Witness Name: Brendan Brown

Statement No: WITN4496001

Exhibits: WITN4496002 to

WITN4496011

Dated: April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BRENDAN BROWN

ON BEHALF OF THE NHS BUSINESS SERVICES AUTHORITY

I, Brendan Brown, Director of Citizen Services of National Health Service Business Services Authority ("NHSBSA"), will say as follows: -

1. I provide this statement on behalf of the NHSBSA in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 July 2020. The statement is based on information available to the NHSBSA from its records of the England Infected Blood Support Scheme ("EIBSS") and the knowledge of members of the EIBSS team. I have made clear where the information is from my own personal knowledge.

Section 1: Introduction

- 2. My full name is Brendan Craig McMahon-Brown (known as Brendan Brown) and I am the Director of Citizen Services at NHSBSA, based at Stella House, Goldcrest Way, Newburn Riverside, Newcastle Upon Tyne, NE15 8NY. My date of birth is GRO-C 1968 and my professional qualifications are Public Administration and Management BA (Hons).
- 3. My career started in June 1985, when I was working for Middlesbrough Council in a clerical role. Within 12 months of starting, I progressed to a Team Leader and my career within management began. Between 1985 and 2001, I worked in various

- departments, including Housing and Social Services and Finance and Leisure Services. By 1999, I had progressed to Principal Officer, responsible for 500 staff and worked closely with the elected Mayor of Middlesbrough, various Councillors and Chief Officers of the Council.
- 4. In October 2001, I left local government to gain commercial experience and joined Hyder Business Services as a Head of Service. This national role involved business development and leading the delivery of services to local government clients. In 2006, I was head hunted by Enterprise PLC and took on a new role where I used my leadership skills and networks to help them grow their government services.
- 5. In late 2007, my skills were once again recognised as I was then head hunted by Northgate Information Solutions and appointed as Director of Business Services. In this national role, I was working with other leadership colleagues to grow the business and increase profitability for the private equity owner.
- 6. I joined NHSBSA as Head of Shared Services to create a world class contact centre for the NHS and lead a portfolio of various services on 14 April 2009. I held that post until 31 August 2017. I was appointed to my current role as Director of Citizen Services on 1 September 2017. In my current role, I am accountable for 1,300 colleagues working across 13 services, EIBSS being one of the smaller schemes that sits within the Health & Community Service as it is comprised of seven staff supporting beneficiaries. In my current role as Director of Citizen Services, I am involved in several corporate committees and other NHSBSA boards which relate to my current leadership role. As a senior leader, I also represent NHSBSA on several working groups and governance boards with NHS England and Department of Health and Social Care ("DHSC") sponsors. Since 29 September 2016 I held the position of Non-Executive Director with SMILE Through Sport (C.I.C), an organisation founded to create increased awareness, opportunity and enjoyment of disability sport in North East England. The role became Trustee on 29 September 2020, when the organisation achieved charity status.
- 7. I can confirm that the content of the five Rule 9 responses previously provided from NHSBSA to the Inquiry are accurate, save that where information previously provided has changed, this has been updated within this statement, where I have

been asked to do so. The dates of the requests and the response dates are shown below:

- 7.1. First rule 9: request 29 October 2018 and response 16 November 2018;
- 7.2. Second rule 9: request 19 December 2018 and response 24 January 2019;
- 7.3. Third rule 9: request 16 April 2019 and response 10 May 2019;
- 7.4. Fourth rule 9: request 24 September 2019 and response 18 October 2019; and 7.5. Fifth rule 9: request 27 February 2020 and response 23 March 2020.
- 8. For ease of reference for the Inquiry, I have included some of the content of these previous Rule 9 responses in this statement to provide context and for clarity.
- 9. I was involved in initial and subsequent discussions with DHSC regarding NHSBSA becoming directed to provide an "Infected Blood Payments Scheme." The scheme was to make payments on behalf of the Secretary of State for Health and Social Care to those infected by hepatitis C and/or Human Immunodeficiency Virus ("HIV") from NHS blood or blood products and to provide additional support to the families of those infected. The detail that sits beneath the directions is defined within both a Memorandum of Understanding ("MOU") between NHSBSA and DHSC and a specification agreed with DHSC. The specification defines EIBSS administrative support services, which are undertaken in adherence to performance measures. EIBSS does, however, aim to always provide the best possible service, learning from feedback to improve wherever possible, and not simply meet agreed measures. Copies of these documents are already held by the Inquiry.
- 10. I confirm that I have no membership, past or present, of any of the committees or groups relevant to the Inquiry's Terms of Reference.
- 11. I confirm that I have never had any role in the Alliance House Organisations ("AHOs") which are discussed in more detail below.
- 12.1 confirm that I have not provided evidence to, nor have I been involved in, any other inquiries, investigations or criminal or civil litigation in relation to HIV, hepatitis B, hepatitis C and/or variant CJD in blood and/or blood products.

