree with the AHOs' view that consent was necessary but, for the reasons below, it had little say in the matter. I exhibit a template letter sent by the Caxton Foundation to beneficiaries in September 2017, seeking consent to transfer data to NHSBSA (Exhibit WITN4496002).

18. Each AHO was the data controller in respect of the beneficiary data it held. I am informed that the AHOs took the view that they, as data controllers, could not automatically share beneficiary data, as they thought this would have amounted to a breach of data protection legislation. I understand that view was based on legal advice received by the AHOs. I exhibit a letter from Jan Barlow, writing as Chief Executive of the Caxton Foundation on behalf of the AHOs, to Ailsa Wight, then Deputy Director in the Emergency Preparedness and Health Protection Policy Directorate, dated 30 November 2017 (Exhibit MACF0000061_012). In this letter Ms Barlow explains that neither NHSBSA nor the Department will be able to access any data which has not been transferred (such transfer only taking place with beneficiary consent) and refers to the General Data Protection Regulation coming into force the following year. Ms Barlow warns that this will lead to many records being inaccessible (page 3). The IBI may wish to direct this issue to the AHOs for a fuller explanation of the approach they adopted.

19. Both the Department and GLD, advising the Department on the issue, could see that some beneficiaries may not provide consent and, as a result, would drop out of the new support scheme.

20. I am informed by a GLD lawyer involved at the time that, when the Scottish Infected Blood Support Scheme ("SIBSS") had sought the transfer of beneficiary data to it from the AHOs prior to the transfer of AHO functions to SIBSS in April 2017, the AHOs' view was that the data could only be transferred to SIBSS with express beneficiary consent. The Department was not directly involved in this and it happened before issues of transferring beneficiary data to EIBSS arose. However, by the time it came to discussions about the English data, it seems the AHOs had a settled position. It may be that the Scottish authorities can assist more with their discussions with the AHOs about transfer of beneficiary data.

21. I am told that the Department's view was that beneficiary data probably could be lawfully transferred to NHSBSA without prior express beneficiary consent, and that this was communicated in meetings with the AHOs. However, ultimately, the view of the AHOs was different and, as I have said, each AHO was the data controller, not the Department. The position taken by the AHOs was not obviously incorrect and the AHOs had adopted the same position with SIBSS. The Department had also been informed that the data transfer process with the Scottish scheme had worked well.

22. I understand that, even for the beneficiaries who provided prior express consent, the AHOs did not transfer to NHSBSA all the data they held on each of those consenting beneficiaries. Rather, the AHOs transferred a limited amount of data considered necessary for NHSBSA to start administering regular payments to those beneficiaries. The Department received advice from GLD that this was likely to be the correct approach: it was not necessary for NHSBSA to have the history of each beneficiary's interactions with the old schemes, and data protection legislation requires that only the minimum necessary personal data be held.

23. However, this did raise concerns about what would happen with the remaining data held by the AHOs, given that beneficiaries or the Inquiry might wish to access it. Discussions on this point led to the creation of Skipton Fund Limited ("SFL").

SFL was and is a company with two directors who are partners in the law firm which advised the AHOs (Russell Cooke LLP, "RC LLP"). SFL took control of all residual data from the AHOs and entered into an agreement, dated January 2019, with the SoS to ensure that beneficiaries and the Inquiry would have appropriate access. The Department has provided funding for SFL to carry out these obligations. This agreement stated that SFL was to be the data controller and the Department would not be entitled to access that data, however that merely formalised the position described above.

24. I am asked what consideration was given to alternative methods of contact with beneficiaries and dispensing with prior consent from beneficiaries.

25. Neither the Department nor NHSBSA knew who the beneficiaries were at the time, and did not hold contact information for any beneficiary. For obvious reasons it has generally been considered inappropriate for the Department to have information about beneficiaries and the Department is generally only aware of the identity of a few beneficiaries, e.g. where a beneficiary has made contact via correspondence about the schemes, Freedom of Information requests or proposed legal action. So alternative direct methods of contact could not have been used.

26. Similarly, the Department was not in a position to dispense with prior consent – it was not the data controller and did have not access to the beneficiary contact information.

27. Both the Haemophilia Society and the Hepatitis C Trust were made aware of the change from the AHOs to EIBSS and so would have been able to signpost anyone who got in touch with them to the new scheme. The public consultations on the future of the financial support schemes, which received a high level of engagement from both campaign groups and individuals, made it clear that the provision of financial support was changing.

28. At a meeting of the Infected Blood Reference Group on 19 September 2017 (Exhibit DHSC0046884_022), Christopher Tempest of NHSBSA confirmed that he had been liaising with Jan Barlow. In relation to positive consent to transfer of data, NHSBSA had been informed that "the bulk of responses from beneficiaries are likely to be returned within the first four weeks." NHSBSA was "working with their

press/comms colleagues to ensure that as many people as possible are reached to inform them of the changes" and that relevant information was to be passed to the Haemophilia Society and, if I understand the reference correctly, the Hepatitis C Trust, so that they could include updates on their websites.

29. Further, from 1 November 2017, when the AHO schemes were all transferred to EIBSS, previous payments to any beneficiary who had not provided consent would have stopped. As I understand it, the AHOs continued to exist for some time after EIBSS began to operate, and so there would or should have been a point of contact for any beneficiary who was not otherwise aware of EIBSS. Inquiry document CAXT0000094_018 states that three of the AHOs (Macfarlane Trust, the Skipton Fund and the Caxton Foundation) retained their websites for at least some time, displaying a message referring visitors to the relevant organisations across the UK. The EIBSS website continues to display a similar statement explaining that the AHOs have now closed and that beneficiaries of those schemes who are not currently receiving support from EIBSS can arrange for their records to be sent to EIBSS.

30. SFL also continues to operate a website, and this signposts visitors to the new schemes. It also explains that, where individuals consented to the transfer of their data, all relevant information held by the Skipton Fund was transferred to the relevant financial support scheme.

31. Only the AHOs knew how many beneficiaries had not replied to their letters seeking consent, and thus the scale of any problem, and only the AHOs were in a position to approach those beneficiaries again. The Department did not formally ask the AHOs to reconsider because it was not, at that point, aware that there was a significant issue with beneficiaries not providing consent. As indicated above, it was also felt to be unlikely that the AHOs would change their approach.

32. It appears from the documents that, around the time of the creation of EIBSS, the number of "missing beneficiaries" was thought to be relatively low. I exhibit a letter from Jackie Doyle-Price MP, Parliamentary Under Secretary of State, to Diana Johnson MP, dated 19 December 2017 (Exhibit WITN4688009), which reports that a "small number" of people have not consented to the transfer of their data, and that "NHSBSA has informed us that less than two per cent of the beneficiaries of

the former payment schemes that have been contacted to seek their consent have not responded." The letter goes on to explain that members of staff from the former AHOs were continuing to try to contact those who have not responded, "to ensure that no-one loses out". The same figure of less than two percent was given by Jackie Doyle-Price MP in response to a Parliamentary Question on 16 November 2017.[2]

33. However, I am told that further to work undertaken between 1 November 2017 and 31 March 2018 NHSBSA determined that there were 460 "missing beneficiaries". This involved AHO staff who had transferred to NHSBSA at the inception of EIBSS being seconded back to the AHOs on a part-time basis in order to try and trace or make contact with individuals who had not provided their express consent to have data shared. Those staff also dealt with correspondence relating to the transfer and handled any further data transfer forms sent to the AHOs during this period. I understand that at least some of these individuals are people who were entitled to and received one-off payments, and did not maintain contact with the AHOs following this. The Department does not know whether any of these "missing beneficiaries" refused consent to the AHOs, were uncontactable, did not reply, or have sadly passed away.

34. I understand from documents that this issue was raised with the Department in 2018 when it became apparent that there would be a significant underspend during the first year of EIBSS' operation. I am told that at this point it was identified that the AHOs had lost contact with 400 to 500 hepatitis C stage 1 beneficiaries. I cannot say whether the Department was aware of the scale of the issue prior to this point, although clearly the information the Department had when Jackie Doyle-Price MP wrote to Diana Johnson MP was incorrect.

35. I am told by a GLD lawyer involved at the time that there had been historic problems with obtaining accurate beneficiary numbers from the AHOs, and that there were concerns that the AHOs had not held reliable data on the number of beneficiaries who might be expected to transfer to EIBSS. For example the Skipton Fund Directors' Report and Financial Statements for 2016 shows, at page 2, that

[2] https://questions-statements.parliament.uk/written-questions/detail/2017-11-13/112592

in spite of its efforts it had not been able to trace 83 people who would have been entitled to payments as bereaved beneficiaries and a further 11 applicants who may still have been alive but whose whereabouts remained unknown (Exhibit WITN4688010).

36. The matter became a point for discussion at meetings between the Department and NHSBSA in late 2019. I exhibit the EIBSS risk register provided to the Department in advance of the October 2019 quarterly accountability meeting (Exhibit WITN4688011). This records that NHSBSA had already spent 6 months attempting to locate these missing beneficiaries. I understand from NHSBSA that as at 11 March 2021, 67 beneficiaries who had previously been registered with an AHO have now approached NHSBSA and received backdated payments. NHSBSA may be able to assist further on the steps it took. The risk register also recorded that NHSBSA and the Department were to explore additional proactive checks that could be taken to ascertain the current status of these beneficiaries.

37. In terms of the Department's current focus on this matter, there are two distinct issues. The first is whether the missing beneficiaries can be identified and contacted in a way which complies with legal obligations and respects the very sensitive nature of the data involved. The second issue is whether the Department has sufficiently accounted for the potential financial impact if missing beneficiaries are identified.