Section 2: Establishment of the Devolved Schemes

13. By way of background, in March 2017, DHSC directed NHSBSA to deliver a single programme of payment support to people in England historically infected with

hepatitis C and/or HIV through NHS supplied blood or blood products. The scheme devised by DHSC was to also provide support for their families, including spouses, civil or long-term partners, children and other dependents. At the time, and up to the point at which NHSBSA went live with the new service, beneficiaries were provided with support from five organisations:

- 13.1. Eileen Trust;
- 13.2. Macfarlane Trust:
- 13.3. Caxton Foundation;
- 13.4. Macfarlane and Eileen Trust Limited ("MFET Ltd"); and
- 13.5. Skipton Fund.
- 14. The first three of these organisations were charities and the last two were companies. Collectively, these organisations were known as the Alliance House Organisations ("AHOs"), as all were based in Alliance House, London.
- 15. NHSBSA worked with DHSC and the AHOs to develop a delivery model that would enable NHSBSA to support beneficiaries in England and a specification document was agreed with DHSC. I can confirm that I was personally involved in consultation with DHSC and AHOs regarding the establishment of EIBSS. My involvement was limited to attending relevant meetings to understand what effect the outcome would have on the establishment of EIBSS. I maintained oversight of the establishment of EIBSS through to inception and eventual project closure once the service had been on boarded successfully. As set out in NHSBSA's first and second Rule 9 response, I held the role of project executive throughout the setup of EIBSS and attended DHSC and NHSBSA Board meetings related to the establishment and oversight of the "Infected Blood Payments Scheme." On 1 November 2017, NHSBSA went live with the new service, EIBSS, and immediately started supporting beneficiaries. The delivery of EIBSS within NHSBSA remains within Citizen Services Directorate.
- 16. As an Arm's Length Body of DHSC, NHSBSA deliver EIBSS by direction from the Secretary of State for Health and Social Care. NHSBSA is held accountable for the scheme administration by the DHSC Policy Team. This team originally sat within the Emergency Preparedness and Health Protection Policy Directorate until July 2019, when the DHSC Policy Team moved Policy Directorates (to the Acute Care and Workforce Directorate), where they remain. DHSC are responsible for the scheme's policies and fund NHSBSA to administer the scheme on their behalf,

- including making discretionary payments to beneficiaries. The DHSC are responsible for determining policy on:
- 16.1. The level of payment provided to infected beneficiaries relating to their infection;
- 16.2. The level of payment provided to bereaved partners of the scheme (i.e. oneoff bereavement payments);
- 16.3. The level of discretionary income top-up support provided to beneficiaries;
- 16.4. The types of one-off discretionary payments and other support provided to beneficiaries.
- 17. Upon taking on the scheme administration on 1 November 2017, NHSBSA continued the model of payments as administered by AHOs. Payments to beneficiaries continued at the same level as previously agreed. This continued until 31 March 2018. Thereafter, DHSC instructed NHSBSA that non-discretionary payments would increase in line with the Consumer Price Index (and this annual increase in line with the Consumer Price Index has happened every year since NHSBSA administered the scheme). However, from 1 November 2017, NHSBSA was required by DHSC to review discretionary levels of payment and circumstances and beneficiaries' views of the current scheme were sought, to inform future changes. Surveys were sent out, focus groups undertaken and information collated and shared with DHSC, who agreed the policy approach with the relevant Minister before working with NHSBSA to draft guidance on payments. A high-level timeline relating to the initial stages of EIBSS commencement is as follows:
 - 17.1. November 2017 EIBSS established. Special Category Mechanism ("SCM") applications posted to beneficiaries.
 - 17.2. December 2017 to April 2018 Review of discretionary payments was undertaken.
 - 17.3. March 2018 Communications sent to beneficiaries about discretionary scheme changes commencing from July 2018.
 - 17.4. April 2018 Initial draft of discretionary report supplied to DHSC.
 - 17.5. June 2018 New policy for discretionary payments implemented.
 - 17.6. July 2018 New payment levels applied (not paid until August, backdated to July).

- 18. DHSC instructed NHSBSA to review the discretionary payments made by the previous scheme administrators because the discretionary schemes were set up at different times by the different scheme administrators and different criteria were used to calculate entitlement and payments. The aim was to combine them under one framework for consistency and fairness, with the aim that no beneficiaries would be worse off. The review of the discretionary payments system took place in December 2017 to early 2018. In January 2018, NHSBSA invited all beneficiaries to participate in the discretionary payments review, through an online survey, telephone survey and focus group. 255 beneficiaries responded to the surveys and two focus groups were held (one in London and one in Manchester) to capture beneficiary feedback and insight on the then current discretionary schemes and to help NHSBSA design a single, revised discretionary scheme around the beneficiaries' needs. The feedback was then shared with DHSC as part of this review to allow DHSC to consider potential policy changes/payment amounts and to develop revised DHSC policy for this aspect of the scheme with the Minister responsible for this area. DHSC subsequently instructed NHSBSA to proceed and implement the revised discretionary scheme. Beneficiaries were informed by NHSBSA that the revised discretionary scheme for EIBSS would open from June 2018, in communications sent to them in March 2018 by EIBSS. The new scheme was communicated early to allow beneficiaries time to pull information together to support their applications and to allow time for assessment of the anticipated levels of application forms. Ahead of June 2018, NHSBSA colleagues worked with the DHSC policy team to design guidance based on that policy to be shared on the website and communicated to beneficiaries. Payments were made from August, backdated to July 2018 if beneficiaries were now entitled to more.
- 19. The SCM was also introduced at the same time as NHSBSA launched EIBSS in November 2017. This new process enabled beneficiaries with hepatitis C stage 1 to apply for higher annual payments, equivalent to hepatitis C stage 2 and HIV annual payments. The intention of this new process was to enable people with a hepatitis C stage 1 infection which was having a substantial and long-term negative impact on their daily lives, to apply for higher annual payments.
- 20. The aims and objectives of EIBSS are to support people historically infected with hepatitis C and/or HIV from NHS blood or blood products. EIBSS also helps families, including civil or long-term partners, after the death of someone infected.

- NHSBSA undertakes its administrative function in accordance with the agreed specification set by DHSC, by operating EIBSS on behalf of DHSC.
- 21.EIBSS is administered with the same principles and philosophies as all other directed NHSBSA services: to provide a high quality service for its users/beneficiaries, striving to continuously improve by listening to users/beneficiaries in order to provide the best possible service.
- 22.NHSBSA is only accountable to DHSC. It is not regulated or accountable to any other body/organisation. This governance structure is described elsewhere in this statement.

Section 3: Transitional arrangements from AHOs to EIBSS

- 23.I attended meetings at the outset of the formation of the EIBSS scheme with our DHSC policy sponsors to input from a NHSBSA perspective. I also attended meetings with the AHOs at the outset of NHSBSA looking to on-board the service.
- 24. For the transition and setup of EIBSS, as set out above, I acted as the project executive for the implementation of the EIBSS service, meaning that I oversaw the project board and had overall responsibility for the project. The project board involved various senior members of staff from different departments and had oversight of the project delivery team, which was headed by the project manager. The project delivery team included Chris Tempest (who was Senior Service Delivery Manager the operational lead for EIBSS and who liaised with the previous scheme administrators and their Chief Executive, Jan Barlow, in the transitional phase leading up to the establishment of EIBSS). Chris Tempest reported into both the project delivery team and attended the project board meetings. I did not directly line manage Chris Tempest; however, I oversaw any work that the project was doing. Chris Tempest was line managed by Chris Calise, who I did line manage directly.
- 25. Beneficiary data was not automatically shared between the AHOs and EIBSS. It was both DHSC's and NHSBSA's preference that data was to be shared automatically and beneficiaries given the option to opt out should they so wish. However, the AHOs in this case acted as the data owners/controllers so NHSBSA had no control over their actions. DHSC liaised with the AHOs on this point, however, they were unable to change the AHOs' approach. As NHSBSA did not

have control of the original data/information, it was not within our gift to dispense with prior consent by beneficiaries to share data with NHSBSA as we did not have access to the data in any way. The AHOs implemented a policy of only sharing data by explicit consent following their own legal advice in this regard. Letters were sent to beneficiaries explaining the shutdown of their services and the transition to EIBSS. An example of one such letter is attached to this statement as my **Exhibit BB1** (WITN4496002). This example letter was shared with the NHSBSA on 6 September 2017 by Chief Executive Jan Barlow, explaining that this had happened at that time.

- 26. Several staff from the AHOs transferred to NHSBSA under TUPE at the inception of EIBSS. An agreement was made to second two staff back to the AHOs for one or two days per week to try and trace or make contact with those who had not provided their express consent to have data shared, to deal with any correspondence relating to the transfer and to pick up any residual data transfer forms being completed and sent back to AHOs after the migration of the service to NHSBSA. These secondments lasted from 1 November 2017 until 31 March 2018 to ensure coverage for an extended period after the scheme had transitioned from the AHOs to NHSBSA.
- 27.NHSBSA does not know what publicity work the AHOs carried out other than to write to all registered beneficiaries and explain on their websites that their schemes were closing. DHSC had also explained the scheme was moving to NHSBSA in their consultation with people who were affected by infected blood. NHSBSA did not undertake any publicity outside of writing to those who consented to the data transfer, although NHSBSA representatives had discussions with both the Hepatitis C Trust and Haemophilia Society ahead of the scheme transfer, to ensure that both organisations were aware and that they had relevant contact details of the scheme in order to be able to signpost to EIBSS.
- 28. Certain data was shared by the AHOs with NHSBSA. However, as explained above, the decision as to which records and the extent of the records that were shared was determined by the AHOs and those decisions were not within the gift of NHSBSA. The AHOs shared beneficiaries' information that consisted primarily of reference number, name, date of birth, contact details and current payment information, which was passed electronically to NHSBSA. Any previous paper applications, letters or correspondence (either e-mail, telephone recording or letter)