38. On the first issue, a number of options have been explored. For example, I understand some work was done between NHSBSA and RC LLP to try to reconcile the records held by NHSBSA and SFL. However, advice from GLD was that this data should not be shared between NHSBSA and SFL because there was a risk some beneficiaries had explicitly refused consent to the AHOs for their data to be transferred. Another strategy considered was whether NHSBSA could take over the directorship of SFL, allowing it to become data controller. However, GLD advised against this approach because there was no legal basis to share the data with NHSBSA (which would not be solved merely by NHSBSA taking over the SFL directorship). The Department was also advised this approach would require a separate team within NHSBSA to act as data controller of the legacy records in order to avoid a conflict within NHSBSA, which would want both to identify missing

beneficiaries and be subject to stringent obligations as data controller. I set this out only to illustrate the challenges in resolving this issue.

39. What was thought to be a solution was agreed following a meeting between NHSBSA and RC LLP in July 2020. I am told that the plan was for SFL to instruct a third party, such as a credit checking agency, to obtain updated details for beneficiaries from whom the AHOs had previously had no response. There was some delay in reaching this position due to Covid-19. In October 2020 RC LLP informed the Department that it intended to instruct a credit checking agency to determine if the individual is still alive and, where possible, obtain current address details. The Department was told that, where the individual is sadly deceased, it will not be possible to obtain next of kin details. As at December 2020 the Department has been informed by RC LLP this cannot be taken forward without disclosing to the credit checking agency that the data comes from SFL. The credit checking agency's position is that it needs to know the identity of the client, which would be SFL, and to know high level information about the purposes for which SFL wishes to use the data. If that information were disclosed, the credit checking agency would be in a position to presume that at least some of those individuals they are asked to check are infected with HIV or hepatitis C, thereby disclosing sensitive personal data. The Department is now carefully reviewing this situation in light of the legal implications and the very sensitive nature of this information. This information relates not only to personal data but also to details of people's often very private health issues, and this has been and remains a determining factor when it comes to the Department's approach to how this information should be handled.

40. On the second issue in paragraph 37 above, analysts within the Department include possible missing beneficiaries when modelling the total number that may be entitled to financial support under EIBSS. The modelling also informs the overall long-term financial liability of the scheme.

41. I am further asked about policies or procedures adopted by EIBSS in relation to data sharing and contact with potential beneficiaries, and any role played by the Department in these.

42. As an ALB operating with a large degree of independence from the Department, NHSBSA is responsible for maintaining its own policies and procedures on data protection and data sharing generally. I am aware that such policies can be found on the NHSBSA website, and cover the operation of EIBSS. NHSBSA will be able to assist further. The MOU and Service Specification between the Department and NHSBSA contain provisions on data protection, retention and storage. NHSBSA must comply with its obligations under data protection legislation. It is for NHSBSA to ensure that any data sharing and contact with potential beneficiaries takes place in accordance with the law. I understand that EIBSS has other strategies in place to ensure that potential beneficiaries are made aware of available support, such as engagement with the Haemophilia Society and the Hepatitis C Trust.

43. I am further asked whether the strategy of transferring data only with explicit consent was made publicly available at the point at which the schemes were transferred in 2017. As I understand it, it was public to the extent that the AHOs had written to existing beneficiaries seeking consent. Beneficiaries should also have been reminded of this situation when they were informed that the scheme or schemes that previously provided support were being wound up. Other than referring to the document at CAXT0000094_018 (paragraph 29 above), I cannot now say if AHO websites included this information at the relevant time.

Section 3: Interaction with the other devolved schemes

44. Question 3 refers to paragraph 72 of the draft witness statement of Donna McInnes. She explained that, due to the devolved nature of the schemes, the Department does not monitor the consistency of policy or the awards made in the four different schemes. I am asked why the Department has not liaised further with the devolved administrations to establish a more systematic approach to information-sharing and monitoring of consistency and disparities. I am also asked whether such an approach has been considered.

45. To provide some context, prior to the reforms of the financial support schemes in 2016/17, the AHOs had operated on a UK-wide basis and so it made little difference where an individual had become infected. However, as healthcare is a devolved matter, when there was to be wholesale reform it was considered

appropriate that each nation should take its own decisions on what type of support to provide and at what level. It was recognised that this could lead to new or additional features being made available to beneficiaries depending on which country they had been infected in.

46. When the AHOs were wound up and replaced with four distinct financial support schemes, I understand there was a significant degree of co-operation between the nations, including regular meetings and correspondence at official and ministerial level. As examples, I exhibit:
    a. A draft letter from Jane Ellison MP, Parliamentary Under Secretary of State for Public Health, to her counterparts in the devolved administrations, seeking agreement for officials to work together to take forward rationalisation of the existing schemes (Exhibit WITN4688012);
    b. A briefing provided to Jane Ellison MP, Parliamentary Under Secretary of State for Public Health, ahead of a conference call with the Health Ministers for the devolved administrations held on 20 January 2016. The call was to alert ministers in the devolved administrations to the forthcoming consultation and outline the policy options being consulted on (Exhibit WITN4688013);
    c. A draft document setting out an approach to stakeholder engagement, jointly agreed between the devolved nations (Exhibit WITN4688014);
    d. An email chain dated 15 July 2016 showing collaboration between the four governments on the text of a letter to be sent by the Department to existing beneficiaries about the outcome of the 2016 Consultation and the creation of an England-only scheme (Exhibit WITN4688015);
    e. A letter from Jane Ellison MP, Parliamentary Under Secretary of State for Public Health to Shona Robison MSP, Cabinet Secretary for Health and Wellbeing, Scottish Government, informing Ms Robinson of the publication of the 2016 Consultation Response, and confirming the contents of a recent telephone call regarding payments for those infected with HIV in Scotland, Wales and Northern Ireland (Exhibit WITN4688016).

47. The Department also liaised closely with the devolved administrations on detailed issues such as benefits exemptions and transitional arrangements, in order to

ensure a smooth transition from the AHOs to the devolved schemes. I exhibit minutes of meetings between the four UK health departments held on 17 April 2015 and 1 August 2016 (Exhibits WITN4688017 and WITN4688018).

48. However, the four schemes do operate independently. As explained in Donna McInnes' draft statement, the Department does not have an oversight role and has not proposed any monitoring mechanisms. Officials do, however, maintain an understanding of how the schemes operated by the devolved administrations work and there is a proportionate flow of information between the four health departments.

49. Officials from each of the four nations meet periodically. Common issues can then be discussed and information is shared about the schemes which are, of course, broadly seeking to achieve the same aim. These meetings act as a forum for the exchange of information, for example, where one administration wants to understand how a particular aspect of another scheme works. The Department is an equal participant in these meetings and does not seek to influence policy or practice. I exhibit a representative sample of minutes of meetings between the four UK Health Departments in 2018 and 2019 (Exhibits WITN4688019 to WITN4688026). These demonstrate ongoing information sharing about the development of aspects of the financial support scheme in each nation, for example the bedding in of new schemes, policy work relating to discretionary support and the impact of hepatitis C, the closure of the AHOs and the establishment of the Inquiry.

50. I am asked to what extent policies and practices and common criticisms from registrants or beneficiaries are shared among the four nations. In my view these exhibits demonstrate that the four health departments do share policies and practices across a range of issues, including payment, discretionary support and eligibility, as well as sharing common issues for discussion, including criticisms. I understand that there is also some contact between the four schemes. NHSBSA may be able to assist more as to what is discussed.

51. Since early 2019 a significant focus of these regular meetings has been the ongoing work on the issue of parity across the UK. There have also been meetings between the four health departments and the Cabinet Office. On the issue of parity

generally, the Cabinet Office plays a key co-ordinating role due to the devolved nature of this area and the Paymaster General, Penny Mordaunt MP, has recently announced planned changes to "the four separate schemes to bring them into broader parity."[3] I am aware that this has been dealt with in response to another rule 9 request from the Inquiry and so I do not go into more detail here.

52. I am asked to provide specific examples of changes or reforms within EIBSS that have resulted from information-sharing, monitoring or co-ordination between the devolved schemes.

53. I think the best example of this kind of co-ordination is the recent work towards greater parity, which will result in EIBSS now adopting features of the other schemes.

Section 4: Medical assessment in the EIBSS and the special category mechanism

54. The special category mechanism ("SCM") provides additional financial support for beneficiaries who suffer from hepatitis C and who are at stage 1, but whose infection, its treatment, complications or associated conditions have a long term negative impact on their ability to carry out daily activities. In this part of the statement I will use the shorthand of a person's hepatitis C infection (rather than infection, its treatment, complications or associated conditions).

55. I am asked why the balance of probabilities is not used to determine SCM applications, but is used for other medically based applications to EIBSS. It is my understanding that, when the EIBSS medical assessors determine whether an applicant is eligible for SCM payments, they do in fact use the balance of probabilities and so the standard of proof is the same as for other medically-based applications. This was confirmed in a briefing paper prepared by NHSBSA for the Department in October 2018, which states that medical assessors use the "balance

[3] Written ministerial statement by Penny Mordaunt MP, Paymaster General, on 25 March 2021: https://questions-statements.parliament.uk/written-statements/detail/2021-03-25/hcws895. In the same statement Penny Mordaunt also confirmed the Government's intention to appoint an independent reviewer to look at options for a framework for compensation.

of probabilities on the evidence provided" (Exhibit WITN4688027). This has also recently been re-confirmed to the Department by NHSBSA.

56. The SCM application form asks an applicant's healthcare practitioner ("HCP") to give a view on the cause of the applicant's symptoms or problems, using a four point scale of:
    - Not likely – explained by other causes
    - Possible
    - Highly likely
    - Definite

    The SCM was set up so that the answer from the HCP was not determinative of the application. Rather, the answers given on the four point scale are part of the evidence that the EIBSS medical assessors consider. The EIBSS medical assessors will use all the evidence to determine the application on the balance of probabilities.