- as well as any system notes, were not passed to NHSBSA. The fact that previous physical application forms or notes/correspondence were not shared was outside of the control of NHSBSA, as the AHOs were unable/unwilling to share this information with NHSBSA.
- 29.A few options were considered to facilitate the transfer of details for those beneficiaries who did not give their consent to AHOs, and thus whose details could not be transferred to EIBSS. Russell Cooke solicitors (the lawyers currently holding and responsible for the AHOs' legacy data) have a data sharing agreement ("DSA") in place, which states that beneficiary information shared between AHOs and their firm 'will not be shared' with the NHS. NHSBSA believe that this restriction was added to be in keeping with the consent exercise undertaken and met with the expectations of beneficiaries. This stipulation within the DSA meant certain options to further identify beneficiaries could not be used, as this would have breached this confidentiality clause within the DSA.
- 30. During 2020, a number of meetings were held with DHSC and Russell Cooke to discuss how to address this issue. Most recently, at the start of March 2021, it was agreed at a meeting between DHSC and NHSBSA that a communication campaign seems like a sensible next step to publicise EIBSS and what the scheme covers, as all other data sharing routes were not considered appropriate. The communication could invite any individual who considers that they may be entitled to financial or non-financial help from EIBSS to get in touch. This recommendation is currently subject to ministerial approval before it can be taken forward. If approved by DHSC, this option would be fully investigated, planned, resourced and funded by DHSC to be sure that it reaches the intended audience.
- 31. Since November 2017, EIBSS has been contacted by 67 beneficiaries who were previously registered with the Skipton Fund but who had not consented to their information being shared with EIBSS. These beneficiaries now receive support from EIBSS. Where EIBSS is contacted by a beneficiary who was previously registered with the AHOs but who had not previously consented to their information being shared with EIBSS, EIBSS asks them to contact Russell Cooke solicitors in the first instance, to transfer their AHO data to EIBSS, and we provide the necessary contact details for them to do this themselves. This has led to time delays for some cases in reinstating payments for beneficiaries. This has also led to disappointment and upset from some beneficiaries as they held a mistaken belief

- that EIBSS did hold their historical information, which may result in them having to repeat upsetting previous events and issues they previously shared with AHOs. In some cases, this could have hampered building relationships or beneficiary perception of the EIBSS service.
- 32. NHSBSA has considered whether we could offer our assistance to these previously registered beneficiaries and act as an intermediary, by seeking an 'authority to act' type agreement with them to source the documents from Russell Cooke on their behalf. However, this was not taken forward as it was considered to be an additional administrative step that may delay the process further, opposed to assisting with it. The rationale for this decision is that an individual would need to provide EIBSS with appropriate identification information, for us to pass this on to Russell Cooke, so that they were assured we were acting appropriately on the individual's behalf. If this was not appropriate, EIBSS would have to seek further information and provide that to Russell Cooke, to allow the information sharing to commence.
- 33. The current process allows a previously registered beneficiary to immediately contact Russell Cooke directly via post, email or telephone and for Russell Cooke to guide them through identification requirements, in order for the information they hold to be released to them and the NHSBSA. Additionally, as Russell Cooke hold the records of all previous beneficiaries, they can use this information to confirm an individual's identity, something that the NHSBSA does not have access to, due to the explicit consent process used prior to the commencement of EIBSS.
- 34. A potential EIBSS beneficiary has varied options to contact EIBSS: post, email and telephone. Russell Cooke also has the same contact options, which provide an individual with reasonable options to aid with any potential technology issues in making contact with either organisation.
- 35. AHOs wrote to each beneficiary for whom they had records to explain the transition to EIBSS as part of the data transfer and their operational shutdown. Both the Haemophilia Society and the Hepatitis C Trust were made aware of the change from the AHOs to EIBSS so would have been able to signpost anyone who got in touch with them to provide the new scheme information. DHSC also ran a public consultation with the infected and affected community regarding the support arrangements that led to the creation of EIBSS, including support groups such as the Haemophilia Society and Hepatitis C Trust. This had been communicated

- widely by DHSC within the community, so further wider communication beyond these three methods was not deemed necessary as public awareness of this new scheme should have been reasonably high.
- 36.NHSBSA were unable to contact previously unsuccessful applicants to each AHO that did not have their data transferred by the AHOs as we did not have contact details. NHSBSA is unable to comment further on any other steps that might have been taken by the AHOs to contact beneficiaries.
- 37. Where NHSBSA did receive contact details for beneficiaries, EIBSS wrote to all registered beneficiaries with a 'welcome letter' that gave contact details and information about EIBSS. A copy of the welcome letter is attached to this statement as my **Exhibit BB2** (WITN4496003). The letter included links to the EIBSS webpages for further information, including information on payment continuation and operation. This initial letter explained that EIBSS would continue current payment arrangements, provided contact details advising beneficiaries to speak to EIBSS about current support as well as sharing the link to the EIBSS website. EIBSS also advised that there would be a review of the discretionary scheme and that eligible beneficiaries for the new SCM would be contacted shortly.
- 38. If the AHOs had shared all their data with EIBSS without requesting further consent, this would have allowed a greater reach by NHSBSA to all beneficiaries who were previously registered with the AHO schemes. Our own information governance experts felt that this approach was allowable, which was shared with the AHOs. However, this decision was outside of the control of NHSBSA as the AHOs acted as the data owners/controllers.
- 39. As explained above, the public communication that led to the establishment of EIBSS was communicated widely by DHSC as part of the consultation within the infected and affected community, so public awareness of this new scheme should have been reasonably high and further wider communication about the scheme at the time of its establishment was not deemed necessary. We have seen further applications coming into the scheme regularly since EIBSS' inception.
- 40.In agreement with DHSC, NHSBSA continued previous arrangements from the AHOs for all new beneficiaries to backdate payments to the date an application was first received by EIBSS. Other options such as providing exemptions or waivers as to documentary record requirements were not considered.