57. Background: There was a limited pot of money available when the financial support scheme was re-designed and the aim of the SCM was to focus additional financial support on those most in need due to the impact of their hepatitis C infection. The SCM provided a route to apply for higher annual payments.

58. Developing the SCM was very challenging. As explained in Donna McInnes' draft witness statement, defining the SCM tests was not easy and there were difficulties such as how to balance the subjective nature of an individual's experience of living with hepatitis C with an objective assessment of the impact of the infection (paragraph 45). Further, the majority of respondents to the Department's consultation on the SCM did not want to have individual health assessments and the Department listened to this and so designed a paper based application process instead.

59. The challenges of designing the SCM application process (and form) can be seen from the contemporaneous documents. For example, Kypros Menicou's[4] email to Professor Geoffrey Dusheiko[5], dated 24 January 2017 (Exhibit WITN4688028), commented that the SCM process had been "extremely difficult to develop.... the responses to such an assessment subjective..." (page 2). With this email Kypros Menicou sent Professor Dusheiko a draft SCM application form. That form did not contain the four point scale. The draft form asked the HCP if the applicant's hepatitis C infection was making it difficult for the applicant to carry out daily activities (including as a result of fatigue or mental health problems). In response Professor Dusheiko suggested using a five point scale to assess the causal relationship.

60. Professor Dusheiko wrote:

> "...I think you have done the best you can to devise a mechanism for stage 1 beneficiaries; it is difficult, I will agree...Clinically I think it could work. There will always be an element of subjectivity.
>
> I wondered whether for some of the latter questions whether the clinician could be asked estimate, on a five point scale the causal relationship of the difficulty to hepatitis C infection:
>
> 1. Not likely: (explained by other causes or co-morbidities)
> 2. Possible
> 3. Probable
> 4. Highly likely
> 5. Definite
>
> That way you could introduce a layer of scoring that might help the department[6] to assess these forms; also if appeal is sought, then consensus could be obtained (or not).
>
> We use this kind of scoring in safety monitoring committees to assess the causality of adverse events to investigational drugs, in an attempt to ascertain

[4] An official working at the time in infected blood policy and part of the Emergency Preparedness and Health Protection Policy team.
[5] A consultant hepatologist and Professor of Medicine who was involved in advising the Department on reforms to the financial support scheme. He also previously worked with the Skipton Fund and became an EIBSS medical assessor.
[6] Of course, it is not officials from the Department who assess the application forms. It is EIBSS and the EIBSS' appointed medical assessors.

whether the adverse event is likely to have been caused by the drug or not. This might also help the assessors…to decide whether it is a "not straightforward" or "straightforward" application" (page 1, sic).

61. I understand this to be making the point that assessing causation of an applicant's difficulties will be, or often will be, a subjective assessment and that, because of this, giving a HCP a scale to express his/her view on causation would be valuable. The marking on that scale could then help the EIBSS medical assessors with conducting a kind of initial sift so that straightforward (or not straightforward) cases could be identified. It does not say (and is not the case) that, unless the HCP ticked "highly likely" or "definite", the application would fail. As the Inquiry will know, Professor Dusheiko became one of the EIBSS medical assessors.

62. I am not now in a position to explain why the five point scale suggested by Professor Dusheiko, which included "probably", became a four point scale on the SCM application form in which "probably" was omitted. The Department's rule 9 response dated 1 May 2020 explained that it had not been possible to find further correspondence on the five or four point scale, and this remains the case. We cannot locate why this decision was made but such changes are a normal part of policy development. I am aware, though, that the SCM application form published with the 2017 Consultation, which included the four point scale, was approved by the Infected Blood Reference Group and reviewed by junior Counsel.

63. It is important to note that each SCM application now goes before at least two EIBSS medical assessors and is determined by the medical assessors on the balance of probabilities. I expand below on this and other reasons for using a scale. Also, as explained from paragraphs 72 and 77 below, the Department has not been made aware that using a four point scale, or indeed using a scale at all, has caused problems for stakeholders.

64. Application assessed by medical assessors on the balance of probabilities: As explained above, the answers given using the scale are part of the evidence that the EIBSS medical assessors consider. It is not the case that applications with "possibly" ticked are automatically unsuccessful. As I understand it, in all cases,

including those where possibly has been selected, the medical assessors will consider this 'likelihood indicator', along with the supporting evidence and reach a view on whether the application should be successful or not. NHSBSA has confirmed that the medical assessors apply the balance of probabilities to this assessment. Those medical assessors are experts in hepatitis C and HIV, as required by paragraph 3.1.5 of the Service Specification.

65. In preparing this statement I have been provided with two rule 9 responses from EIBSS. I note that the first, dated 16 November 2018, says that "[t]he burden of proof for medical applications is on the applicant and a decision is made by an independent medical expert [what I have called a medical assessor] on the balance of probabilities that the person was infected with HIV and/ or hepatitis C stemming from treatment with NHS supplied blood or blood products prior to September 1991." The second rule 9 response from EIBSS, dated 19 December 2018, also says that the medical assessors have used the balance of probabilities (page 5).

66. Thus, using the scale has not prevented any application from being considered by medical assessors and the application is to be decided on the balance of probabilities.

67. Scale intended to be inclusive: A HCP could have been asked to give a view on the causation of symptoms using the balance of probabilities. The response would then either be "yes" or "no". It seems to me that posing this binary question risked being a rather blunt approach. By contrast, using a scale allowed for greater flexibility for the HCP to answer these causation questions, which will not always be straightforward. It seems to me that this flexibility was probably informed by some of the challenges of assessing paper applications for the SCM, already touched on above. In addition:
    a. Assessing the existence and severity of mental health problems (such as depression and anxiety) or fatigue may be more subjective than an assessment of whether a person suffers from one of the conditions listed in Section 5 of the SCM application form, or whether that person was infected with hepatitis C through treatment with NHS blood or blood products prior to September 1991 (i.e. for stage 1 applications). The reference group advising the Department on

the reforms repeatedly stressed the subjective nature of these kinds of health problems. A similar point can be made for the question of whether a person has difficulties carrying out regular daily activities.

b. Clearly, both mental health problems and fatigue can have a large number of causes and it may not be straightforward to attribute these problems to an applicant's hepatitis C infection. For example, a note of a meeting of reference group members on 15 July 2016 records concerns about the difficulties of attributing psychological diagnoses to a person's hepatitis C infection (Exhibit - WITN4688029). Indeed there were some members of the reference group who thought that psychological symptoms should not be included in the criteria for the SCM at all (Exhibit WITN4688030).

c. The HCP completing the SCM application form may not be fully aware of other aspects of the applicant's health. It may be difficult for the HCP to determine from an individual's medical records the impact that the infection is having on the applicant's ability to carry out daily activities. It may also be difficult to know if such impact is caused by the applicant's hepatitis C infection or something else, or a variety of factors.[7] In advance of an expert panel workshop held on 26 February 2016, a GP member of the panel expressed the view that an applicant's GP may or may not be aware of psychological symptoms (Exhibit WITN4688031).

d. Where the issue is causation of mental health problems, the HCP completing the form will not be a psychiatrist or mental health professional. The HCP may sometimes be a GP, but most often it will be the applicant's treating hospital consultant or a viral hepatitis nurse. Depending on which HCP is completing the form, the ability to determine the cause of a mental health problem, fatigue or difficulty carrying out regular daily activities will likely differ.

68. I also understand from an official involved in the setting up of the SCM that there was a concern, shared by experts on the reference group, that it may be too much

[7] On this, the 2017 Consultation Response (Exhibit WITN4688038) stated that one of the most common reasons for respondents not agreeing with the SCM proposals (as they then were) for how beneficiaries would be assessed was a concern that "[a]ssessments will be difficult to conduct and assess fairly, given that beneficiaries have other health ailments that occur which are not directly caused by hepatitis C infection alone or may be difficult to provide medical evidence for" (page 13).

to ask, e.g., a GP or a haemophilia nurse, to answer these questions on the balance of probabilities. It was felt that the expert medical assessors appointed by EIBSS would be well positioned to make a judgment in difficult cases, using all the available evidence.

69. By contrast, for other parts of medically based applications, HCPs completing the forms are asked to provide their assessments on the balance of probabilities. This is because those assessments were considered to be more objective. For example, an application for a stage 2 hepatitis C payment is dependent on a person having serious liver damage. There is a list of specified conditions which indicate the hepatitis C is advanced. These are more objective criteria – either they apply to the applicant or they do not. Such an assessment is also likely to be within the HCP's area of specialism.

70. I am asked about whether the Department has considered that the requirement for medical practitioners (what I have been calling HCPs) to assess impact by reference to multiple categories (i.e. the four point scale) can lead to inconsistent classification, time and expense in preparing and determining SCM applications, and greater scope for appeals.

71. As stated, developing and designing the SCM was a difficult exercise. That is why a reference group was set up. Donna McInnes' draft statement also explains that the Department listened to responses to the 2017 Consultation and amended its proposals in response to that consultation. For example, the Department decided not to ask applicants to undergo an assessment. As Donna McInnes also says, from the outset the intention was to ensure that the process would be as simple and user friendly as possible for applicants, their HCPs and for the efficient operation of EIBSS, while also producing fair and consistent results.

72. As far as I am aware, to date the Department has not received negative feedback from NHSBSA about the operation of the four point scale. By this I mean, as far as I am aware, EIBSS has not informed the Department of any complaints or negative feedback from applicants, HCPs or medical assessors, or detected a groundswell of opinion; nor has EIBSS suggested that the scale has led to a greater number of

appeals. The Department has not been informed that applicants, HCPs, medical assessors or EIBSS are of the view that it would be easier or better to abandon the four point scale in favour of HCPs making an assessment on the balance of probabilities. I am aware that the Scottish and Welsh schemes ask beneficiaries to self-assess the impact of their hepatitis C and that some beneficiaries in England would prefer that approach.

73. I am informed that, in the early days of the SCM, there was a very small number of complaints about the SCM but these did not relate to the use of the four point scale. NHSBSA had also reported, again in the very early days, some queries about the SCM process. I think that is to be expected with the introduction of a new category of payment. Again my understanding is that these queries did not relate to the use of the four point scale.

74. I have considered that, if the application of the four point scale presents significant problems in practice, one might expect to see this reflected in the number and content of appeals against SCM decisions, or in complaints to EIBSS, or possibly by calls from HCPs to EIBSS (the SCM application form gives a number to call if there are any queries about completing the form).

75. In the course of preparing for the Inquiry, the Department has asked NHSBSA if it can provide data on the number of SCM applications on which "possibly" on the four point scale is ticked on the SCM application form, and the proportion of these applications that are awarded the SCM. I understand that NHSBSA has informed the Department that it does not routinely record that information, and that obtaining this information would require NHSBSA to go back to each individual SCM application.

76. However, I can see from the EIBSS annual reports[8] that:

[8] Available at https://www.nhsbsa.nhs.uk/eibss-annual-reports.

a. In the 5 months up to 31 March 2018, there were 715 SCM applications. 498 (70%) were approved.[9] 150 were declined and 67 required further information. Due to timings there were no appeals determined in that period. The main reasons for SCM applications being declined are not set out in the report.

b. In 2018/2019 there were 99 SCM applications. 73 (74%) were approved, 20 were declined and 6 required further information. The main reason for declined applications was that there was an unsupported link between the applicant's symptoms and the hepatitis C infection and/or treatment. The report says there were 34 appeals. 6 were successful and 26 were not. I assume, but cannot be certain, that this number of appeals includes appeals against decisions made in 2017/18.

c. In 2019/2020 there were 41 SCM applications. 34 (83%) were approved. Only 1 was declined. The main reason was an unsupported link between the applicant's symptoms and the hepatitis C infection. 6 applications required further information. There were no appeals.

There is an appeals process for beneficiaries to use and this applies to the SCM (as it does to other aspects of the scheme). These figures show that it is used, and that in percentage terms the number of approvals in each year is broadly consistent.

77. At the regular accountability meetings between the Department and NHSBSA, the Department is informed about the numbers of appeals that EIBSS receives and how many of these are successful/unsuccessful. I understand that the Department is not usually told about the substance of appeals because NHSBSA is responsible for handling complaints and it would not be appropriate for the Department to become involved in the handling of individual issues. This is because NHSBSA administers the scheme on the Department's behalf. However, under the governance arrangements in place, if issues become recurrent or point towards a

[9] The EIBSS annual report says (at page 11) that 76.85% of applications were approved. I think that calculation excludes the 67 applications which required further information. If those 67 applications are included there was a 70% approval rate.

theme, the Department would expect to be informed.[10] So, for example, if there was a problem with how the four point scale operates, the Department would expect to be informed. The Department is very largely reliant on NHSBSA to identify issues with how the scheme operates and to communicate these to the Department. I give further information on the handling of complaints generally at paragraph 152 below.

78. The current Service Specification provides that "applications for the SCM should be reviewed and compared [by NHSBSA] to ensure consistency of decision making" (Annex C). I also refer to Exhibit WITN4688027 (NHSBSA Paper – Medical Assessment Process, dated October 2018) which stated that, where it was clear an applicant satisfied the criteria for the application being made, the application was assessed by one medical assessor. Where the evidence was not clear then the opinion of a second medical assessor may be sought. In addition, this paper states that NHSBSA was introducing a quality assurance check "to ensure consistency". I also understand that in the first quarter of 2020/21, NHSBSA changed its processes so that each SCM application form is considered by at least two medical assessors and, where there is disagreement, a third medical assessor considers the application.

79. I am aware that Annex C of the Service Specification sets out some guidance to be used when the EIBSS medical assessors consider the SCM application. For the questions in Section 6 and 7 of the SCM form that use the four point scale, Annex C includes:
    - "Where the medical practitioner ticks "not likely" and the information provided confirms this, the application would not generally be passed.
    - Where the medical practitioner ticks "highly likely" or "definite" and the information provided confirms this, the application would generally be passed…".

[10] See, for example, the MOU provides "NHSBSA will work collaboratively with DHSC and other stakeholders to improve the Scheme application process and information provision…" (paragraph 15.1) and "NHSBSA will share insight with DHSC in order to assist with continuous service improvement" (paragraph 15.3).

80. The Service Specification does not expressly address those cases where "possibly" is ticked, to make clear that the medical assessors should consider all of the evidence (as they should do in all cases). The Department will consider if it would be helpful to amend the documents to include express guidance for EIBSS (a) on what to do when "possibly" is ticked by a HCP and (b) that the medical assessors should decide all medically-based assessments on the balance of probabilities. The Service Specification between the Department and NHSBSA is being redrafted, with input from both parties. This includes provisions relating to the SCM. During the redrafting process, NHSBSA has not communicated concerns about the application of the four point scale for HCPs.

81. However, as explained above, it was recognised that designing the SCM process was difficult, in particular because the assessment will always be considerably subjective. The Department accepts that this might mean different HCPs approach parts of the form differently. I cannot say with certainty if asking a HCP to give his/her view on the balance of probabilities would lead to a more or less consistent classification of the impact on beneficiaries. The words used in the four point scale are plain English and should not, in themselves, cause confusion.

82. As a discrete point relating to the expense of making a SCM application, NHSBSA will refund the applicant if she/he has to pay to obtain medical evidence (see SCM application form, page 2).

83. I am asked about improvements to the medical assessment process that the Department was working on with NHSBSA earlier in 2020. In 2019 the Department became aware that there was only one medical assessor at EIBSS. The main issue behind this turned out to be related to retention and pay. EIBSS only having one medical assessor clearly created a number of risks, including interrupting and delaying decision-making. The Department gave instructions to NHSBSA that the number of medical assessors should be increased to four. It was able to confirm to EIBSS that the medical assessors' pay could be increased and the Department's approval for this was not needed. The EIBSS risk register as at December 2020 (WITN4688008) states that EIBSS now has four medical assessors and that rates of pay have gone up.

84. The Department wishes to continually improve EIBSS and welcomes and will carefully consider any recommendations by the Inquiry in the area of the SCM (or more generally).

Section 5: EIBSS funding arrangements

85. I can confirm that the funding position for infected blood support schemes from 2015/2016 to 2020/2021 as stated in Donna McInnes' draft witness statement was correct at the time of writing; the Inquiry will note that EIBSS itself was only operational from 1 November 2017. The funding position in Donna McInnes' draft statement is reflected in paragraph 2.8 of the Service Specification.

86. However, EIBSS' funding has increased since that statement was prepared. On 30 April 2019 the then Parliamentary Under Secretary of State for Health and Social Care, Jackie Doyle-Price MP, announced the Government's intention to increase funding for EIBSS from £46.3 million to over £75 million per annum in order to implement a major uplift in financial support. This increased the level of support available by way of annual payments and raised the upper threshold level of household income used to means-test support provided for the bereaved, meaning that more bereaved beneficiaries were entitled to these income top-ups. These income top-ups were also increased. It also raised the upper threshold of household income for the purposes of applying for means-tested support for dependent children. All new payments were backdated to 1 April 2019. This increased funding was implemented following engagement with the Chair and Secretariat of the Infected Blood Inquiry, the Chancellor of the Duchy of Lancaster and beneficiaries of EIBSS. I exhibit a Hansard extract detailing the announcement (Exhibit WITN4688032).

87. EIBSS only became operational in November 2017 and as such had no funding position prior to that point. The table below sets out the Departmental figures for the year by year funding position from then. As can be seen, between November 2017 and March 2021 the Department has allocated £213.1 million for the funding of EIBSS.

Year	Allocation
2017/2018	£14.7 million[11]
2018/2019	£46.3 million
2019/2020	£76 million
2020/2021	£76.1 million

88. In addition, since 2018/2019 the administrative costs associated with NHSBSA's role in operating EIBSS have been funded separately. This means that the cost of administering EIBSS is completely separate from funds which are distributed to beneficiaries. This provides financial transparency and ensures a clear separation between the money received by beneficiaries and the costs of administering the scheme.

89. The Inquiry will be aware that the current spending arrangement for EIBSS was intended to last until 2020/2021, with a further financial package to be determined as part of the Spending Review (see paragraph 2.12 of the Service Specification). As a consequence of Covid-19 the recent Spending Review (November 2020) covers just one year of spending plans (2021/2022) rather than the more usual three years.

90. Spending plans for individual budget areas in 2021/2022 are subject to detailed financial planning but funding for EIBSS is treated as part of the Department's "baseline" or business as usual funding, and this position has been confirmed for 2021/2022.

91. I am asked about any policy statements from the Prime Minister, the SoS or junior ministers in the Department on the EIBSS funding position beyond 2020/2021.There are no policy statements on this issue from the Prime Minister.[12]

[11] Funding of EIBSS began on 1 November 2017.

[12] The previous Prime Minister did write to a campaigner in May 2019, noting that "[t]he Government is committed to providing those infected and affected with a fair and transparent support scheme, and addressing the disparity in financial support across the different parts of the U.K. Discussions with the Devolved Administrations are now under way, and DHSC and the Cabinet Office officials are arranging to meet their Northern Irish, Scottish and Welsh counterparts in the next week to discuss a way forward" (letter from The Rt Hon Theresa May MP, Prime Minister, to Mr Bill Wright, Chair of Haemophilia Scotland, 10 May 2019).