- 41. EIBSS does not provide for exemptions or waivers to documentary evidence requirements for any reason. Medical assessors (and the appeals panel where required) will consider all available evidence against the balance of probabilities to decide whether someone is eligible for payments under the scheme. The EIBSS website provides details of the types of information that can be provided in support of an application, which is not exhaustive. For the different application types, our website includes "Supporting Evidence" guidance under the "How to Apply" section, which aims to make clear what can be provided in support of an application. https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-howapply/people-infected-hepatitis-c-stage-1-payment Medical assessors could consider a witness statement on its own merits. The detail of that witness statement would determine whether or not this would be sufficient; obviously, a witness statement that provides other supporting evidence strengthens an application and provides the assessors with more to assist in their decision-making capacity.
- 42. The EIBSS service is responsible for the distribution of public monies to beneficiaries and has a duty to beneficiaries that this money, which is dedicated to their welfare and support, is distributed correctly and fairly, in accordance with the scheme rules. NHSBSA is required to formulate procedures that reduce the potential for fraud and claimant error, as well as making sure that payments and applications approved are done so consistently against set criteria. EIBSS asks for evidence to demonstrate eligibility for payments and is unable to reduce this requirement without lessening safeguards around the EIBSS monies.
- 43.EIBSS had webpages from 1 November 2017 when it was initially set up. The website covered contact details and the different types of support available, as well as application forms that could be downloaded. Since the beginning of the scheme, information has been added to this website following feedback and internal reviews, to help improve beneficiary experience, accessibility, guidance, and other supporting information. The latest updates and communications to beneficiaries are also added, as well as the EIBSS Annual Report.

Section 4: Relationship with Government

44. NHSBSA has no role in monitoring the differences between the devolved schemes.

- 45. NHSBSA designs and operates internal processes for the administration of the EIBSS service. All the policy-related elements of the service are owned by DHSC who direct NHSBSA in this regard, such as levels of payment, criteria for payments (i.e. what will be paid out for). NHSBSA administers a wide range of other schemes for DHSC. Amongst other things, NHSBSA administers the NHS Pension scheme and the NHS Help with Health Cost schemes. It therefore has the expertise to design internal processes in support of the work it has been directed to undertake by DHSC for the administration of EIBSS. Once a policy decision has been determined by DHSC and communicated to beneficiaries, the day-to-day interaction with beneficiaries and application decisions is undertaken by NHSBSA acting on behalf of DHSC.
- 46.EIBSS is independent of other NHS bodies, and as set out elsewhere in this statement, as an Arm's Length Body of DHSC, NHSBSA delivers EIBSS by direction from the Secretary of State for Health and Social Care. NHSBSA is held accountable for the scheme administration by DHSC Policy Team (Acute Care and Workforce Directorate). DHSC are responsible for the scheme policies and fund NHSBSA to administer the scheme on their behalf, including making discretionary payments to beneficiaries.
- 47.NHSBSA have the day-to-day interaction with beneficiaries through calls, emails, post and, additionally, face to face through focus groups. As such, beneficiaries will feedback their experiences of certain elements of scheme support, ask for additional support or propose a new type of support. NHSBSA take this insight and inform DHSC of this feedback.
- 48. In January 2020, the EIBSS Joint Review Group ("JRG") was established. The group is a decision-making forum, to consider specific questions, cases and feedback regarding the existing scheme rules, to determine whether a change may be required. The attendees are DHSC (Policy), NHSBSA (operations/administration) and a medical expert. The group will meet as required, based on the number of items for it to review. The quorum will allow for informed decisions to be made. The agreed decisions do not absolve the relevant organisation from their responsibilities as defined within the EIBSS MOU. The Terms of Reference for the JRG can be found at Exhibit BB3 (WITN4496004).
- 49. Prior to the establishment of the JRG, consideration of specific questions, cases and feedback regarding the existing scheme rules from beneficiaries were

reviewed on an ad hoc basis via emails, meetings, or a combination of both. DHSC requested the establishment of the JRG as they felt that these decisions required a formal review mechanism, which allowed for considered opinion from staff of different backgrounds to allow an informed decision to be made. Items and changes can be approved, declined and deferred following a thorough discussion on each item.

- 50. By way of an example, at the January 2020 JRG, an item for discussion was regarding simplifying the application processes for a respite break, where a partner needs to accompany the beneficiary. By way of background, a respite break is available to recover from an exacerbated period of ill health or to recover from treatment. Short haul travel can be covered; £750 for a beneficiary and an additional £750 if a medical specialist can confirm they require a carer to travel. The request asked, 'when applying for respite breaks, is it necessary to have a medical recommendation when applying for a carer payment?' because the recommendation can delay the application process. Usually partners are the carer and provide both physical and mental support, so it was requested that a commonsense approach be applied here. This change was approved. EIBSS discussed applying a common sense 'self-declared' approach where a partner of a beneficiary is also their carer, which removes the need for a medical professional to declare that a beneficiary is required to be accompanied on a respite break.
- 51. Also, at the January 2020 JRG, another item for discussion was raised from a beneficiary as to why, when EIBSS knows a beneficiary's medical history, beneficiaries had to keep paying £25.00 for a doctor's letter each time they are asked to provide medical history. It was noted that beneficiaries can find getting out difficult, in addition to trying to get a doctor's appointment.
- 52. However, this request was declined. Requests for medical history are made as health conditions can change and previously supplied information may be outdated. Medical letters are reimbursed if a beneficiary incurs a cost for such a letter. The group felt that this current process was appropriate. However, the group felt that the process could be simplified. EIBSS agreed to investigate the design of a pro-forma that can be used by the beneficiary to obtain the necessary information from their medical professional. New forms were created and uploaded to the EIBSS website.

- 53. All items considered at the JRG have a supporting explanation, which summarises the group's view on why an item is either approved, declined or deferred. The full notes for the two items described above are attached at my **Exhibit BB4** (WITN4496005).
- 54. I confirm that the details provided in answer to questions 2(b), 3(a), 6(c) in our first Rule 9 response dated 16 November 2018 remain correct.
- 55.NHSBSA administers EIBSS on direction from the Secretary of State for Health and Social Care. The service is delivered within an accountability and reporting arrangement with DHSC. The senior official who manages NHSBSA's accountability on behalf of DHSC is Helen Causley, Deputy Director, Inquiries and Investigations Acute Care and Workforce Directorate.
- 56. EIBSS operates within the Citizen Services Directorate at NHSBSA, which is the public facing Directorate that delivers services to a wide range of beneficiaries, patients and customers. As the Director of Citizen Services, I report to NHSBSA's Chief Executive and I am a member of NHSBSA's Board.
- 57. As set out in our first Rule 9 response dated 16 November 2018, policy is set and determined by DHSC. DHSC set the policy for payments for medical conditionrelated payments, bereavement payments and discretionary payments. NHSBSA recently reviewed the discretionary payments schemes acquired from AHOs to determine the level of payments being made to beneficiaries and to ensure there was a consistent and fair payment process for all beneficiaries, including EIBSS income top-up ("ITU") payments and one-off payments. At the time, there had been ministerial commitment to ensure that beneficiaries did not lose out, which was one of the key aims behind the review. NHSBSA applied this instruction to ensure that this was the case for most beneficiaries. NHSBSA analysed the information on the support provided by the former payment schemes and considered the input of beneficiaries in this review via surveys and focus groups. One of the difficulties in forecasting what changes to ITU payments would mean for beneficiaries in terms of monetary impact was that we only had some of the previous schemes' income brackets and the current payment level that beneficiaries registered with them received. We did not have detailed income information, such as earnings information and any state benefits information from those previous administrators and we were aware income had not been assessed in two years. (Usually ITU payments require annual assessment and verification of household income.) In

some cases, no data was received for how some beneficiary ITU payments were calculated previously, such as in the case of three Eileen Trust beneficiaries about whom no information could be provided as there was no set criteria and each appeared to have been assessed on an individual basis for how their ITU assessment had been calculated, unlike the Caxton and Macfarlane ITU processes. Without detailed information on the income of all beneficiaries currently receiving support, we were not able to forecast monetary impact on beneficiaries accurately and the achievement of the ministerial commitment is not guaranteed.

- 58. NHSBSA also did not know the extent to which those registered with EIBSS were aware of the discretionary support available to them, including ITU payments. This made it difficult to estimate any prospective increases in applications that may occur in the future. NHSBSA anticipated that there would be an increase in applications to the discretionary scheme as more individuals would be eligible to apply and also be eligible for higher levels of ITU. It was particularly difficult to accurately estimate the increase from the following groups:
 - 58.1. Hepatitis C stage 1 beneficiaries who were not receiving ITU from the Caxton Foundation:
 - 58.2. Hepatitis C stage 2 beneficiaries who were not receiving ITU from the Caxton Foundation; and
 - 58.3. Widows who did not realise that they were eligible for support from the Caxton Foundation.
- 59.A draft report was produced by NHSBSA and shared with DHSC in April 2018, which contained options to address the inconsistencies between the former schemes' support for both ITU and one-off payments, alongside the estimated potential costs to implement each option. All options were considered on a guiding principle of ensuring that beneficiaries were no worse off as a result of changes to discretionary support under EIBSS (as per the ministerial commitment) and that any new payment scheme should encompass all of the aspects that DHSC had outlined in their 2017 consultation response. DHSC then approved the current discretionary payments policy. DHSC had previously consulted beneficiaries on discretionary support and considered key elements of the discretionary scheme which they required should remain. All elements were factored into the new discretionary payments scheme proposals and approved by DHSC. NHSBSA also