In 2020 and to date in 2021, the Department answered the parliamentary questions set out below.[13] In addition, as the Inquiry is aware, Penny Mordaunt MP, the Paymaster General, made a Written Ministerial Statement on 25 March 2021, which is covered in more detail in another rule 9 statement:

a. In March 2020, Nadine Dorries, Minister of State, responded to a Written Question which asked, amongst other things, about financial allocations the Department planned to make to EIBSS in 2021/2022. In her response, the Minister stated that the allocation for the financial year 2021/2022 had not yet been agreed.[14]
b. In July 2020, Nadine Dorries responded to a Written Question asking whether those receiving hepatitis C stage 1 and SCM payments will receive annual payments for the rest of their lives. As part of her response, the Minister confirmed that the Department will consider any recommendations the Inquiry makes around financial support.[15]
c. In March 2021, Nadine Dorries responded to a Written Question asking what steps the Department was taking to provide assurance to people receiving regular support through EIBSS that they will not be forced to leave that scheme after the Inquiry. Nadine Dorries explained that the Department would consider any recommendations when the Inquiry reports, including those around financial support, and confirmed "[t]here is no intention to reduce the amount of financial support given to beneficiaries."[16]

92. I am referred to paragraph 71 of Donna McInnes' draft witness statement and asked to elaborate on the mechanism by which the total amount of funding is

[13] The Department responded to a number of questions relating to parity of support within the same period. These can be found at: https://questions-statements.parliament.uk/written-questions/detail/2020-02-10/14760; https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2020-06-25/64991/; https://questions-statements.parliament.uk/written-questions/detail/2020-08-28/82599; https://questions-statements.parliament.uk/written-questions/detail/2020-09-09/87705; https://questions-statements.parliament.uk/written-questions/detail/2021-03-04/163176; https://questions-statements.parliament.uk/written-questions/detail/2021-03-19/172020.
[14] https://questions-statements.parliament.uk/written-questions/detail/2020-02-28/22379
[15] https://questions-statements.parliament.uk/written-questions/detail/2020-06-30/66829
[16] https://questions-statements.parliament.uk/written-questions/detail/2021-03-02/161705. See also a similar question at: https://questions-statements.parliament.uk/written-questions/detail/2021-03-02/161706

determined for each devolved nation within the UK, both as to hepatitis C and HIV. I will take each in turn.

93. As regards hepatitis C, Donna McInnes' draft statement says that "Hepatitis C payments are accounted for under devolution." This means that, because financial support for hepatitis C was introduced post-devolution, the devolved administrations are responsible for determining how much funding is allocated to hepatitis C payments from within their own budgets. The Department is not involved in determining the overall financial allocations made to the devolved administrations by Her Majesty's Treasury ("HMT"). It does not play a role in determining the funds made available for the devolved financial support schemes in relation to hepatitis C payments.

94. In the light of this, I am unable to answer the Inquiry's questions as to the mechanism by which the total amount of funding for hepatitis C payments is determined for each devolved nation within the UK.

95. With regards to funding for HIV payments, Donna McInnes' draft statement says that "The DHSC makes payments to the devolved administrations for HIV as per normal funding rules. The DHSC is required to match the HIV payment that is made to infected individuals and specific family members in England, for those infected in the devolved administrations. The total amount of funding that is transferred to each country will be calculated based upon the number of people infected with HIV that reside there. It is entirely a matter for the devolved administrations as to whether or not they want to increase funding of the devolved schemes."

96. The Department provides funding for HIV to the devolved administrations, supplying payments that are equivalent to the EIBSS HIV payments to each beneficiary resident in the devolved administrations. The Department initially entered into this arrangement with the devolved administrations for the period 2015/2016 – 2020/2021. These payments were agreed to correct a payments miscalculation that had been made in the Spending Review 2015 and so the Department has continued to make these payments to the other three administrations to address the miscalculation, rather than devolve them.

97. The amount redistributed by the Department to each of the devolved administrations comprises two elements. Firstly, an annual payment for all existing HIV beneficiaries in each respective scheme, where the annual payment amount is equivalent to the HIV annual payment provided in England. Secondly, there is an amount representing discretionary payments for each devolved scheme. This is calculated by applying the Barnett formula[17] to the total actual discretionary payments made to HIV beneficiaries by EIBSS over a twelve-month period preceding the allocation.

98. This arrangement was initially entered into for the period 2015/2016 – 2020/2021. Emails confirming the arrangement and figures in relation to each devolved administration for 2020/2021 are exhibited (Exhibits WITN4688033 to WITN4688035). The Department has committed to continuing these payments for 2021/2022. The Inquiry will note that the amounts provided to each devolved administration reflect the small number of beneficiaries registered with the devolved schemes. As I have already explained, future funding is considered as the Department approaches each funding period. That is the case in respect of these payments also.

Section 6: EIBSS payment levels

99. Donna McInnes' draft statement set out the Government's aim, at the time of the reforms, that existing AHO beneficiaries should not be financially worse off under the reformed support scheme. When considering this aim, annual non-discretionary payments and discretionary payments should not be viewed as two distinct categories. Each is a part of the overall financial support made available to beneficiaries. The principle being applied was that no beneficiary should be worse off after the reforms, taking into account the overall payments administered by EIBSS. This was expressed by Nicola Blackwood, then Parliamentary Under Secretary for Health, in a House of Commons debate on Infected Blood on 24 November 2016 (Exhibit WITN4688036, at page 23), when she said the aim was that no one would be worse off under the new support scheme. As stated in Donna

[17] If the Inquiry is interested in the Barnett formula, it may wish to obtain further information from HMT, which will be better placed to give a comprehensive account of its operation and effect. An overview of the Barnett formula can be found here: https://commonslibrary.parliament.uk/research-briefings/cbp-7386/.

McInnes' draft statement, Ministers had previously indicated that there should be "no losers" from the scheme reform.

100. Before providing more information on this, the question posed states that "the approach underlying the reforms" which led to EIBSS "was that existing beneficiaries…should not be financially worse off." I entirely agree that this was one of the principles underpinning the reforms but it was not the only approach or principle that was important in the process of reforming the support schemes, as explained in Donna McInnes' draft statement.

101. Although EIBSS took over all functions from the AHOs on 1 November 2017 there were two stages to the reform of the AHO support schemes. The first stage, which was in place from 1 November 2017, was that EIBSS administered the lump sums and annual non-discretionary payments made to new and existing beneficiaries. That included the SCM. The second stage covered reform of the system for discretionary payments. Payments from the new discretionary scheme began from August 2018 and were backdated to April 2018. Between November 2017 and 31 July 2018, and until a review of the discretionary scheme was completed by NHSBSA, EIBSS administered discretionary payments by largely continuing with what the AHOs had done.

102. The Department had consulted on discretionary payments as part of both the 2016 and 2017 Consultations. Before the 2016 Consultation was launched the Department was aware of dissatisfaction with the discretionary support schemes and, at that time, the Department's thinking was that the role of discretionary payments should be significantly reduced. However, consultation responses indicated that many beneficiaries valued being able to access discretionary support.

103. This changed the Department's approach, and the 2017 Consultation stated the Department's intention to maintain the discretionary fund as far as possible and that it was committed to a scheme that provided, wherever possible, discretionary support in aid of those who needed it most (paragraph 2.29 of the 2017 Consultation, Exhibit WITN4688037). The Department was also aware that some beneficiaries were concerned that reforms to the scheme, including the discretionary element of the scheme, would impact negatively on their financial

situation (see paragraph 2.32 of 2016 Consultation response, Exhibit WITN3953052). As far as the discretionary element of the support scheme was concerned, the aim of the reforms was to harmonise and streamline the discretionary schemes that had been in place under the AHOs, seeking to ensure a fair level of support for all and to provide transparent and flexible support to beneficiaries most in need. As explained above, there was also an aim that no beneficiary should be worse off overall as a result of reforms.

104. Of course, it was necessary to take account of the overall affordability of the reformed scheme but in recognition of these factors and concerns, from 2018/2019 the EIBSS-administered scheme was to have an increased budget for discretionary payments. The 2017 Consultation Response (Exhibit WITN4688038) stated:

> "In recognition of the concerns raised in the consultation process, we are increasing funding for discretionary support and harmonising the way it's allocated in a new, fair, transparent and flexible system under the new administrator" (page 5).

105. When the Department asked NHSBSA to conduct a review of the system for discretionary support, beneficiaries' concerns about being worse off were put front and centre. The principle being applied was that beneficiaries should not be disadvantaged overall under the reformed financial support scheme.

106. NHSBSA carried out its review of discretionary payments between December 2017 and April 2018. The product, the EIBSS Discretionary Support Review (the 'Review'), stated:

> "All options considered have used a guiding principle of ensuring that beneficiaries are no worse off as a result of changes to discretionary support under the….(EIBSS) (as per ministerial commitment)…" (page 2).
>
> "NHSBSA are committed to ensuring that no beneficiary will be disadvantaged because of the changes that have been made to the discretionary element of EIBSS. This has been the overriding principle of all the potential options that have been considered as part of this review." (page 5).

107. I exhibit a copy of the finalised Review, dated July 2018 (Exhibit WITN4688039). I do not go into detail about what the Review says, but to respond to the Inquiry's question, I think the key points are below.

108. NHSBSA analysed information from the previous discretionary schemes and obtained input from beneficiaries in order to carry out the Review. It considered discretionary support including income top-up payments, one-off grants, payments for children, support for bereaved partners/spouses and non-financial support.