- spoke with beneficiaries when reviewing key elements of the scheme for their feedback.
- 60. The changes made to how ITU was calculated and the effect of those changes must not be considered alone, as another payment change made at the beginning of 2018/19 was to uplift the annual payment value too. Holistically, considering the uplifts in annual payments for beneficiaries during 2018/19 and all the ITU options, meant that, overall, no one should be worse off under the new scheme based on the information NHSBSA had received. Indeed, as predicted, the introduction of the EIBSS ITU resulted in increased application numbers and as at the end of December 2018, 1,017 beneficiaries were in receipt of ITU payments. This is an increase of 607 beneficiaries in receipt of ITU when compared to the 410 in receipt of ITU under the old schemes.
- 61. NHSBSA was aware of some particular circumstances where beneficiaries may have been impacted. There was a risk that the Caxton Foundation beneficiaries who were previously assessed using the income of the beneficiary (and partner where relevant) may be impacted by the change to using the household income (i.e. income of all adults in the household apart from dependents in full-time education until the age of 21). As information was not available on the make-up of the households for these beneficiaries, it was not possible to understand exactly what impact this change might have. This point was however considered alongside the fact that the Macfarlane ITU brackets were more generous and therefore would take into account an increase on their previously assessed income if anyone else in the household was taken into account.
- 62. Where anyone was identified as receiving (through the combined change to ITU and annual payments) a lower amount paid, the changes in payment were to be phased in, as per the consultation response on discretionary support. This was determined following the launch of the new scheme and new income assessment for those wishing to continue to apply for ITU.
- 63. The discretionary review shows that there was a total of 410 beneficiaries receiving ITU payments who were registered with either the Macfarlane Trust or the Caxton Foundation. Once the EIBSS ITU was introduced and beneficiaries' incomes were assessed using this model, it was identified that a total of 57 beneficiaries were initially affected and therefore financially worse off. These 57 beneficiaries fell into the following categories:

Qty	Category			
34	Beneficiaries that didn't reapply for ITU/child supplements			
10	Beneficiaries that applied and didn't provide the full information to be able to			
	assess their claims			
9	Beneficiaries that were declined as over thresholds			
4	Applied and the resulting ITU payment was less than previously paid under			
	the old schemes			
57	TOTAL			

- 64. NHSBSA informed DHSC that 57 beneficiaries were affected by the introduction of the changes and it was agreed that letters would be sent to those beneficiaries explaining the rules had changed and that their payments would be tapered down over a period of adjustment. DHSC created a submission for the approval of the Minister at the time for their confirmation of this approach for anyone affected. This approach was consistent with paragraph 3.19 of the Government's response to the consultation on infected blood support published in October 2017, which stated 'Where payments may be discontinued or reduced, the move will be phased in over a period of time in order to avoid an immediate reduction in payments received'. It should be noted that ITU letters issued when EIBSS took over the scheme to beneficiaries prior to the discretionary review included the text 'Please also be aware that the discretionary income top-up payments are due to be reviewed by the scheme. We are therefore only able to guarantee the top-up payments you are currently receiving until June 2018.
- 65. As explained previously, NHSBSA takes on board feedback from the beneficiaries it supports. We will pass on this feedback to DHSC for consideration regarding a possible change in support. Depending on the size and scale of the change it may be added as an item for consideration within the JRG, discussed above, or DHSC may choose to investigate and analyse the request themselves and/or request any supporting information or views from EIBSS to help inform their decision.
- 66.NHSBSA are expected to make final decisions on any application for discretionary support, without input from DHSC. However, for:
 - 66.1. any individual, one-off payment over £5,000;
 - 66.2. any recurring payment which would exceed £10,000 in a 12-month period; or
 - 66.3. any payment outside of agreed policy

- NHSBSA will need to seek prior written DHSC approval before the payment is committed.
- 67. As set out elsewhere, the purpose of discretionary support is to provide additional, time-limited financial (and non-financial) support to primary and secondary beneficiaries to address immediate needs. The needs considered are those that have a direct effect on an individual's independence, have been brought about as a result of their infection or its treatment and are otherwise unable to be met.
- 68. There was a previous issue with obtaining timely funding for a specific quarter's funding, which was highlighted to DHSC. The issue was attributed to the new DHSC Policy Lead being unfamiliar with the relevant funding request process and taking longer to resolve. Funding was received just in time to pay all beneficiaries but involved a disproportionate amount of effort. No future occurrences of this issue have taken place and DHSC include this process as part of any handover processes to subsequent Policy Leads.
- 69. At the point of commencement of the EIBSS service by NHSBSA in November 2017, Donna McInnes and Ailsa Wight were the primary DHSC contacts responsible for Infected Blood Policy. NHSBSA worked with them as we do now with the current DHSC Policy leads, where NHSBSA provide information based on beneficiary feedback to inform DHSC policy decisions.
- 70. Ailsa Wight's successor was Tim Jones (Deputy Director Infected Blood). Tim was responsible for DHSC's Inquiry and Policy teams. Tim held this post from August 2019 until February 2020, before moving to support the Covid-19 response. Tim Jones' successor is Helen Causley (Deputy Director, Inquiries and Investigations Acute Care and Workforce Directorate). Helen took over from Tim in February 2020 and is currently still in post.
- 71. Neither Tim nor Helen have the detailed background that Ailsa had, being new to the policy area. That was understandable given Ailsa's previous experience in this policy area. At the outset, that may have resulted in slightly less timely responses, due to first having to research the background prior to responding. Other than this slight delay, relationships were collaborative, with a firm focus on quality and improvement of service wherever possible.
- 72. Whenever a new policy team/team member is introduced there is the potential for disruption, whilst they settle into their role and gain sufficient knowledge of the Infected Blood policy area. DHSC provide handover notes to their colleagues and