109. Income top-up payments are a discretionary monthly payment to increase a beneficiary's household income to help with general living costs, where a household's income is below a set threshold. Income top-up payments had been part of the discretionary support provided by the AHO charities. As far as income top-up payments were concerned, NHSBSA worked up three options or models for the Department to consider. Its analysis concluded that "all [of those three] models will result in an increase in beneficiary income overall once the 2018/19 uplift on regular payments is applied" (page 8). The model NHSBSA recommended, and the one accepted by Ministers, was that EIBSS should apply income assessments and income top-up payments consistent with the Macfarlane Trust's practice. NHSBSA's view was that, if this was done, no one should receive less, because the Macfarlane Trust's income top-up scheme was more generous than the scheme operated by the Caxton Foundation.

110. NHSBSA also recommended that the new scheme provide regular income top-ups to bereaved spouses/partners at the same level as the Macfarlane Trust, and based on the same income assessment. NHSBSA reported, "This will ensure that all bereaved spouses/partners receive at least the same level of income top-up as from the old schemes and most will be better off" (page 20).

111. I am also aware that discretionary means-tested payments were put in place for children of beneficiaries, aimed at helping with the costs of bringing up the children of an infected beneficiary.

112. Turning to discretionary one-off payments, NHSBSA analysed the information it had available from the AHOs and feedback from beneficiaries, which included that they would rather have increased payments than apply for one-off grants. The

Department listened to this and, with NHSBSA, agreed a list of types or categories of one-off support that could be applied for. The current list is found on the EIBSS website.

113. It is the nature of discretionary one-off payments that these are not regularly applied for, and applications will be for different things. This means comparing whether an individual beneficiary is worse or better off after the reforms, from the perspective of one-off payments only, is a difficult or impossible exercise. The principle underlying the reforms was that beneficiaries should not be worse off overall and the intention was that higher payments elsewhere in the scheme meant that one-off payments, particularly lower value payments, would be needed less often.

114. One-off payments for bereaved spouses were also made available, along with a winter fuel payment. A winter fuel payment is also made to infected beneficiaries.

115. NHSBSA's Review set out limitations in the analysis it could carry out. These limitations included that it did not have the criteria for income top-ups and one-off grants used by the Eileen Trust. I am not in a position to say why that was but NHSBSA may be able to help. Also, according to the Review, NHSBSA did not have information on the make-up of households to be able to assess how using the Macfarlane Trust's assessment of household income might impact Caxton beneficiaries. Again NHSBSA may be able to assist with the information that was made available to it by the AHOs.

116. Shortly after the new discretionary scheme was introduced, the Department became aware that the discretionary support payments of 122 beneficiaries had stopped when the scheme changed in August 2018. The Department sought to understand why and to consider what, if anything, should be done. I exhibit two relevant submissions to Ministers prepared by Department officials, dated 30 November 2018 and 20 December 2018 (Exhibits WITN4688040 and WITN4688041). Investigations showed that some beneficiaries had not re-applied under the revised scheme, some had re-applied but their application was incomplete, and some re-applied but were no longer eligible. The information initially available to the Department was that only two of these beneficiaries were known to be worse off under the revised discretionary payments scheme. However

the Department wished to understand this better because of (a) the commitment that no one should be worse off and (b) if payments were to be discontinued or reduced this should happen gradually. On this second point, the Equality Analysis accompanying the 2017 Consultation Response (Exhibit WITN4688038, page 31 onwards) stated that any reduction of regular discretionary support would happen over a reasonable period of time to allow those affected to adjust to the change. This principle was also identified in NHSBSA's Review.

117. Further analysis showed that 58 of the 122 beneficiaries were receiving a higher level of support from the scheme overall after changes to the discretionary scheme. Of the remaining 64:

    a. Six had sadly passed away and so no application had been made for support;
    b. One beneficiary was a bereaved parent who was no longer covered by the discretionary scheme;
    c. One beneficiary had been receiving a large income top-up from the Eileen Trust; and
    d. There were 56 beneficiaries who either had not re-applied for support (33 people), had submitted incomplete applications (15 people), or were no longer eligible to receive income top-ups or child supplementary payments because their household income now exceeded the upper threshold (8 people). The threshold itself had not been lowered under the revised discretionary scheme. The Department did not know why 33 beneficiaries had not re-applied but considered this might be (a) because their household income had increased since the last review of income had been carried out by the AHOs (in January 2016), and so they realised they were no longer eligible, or (b) because children in the household were now too old to be eligible for child supplementary support.

118. Ministers considered this information and decided that:

    a. A tapered support scheme should be introduced for all 56 beneficiaries who were receiving less support due to changes in the revised discretionary scheme (i.e. the support would be gradually reduced in line with the 2017 Consultation Response). The Department treated each of these

beneficiaries the same, even though only 8 had had their application declined. The tapering support scheme was to run over 15 months;

b. No action should be taken in relation to the 58 beneficiaries who were receiving more support overall from the revised scheme;
c. Discretionary support for any bereaved parent should be reinstated; and
d. Support for the beneficiary who had been receiving a large income top-up from the Eileen Trust should also be tapered over a 15 month period.

119. With regard to the 56 beneficiaries referred to above, their payments were gradually reduced either because they had not reapplied or because they were now known to fall outside the scheme rules due to their overall income having increased, i.e. the reduction in income top-ups brought them into line with the maximum payments available within the scheme rules.

120. As explained elsewhere in this statement, at the end of April 2019 Jackie Doyle-Price, the then Parliamentary Under Secretary for Health and Social Care, announced the Government's intention to increase funding for EIBSS from £46.3 million to over £75 million per annum in order to implement a major uplift in financial support of around 62%. As far as the discretionary support scheme was concerned, this funding uplift led to some changes from 1 April 2019. First, the need for infected beneficiaries to apply for income top-ups was removed – that support became part of the non-discretionary scheme of annual payments (which themselves were increased). Secondly, the income top-up brackets for the bereaved changed so that those with higher incomes could receive payments. Thirdly, those income top-up amounts increased. Fourthly, the income threshold to receive additional support for dependent children also increased, so that those with higher incomes could receive these payments. To be clear, winter fuel payments and one-off discretionary support have remained part of the scheme. Again, a principle behind the changes made was that no beneficiary should be worse off.

Section 7: Division of responsibilities between DHSC and EIBSS

121. I am asked about the design of the original SCM application form, whether changes to it have been considered and implemented, whether the Department or NHSBSA has primary responsibility for updating the forms (I am not sure if this

means the SCM form or EIBSS' forms generally) and what mechanisms are in place for gathering feedback on forms.

122. The 2017 Consultation included a draft SCM application form. That was drafted by the Department, with input from the reference group that the Department had convened. After the 2017 Consultation the SCM form was amended and a further draft application form was published with the 2017 Consultation Response. NHSBSA was not involved in this process of drafting and re-drafting the application form between the 2017 Consultation and the Response. This pre-dated NHSBSA acting as scheme administrator.

123. Between the 2017 Consultation Response and the SCM opening for applications, further amendments were made to the SCM application form. Changes were made on things like formatting, instructions to applicants on how to complete the form, adding a privacy notice and information about data sharing. However, the substance of the form, including the eligibility questions, was not changed.

124. I understand that, since 1 November 2017, there have been five versions of the SCM application form (including the current form). The changes have not been of substance, but rather have been on matters such as EIBSS' postal address and updating data protection guidance. These changes were instigated by NHSBSA, in keeping with its operational role.

125. Since taking on the administration of the EIBSS, NHSBSA has had responsibility for updating the design of the application forms. Paragraph 4.14 of the Service Specification provides:

"NHSBSA shall create application forms for:

- New Applicants to the scheme;
- Applicants applying for the hepatitis C Stage 2 payments;
- Applications for the special category mechanism;
- Applications for bereaved partners/ spouses; and
- Applications for discretionary support."

126. Annex C of the Service Specification also says that NHSBSA should use the draft application form included with the 2017 Consultation Response as a guide to the SCM application form (although that draft had been amended before EIBSS started operating, the eligibility criteria remained the same).

127. If NHSBSA was considering amending any application form, the Department would expect to be informed of this, in order to understand why and to ensure the eligibility criteria were not inadvertently amended. NHSBSA should not amend the application forms in such a way as to substantively change the eligibility criteria or policy (and it has not done this). Consistent with its operational role, NHSBSA could change aspects of the application form, e.g. layout, accessibility, options for applying online. The Department would expect to be notified of the intention to make changes to a form at the regular accountability meetings.

128. NHSBSA, as administrator of the scheme, is responsible for gathering feedback about all parts of the financial support scheme. I understand it has done so in a variety of ways, e.g. applicants and beneficiaries can offer feedback by telephone and email, and NHSBSA has held focus groups seeking feedback. Updates on beneficiary engagement are provided by NHSBSA to the Department but NHSBSA will be best placed to assist with whether it has gathered feedback specifically on application forms.

129. The Department expects NHSBSA to analyse and act on feedback, and to exercise its judgment as to when issues raised with it should be brought to the Department's attention. As indicated above, if feedback led NHSBSA to conclude it was appropriate to amend the application forms, I would expect that to be raised with the Department.

130. I am asked why the Department continues to have primary responsibility over matters such as the Service Specification. As described in Section 1A of this statement, the Department is responsible for EIBSS but has delegated operation of the scheme to NHSBSA. The Service Specification is an important document that sets out the services to be provided by EIBSS, on behalf of the Department, along with roles and responsibilities, financial arrangements and performance

levels. Given this, it was appropriate that the Department had primary responsibility for drafting the Service Specification when EIBSS was being set up. In its simplest terms, the Department needed to define what it wanted NHSBSA to do, and what it would do in return.

131. The Department continues to be responsible for the overarching policy in this area, including determining central components of the scheme such as eligibility criteria. Where appropriate, discussions as to the content of that policy will take place in conjunction with NHSBSA and this is reflected in the Service Specification. As noted above, at paragraph 14, that document is being revised. The Department and NHSBSA have worked together in this exercise and it has been a collaborative effort. Ultimately however, the Department remains responsible for the policy and must also set out what it expects NHSBSA to deliver.

132. I refer to paragraphs 121 to 129 above in relation to the responsibility for application forms

133. I am asked why the Department has primary responsibility over the provision of information about eligibility requirements. I think the premise of this question misconstrues how information is provided about eligibility requirements and where responsibility for determining those requirements lies. The Department is responsible for determining policy on eligibility requirements and NHSBSA is responsible for making payments in accordance with the eligibility requirements. The Service Specification (paragraph 4.12) requires NHSBSA to have a website that includes clear information on eligibility criteria for all payment types. This information is publicly available on the EIBSS website, which can be found at https://www.nhsbsa.nhs.uk/england-infected-blood-support-scheme.

134. I am asked why the Department continues to have primary responsibility over information sharing and other forms of co-operation and co-ordination with the other devolved schemes. To be clear (and as explained in paragraph 73 of Donna McInnes' draft statement), the Department does not liaise directly with the devolved schemes as this question appears to suggest. The Department liaises with the devolved administrations (as explained above in Section 3). It is those devolved administrations that then work with their respective devolved schemes.

135. The Department can and does share information on EIBSS with the devolved administrations where appropriate, and similarly information obtained from the devolved administrations is provided to EIBSS where it may influence or assist with service delivery. In this regard, I would refer the Inquiry to Section 3 of this statement, where I provide details of the nature of liaison with takes place between the four health departments. It is for the Department to participate in discussions on this subject, and the policy team subsequently provides updates to EIBSS.

136. I am asked about responsibility for policy and operational decisions. I refer the Inquiry to paragraphs 10 to 15 above for a description of the division of responsibility between the Department and NHSBSA, which is governed by the MOU and Service Specification. In very general terms, the Department is responsible for policy matters, such as determining eligibility criteria. Where a decision is purely a policy one, it will be for the Department to take, although the Department may seek NHSBSA's input. NHSBSA is responsible for operational decisions. Examples include determining individual applications, which medical experts to engage and establishing and operating appeal mechanisms (the Department requires that there is an appeal mechanism, as per paragraph 3.1.11 of the Service Specification).

137. Most of the day-to-day operation of EIBSS is carried on entirely independently of the Department, but consultation is expected in relation to significant issues, such as anything which might impact the application of eligibility criteria, or interfere with the service provided to beneficiaries, or have a notable impact on the budget.

138. Of course, there are times when the edges of this division are not entirely distinct. One such example, as provided for in the Service Specification, relates to larger discretionary payments (as distinct from income top-ups). Under paragraph 3.2.16 of the Service Specification, NHSBSA is responsible for making decisions about beneficiary applications for discretionary support without any input from the Department. However, if a one-off payment is in excess of £5000, or a recurring payment would exceed £9000 in a 12 month period, or the payment is outside the agreed policy, Departmental approval must be sought. An extraordinary payment of this nature should be confirmed by the Department so that it can, if considered

necessary, carry out its own assessment of the justification for the payment, as well as being informed for financial planning reasons.

139. EIBSS also keeps the Department informed on operational issues which could impact delivery of its services. For example, EIBSS recently advised the Department that the need to quarantine incoming post for two days in light of the Covid-19 pandemic could impact its ability to meet the KPI of acknowledging all new claims within three working days. The KPI was not in fact impacted by this, but it is this kind of operational update which the Department may receive and which assists it in overseeing the work of EIBSS.

140. A further recent example relates to the income top-up payments (see paragraph 3.2.5 of the Service Specification). These are discretionary monthly payments made to increase household income in order to help with general living costs of a bereaved spouse, civil or long-term partner who lived with an infected beneficiary and is on a low income. NHSBSA recently conducted a review of payments previously made in order to ensure that, in line with applicable guidance, any social security benefits received were to have the disability premium element disregarded in calculating the applicant's income (Exhibit WITN4688042). The results of that review were reported to the Department, which advised that back payments should be made to those impacted.

141. I can confirm that the details provided by EIBSS in response to questions 2(b), 3(a) and 6(c) of EIBSS' first rule 9 response, dated 16 November 2018, were and remain accurate, subject to noting that Ailsa Wight is no longer the senior official to whom NHSBSA is accountable for the administration of EIBSS. That role is now occupied by Helen Causley, Deputy Director with responsibility for Inquiries and Investigations. I am Helen's line manager.

142. At question 10 of EIBSS' second rule 9 response (dated 24 January 2019) EIBSS describes the role NHSBSA played in reforming the system for discretionary payments. I consider that to be a good example of collaborative working: the Department tasked and worked with NHSBSA to determine the parameters of the discretionary scheme. I provide further detail on this process in Section 6 above.

143. I am asked about EIBSS providing advice to the Department and the Department either taking or not taking that advice. In my view that depiction does not really

capture how the parties work together, when that is necessary outside of NHSBSA's day-to-day running of the scheme. NHSBSA delivers the scheme and engages with beneficiaries and the Department is open to hearing its advice and feedback on any issues it considers relevant. This can be done through the monthly or quarterly accountability meetings described in Section 1A and at paragraphs 147 to 151 below, or through informal contact between NHSBSA and departmental officials. The Department will actively seek advice where it considers that EIBSS' expertise and insight may be valuable to policy development (e.g. when the Department asked NHSBSA to review the discretionary payments scheme). Advice from NHSBSA is generally taken, as the Department greatly values the expertise and experience it is able to share. If the Department decided not to take the advice it would provide an explanation as to why, either during one of the regular accountability meetings or informally, depending on the context.

144. The Department also seeks, and EIBSS provides pro-actively, advice on how changes in policy may affect the administration of services provided by EIBSS, as well as advice to assist with policy development.

145. In March 2020, EIBSS proposed amending the existing policy on accessing mental health support, in order to make this easier during the Covid-19 pandemic. Prior to the pandemic, an applicant could apply for a discretionary payment to fund mental health support. To support that application, the individual had to obtain a letter from his/her GP and be on an NHS waiting list. In most areas this meant waiting a long time before being assessed. Recognising that the pandemic put extra pressure on vulnerable groups, EIBSS sought agreement from the Department to remove this extra layer and beneficiaries can now receive funding without GP approval or the need to access waiting lists. This payment can be used to access private mental health services. Further information on this is available on the EIBSS website: https://www.nhsbsa.nhs.uk/discretionary-support-scheme.

146. Similarly, over the course of 2020, NHSBSA has raised with the Department the potential for creating an immediate hardship fund (see, for example, Exhibit WITN4688049, the minutes of EIBSS Quarterly Accountability Review Meeting of 28 April 2020). The Department has considered this issue and has agreed with NHSBSA that EIBSS' ability to make discretionary payments is sufficient to meet

the objectives such a fund would be intended to meet. An immediate hardship fund was also discussed as a result of the Covid-19 pandemic. The Department was prepared to consider this but this was superseded by HMT's wider financial support measures across the population.

147. I am asked about regular meetings between the Department and NHSBSA. Paragraph 12.4 of the MOU provides for quarterly meetings between the Department and NHSBSA to "monitor compliance with the requirements of the Services...". In addition, it requires NHSBSA to provide quarterly reporting to inform these meetings (and monthly reporting, where appropriate) in accordance with the requirements in the Service Specification (see Section 9 of that document).

148. Attendance at the meetings is in part governed by the MOU and Service Specification. Paragraph 12.4 of the MOU states that quarterly progress meetings are to be held between the Senior Departmental Sponsor and the Head of Patient Services, and this requirement is reiterated by paragraphs 9.7 and 9.8 of the Service Specification, although the relevant individuals are currently Helen Causley and Chris Calise, Head of Health and Community Services at NHSBSA. In addition, these meetings will be attended by relevant policy officials within the Department and EIBSS staff members.

149. The standard agenda for the quarterly meetings (an example of which is exhibited as Exhibit WITN4688043) covers the following items:

a. Introductions and apologies;
b. Previous minutes and actions;
c. Policy updates;
d. NHSBSA updates;
e. Data;
f. Finance;
g. Governance; and
h. AOB.

150. Since March 2020 additional monthly meetings have been held, reflecting the need to ensure regular communication on the impact of Covid-19 and the need to obtain information relevant to the Inquiry as efficiently as possible. There have also been monthly meetings at times in the past. The greater regularity of the monthly

meetings means that they do not have a standard agenda - this allows discussion of any issues arising since the last meeting. The agenda will generally feature updates from both the Department and NHSBSA, a review of the dashboard which provides for monitoring of KPIs and of the risk register, and a finance item.

151. Minutes of all meetings are taken by NHSBSA administrative staff and subsequently provided to attendees. A number of minutes of both quarterly and monthly meetings are exhibited with this statement and I would invite the Inquiry to refer to these for examples of the types of matters discussed (Exhibits WITN4688044 to WITN4688050). Further minutes can be provided if necessary.

152. I am asked about any other review mechanisms between the Department and NHSBSA. Paragraph 12.5 of the MOU allows the Department to request that NHSBSA furnishes any other information, and paragraph 14.1 requires NHSBSA to inform the Department of complaints on a quarterly basis unless NHSBSA considers that the Department needs to take action as well, in which case NHSBSA should inform the Department at the earliest opportunity. The dashboard (an example of which I exhibit at Exhibit WITN4688051), which is updated by NHSBSA on a monthly basis and shared with the Department on a quarterly basis, provides data on each of the KPIs as well as the number of complaints received, if any, and associated performance data. The GIAA Audit noted that complaints are closely tracked through governance meetings (Exhibit WITN4688007, page 4). As NHSBSA is responsible for the day-to-day operation of EIBSS, the Department does not expect to be informed of the content of complaints relating to those matters, unless complaints demonstrate a systemic problem.

153. There are also ad hoc meetings between EIBSS and the Department. Either party can call for such a meeting and arrangements will be made jointly. There are no formal agendas for such meetings; they usually centre round a specific issue hence there is no need for a formal agenda. These ad hoc meetings are usually attended by the Department's policy lead and policy manager for EIBSS, as well as relevant NHSBSA staff. There are no formal meeting minutes, however issues and follow up items are communicated in email correspondence.

154. Recent ad hoc meetings have taken place on issues such as efforts to contact beneficiaries from the AHO schemes in order to inform them of their eligibility for financial support (see paragraphs 36 to 39 above).

155. A group called the 'Joint Review Group' ("JRG") was established in around November 2019 and has met three times, most recently in April 2021. These meetings were attended primarily by EIBSS officials and medical assessors. A Departmental official also attended. The purpose of the JRG was to consider discretionary financial support in cases which fell outside normal parameters. Departmental officials have previously provided a limited contribution to these meetings because the decision making has been largely operational. The Department's view is the purpose of the JRG now requires re-consideration in the light of the announcement of parity on 25 March 2021.

156. As far as I am aware, no concerns or issues have been raised with the Department by NHSBSA personnel about the funding, structure, organisation or running of EIBSS, about the Department's involvement with the scheme or about any other matter.

157. NHSBSA personnel would be welcome to raise such issues at any of the regular or ad hoc meetings held with the Department, either formally through the sponsorship team within the Department or informally with the Department's policy manager or policy lead. As set out above, the MOU and Service Specification make provision for the ongoing review of the scheme and its operation.

Section 8: Updates to previous witness statements

158. Further to the draft witness statement of Tim Jones, I exhibit a revised list of senior officials who were, or are thought to have been, involved in the establishment of the AHOs (Exhibit WITN4688052). This list should be read with the caveats in the exhibit and also in Tim Jones' draft statement. I also exhibit an updated list of Secretaries of State, Ministers and Parliamentary Under Secretaries since 1970 (Exhibit WITN4688053). Again, that list should be read with the caveat in Tim Jones' draft statement, i.e. that naming an individual is not intended to imply that he/she had any responsibility for blood policy generally or the trusts and schemes.

159. In addition, Helen Causley has replaced Tim Jones as the official responsible for EIBSS. Although responsibility for EIBSS used to sit within a broader blood policy team, as I explain in paragraph 3, it now sits within my Directorate, independent of the Blood Donation and Blood Safety policy teams.

160. I have reviewed the draft statements of Donna McInnes and Ailsa Wight. I am asked to provide any necessary updates, including on ongoing policy proposals and strategic steps and discussions. As the Inquiry will appreciate there are many discussions about issues relevant to EIBSS. I cannot attempt to describe all of these and so I have tried to identify the most significant ones in this statement and in the paragraphs below. I am aware that a response to another rule 9 request has addressed the issue of parity in support and I have prepared another statement which deals with psychological support. Therefore I do not cover these matters in more detail in this statement.

161. I am aware that some campaigners and beneficiaries have expressed discontent about assessments/re-assessments done by the Department of Work and Pensions ("DWP") for the purposes of state benefits. It has been suggested that beneficiaries could be managed through the benefits' system so they do not have to undergo these assessments. I am aware this was raised at a meeting with the Health Minister and Cabinet Office Minister on 28 January 2020, which I attended. I understand the Cabinet Office has raised this issue with the DWP, and it will be for the DWP to take decisions on this.

162. I would like to bring to the Inquiry's attention one issue which arose further to the reform of discretionary support which followed the uplift in payments announced on 30 April 2019. I exhibit as WITN4688054 a submission dated June 2019 which brings to Ministers' attention the position of secondary infected bereaved beneficiaries, that is to say beneficiaries who were sadly infected by someone who was infected through NHS supplied blood or blood products and are also bereaved due to having lost their spouse or partner. Under the revised scheme introduced in November 2017, this small group of individuals could apply for discretionary support in the form of income top-up payments as either an infected beneficiary or

a bereaved beneficiary, according to whichever route would give them the best financial outcome.

163. As part of the payment uplift, income top-up payments for infected beneficiaries were consolidated into the regular non-discretionary payments, such that all infected beneficiaries, including those who are secondary infectees, automatically receive the maximum income top-up payment. NHSBSA's analysis showed that the majority of this group previously applied for income top-up payments linked to their bereaved status. As the exhibited submission sets out, this raised the question of whether this group should be able to continue to do so. Ministers agreed that NHSBSA should continue to treat this group with flexibility, in order to ensure they obtained the best possible financial outcome.

Statement of Truth

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

Signed GRO-C

Dated 29 April 2021

Table of exhibits:

Date	Notes/ Description	Exhibit number
27 April 2018	Framework Agreement between the Department of Health and Social Care ("DHSC") and NHS Business Services Authority ("NHSBSA")	WITN4688004
23 February 2017	NHS Business Services Authority (Awdurdod Gwasanaethau Busnes y GIG) (Infected Blood Payments Scheme) Directions 2017	EIBS0000028

26 June 2018	Memorandum of Understanding between the Secretary of State for Health and Social Care and NHS Business Services Authority for the (England) Infected Blood Support Scheme	WITN4688005
August 2018	Service Specification	WITN4688006
15 May 2019	GIAA Audit	WITN4688007
December 2020	EIBSS Risk Register	WITN4688008
4 September 2017	Template letter from Caxton Foundation seeking beneficiaries' consent to transfer data	WITN4496002
30 November 2017	Letter from Jan Barlow, Chief Executive of the Caxton Foundation, to Ailsa Wight, Deputy Director, DHSC	MACF0000061_012
19 September 2017	Minutes of meeting of Infected Blood Reference Group	DHSC0046884_022
19 December 2017	Letter from Jackie Doyle-Price, Parliamentary Under Secretary of State to Diana Johnson MP	WITN4688009
31 March 2016	Skipton Fund Directors' Report and Financial Statements	WITN4688010
October 2019	EIBSS Risk Register	WITN4688011
[March?] 2014	Draft letter from Jane Ellison MP, Parliamentary Under Secretary for Public Health, to Alex Neill MSP, Cabinet Secretary for Health and Wellbeing, Scottish Government; Mark	WITN4688012

	Drakeford AM, Minister for Health and Social Services, Welsh Government; Edwin Poots MLA, Minister of Health, Social Services and Public Safety, Northern Ireland Executive	
January 2016	Briefing provided to Jane Ellison, Parliamentary Under Secretary of State for Public Health	WITN4688013
[Date unknown]	Draft stakeholder engagement plan developed between UK Health Departments	WITN4688014
15 July 2016	Email chain between UK Health Departments agreeing text of letter to beneficiaries	WITN4688015
July 2016	Letter from Jane Ellison MP, Parliamentary Under Secretary of State for Public Health to Shona Robison MSP, Cabinet Secretary for Health and Wellbeing, Scottish Government	WITN4688016
17 April 2015	Minutes of meeting between UK Health Departments	WITN4688017
1 August 2016	Minutes of meeting between UK Health Departments	WITN4688018
25 January 2018	Minutes of meeting between UK Health Departments	WITN4688019
8 May 2018	Minutes of meeting between UK Health Departments	WITN4688020
5 June 2018	Minutes of meeting between UK Health Departments	WITN4688021
10 July 2018	Minutes of meeting between UK Health Departments	WITN4688022
16 October	Minutes of meeting between UK Health	WITN4688023

2018	Departments	
21 November 2018	Minutes of meeting between UK Health Departments	WITN4688024
14 January 2019	Minutes of meeting between UK Health Departments	WITN4688025
22 March 2019	Minutes of meeting between UK Health Departments	WITN4688026
18 October 2018	NHSBSA Paper - Medical Assessment Process	WITN4688027
24 January 2017	Email exchange between Kypros Menicou and Professor Dusheiko	WITN4688028
15 July 2016	Note of meeting of reference group members	WITN4688029
24 August 2016	Email from Kypros Menicou to Monica Preuss re SCM – progressing psychological conditions	WITN4688030
23 February 2016	Dr Ewen Stewart, Thoughts on assessment of stage 1 Hepatitis C infected patients	WITN4688031
30 April 2019	Hansard extract, Infected Blood Support Scheme	WITN4688032
9 December 2020	HIV Funding Email – Scottish Government	WITN4688033
9 December 2020	HIV Funding Email – Welsh Government	WITN4688034
11 December 2020	HIV Funding Email – Northern Ireland Executive	WITN4688035

24 November 2016	Hansard Extract, Infected Blood	WITN4688036
6 March 2017	Infected Blood: Consultation on Special Category Mechanism and financial and other support in England	WITN4688037
13 July 2016	Infected Blood: Government Response to Consultation on Reform of Financial and Other Support	WITN3953052
28 September 2017	Government Response to Consultation on Special Category Mechanism and other support in England	WITN4688038
July 2018	NHSBSA EIBSS Discretionary Support Review	WITN4688039
30 November 2018	Submission to Ministers on Discretionary Support	WITN4688040
20 December 2018	Submission to Ministers on Discretionary Support	WITN4688041
5 November 2019	EIBSS Income Top-ups and Child Supplement Payments	WITN4688042
22 October 2019	Agenda for Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688043
29 March 2018	Minutes of Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688044
18 October 2018	Minutes of Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688045

29 January 2019	Minutes of Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688046
21 January 2020	Minutes of Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688047
19 March 2020	Minutes of Monthly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688048
28 April 2020	Minutes of Quarterly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688049
22 September 2020	Minutes of Monthly Accountability Meeting between DHSC and NHSBSA/EIBSS	WITN4688050
November 2020	EIBSS Performance Data Dashboard	WITN4688051
January 2021	Updated list of key personnel involved in setting up of AHOs	WITN4688052
January 2021	Updated list of health ministers	WITN4688053
25 June 2019	Ministerial Submission on managing support for bereaved secondary infectees.	WITN4688054