NHSBSA staff provide any background knowledge and signposting to relevant documents/policies and procedures, to assist them in settling into the role.

Section 5: Funding/Finances of the Devolved Schemes

- 73.I can confirm the details as specified in our response to our first and fourth rule 9 responses relating to funding remain correct.
- 74. I can confirm the details provided in our response to question 2(c) of our first rule 9 response remain correct.
- 75.On Tuesday 30 April 2019, the Government announced that additional funding would be made available to support those infected and affected by the infected blood tragedy. Following this announcement, DHSC worked with NHSBSA to communicate the changes to beneficiaries, including what these changes meant to them personally. All uplifted payments were made to beneficiaries in July 2019, backdated to April 2019.
- 76. The funding process remains the same as it has since scheme inception.
- 77. For DHSC to set the budget for EIBSS, the end-of-year spend from the previous financial year is taken as a starting point for the following financial year's forecasted spend. EIBSS report monthly on the scheme's spend and provide a forecast for the following year's spend. DHSC can use the forecast, which includes an increase to certain payments based on CPI. The current process allows the future funding to be based on known figures, which is the best possible starting point. EIBSS therefore consider the current process appropriate.
- 78.DHSC receive feedback from beneficiaries via NHSBSA focus groups and feedback at the JRG (discussed above), which they are part of and where this feedback is considered and acted upon as appropriate. The decision may result in scheme changes and this will likely affect scheme funding also. Significant changes will always require analysis prior to a decision being made.
- 79. To my knowledge, there has not been any requirement by NHSBSA to request additional funds from DHSC within a financial year to date.
- 80. Any amount over or under spent within a financial year will be adjusted within NHSBSA's quarter one funding request in the following financial year. There would be no practical effect on beneficiary applications because of overspend in a previous year. The agreed process with DHSC is to base the subsequent year's

- budget forecast on the previous year's actual spend and trend patterns. This also allows for any previous year's overspend to be incorporated in the budget.
- 81. To my knowledge, there has not been a requirement to submit a further drawdown request for additional funding from DHSC for the same quarter.
- 82. Each month, a financial report is provided to DHSC by NHSBSA, the report is reviewed by DHSC's finance team and the report is discussed at the EIBSS accountability meetings with DHSC. The spend-to-date is compared to the yearly forecast, which allows both parties to gauge whether additional funding may be needed within the financial year.
- 83. Discretionary one-off payments are a form of financial support that beneficiaries and bereaved spouses/partners may apply for to cover the cost of certain essential health-related items or services. It is additional, time-limited financial (and non-financial) support to primary and secondary beneficiaries to address immediate needs. The maximum payment levels for each type of discretionary one-off payment are shown in the guidance document on NHSBSA's website, under the heading 'Discretionary one-off payments available at:
 - https://www.nhsbsa.nhs.uk/discretionary-support Different maximums apply to different discretionary one-off payments.
- 84. There is no other procedure for EIBSS to seek additional monies and/or apply for top up monies from the DHSC in a financial year. The process outlined in the paragraphs 6.9-6.12 of the 'DHSC Specification England Infected Blood Support Scheme' ("EIBSS Specification") (version 7) and within our fourth rule 9 response are the only procedures to request EIBSS funding for beneficiaries.
- 85. The total funding provided to EIBSS for each financial year is shown below:
 - 85.1. 2017/18 (Note that EIBSS was operational from 1 November 2017 so this funding applies from 1 November 2017 31 March 2018) £14,701,460;
 - 85.2. 2018/19 £46,162,492;
 - 85.3. 2019/20 £75,132,283.
- 86. There are quarterly accountability meetings, monthly operational meetings and an annual review process between NHSBSA and DHSC. The agendas are a fixed format, covering core areas updates (from both DHSC/NHSBSA), reporting, finance and risks and issues. Updates from DHSC will relate to policy, Inquiry, and wider Government. The agenda is now the responsibility of NHSBSA to circulate

but DHSC is asked for any specific items that they may want to be added. Previously DHSC led on the agenda and NHSBSA were asked for contributions.

- 87. Quarterly meetings are attended by:
 - 87.1. DHSC Deputy Director, Policy Lead, Finance Lead and NHSBSA Sponsor (DHSC);
 - 87.2. NHSBSA Head of Service, Senior Service Delivery Manager, Service Delivery Manager, Administrative Support.
- 88. Monthly meetings are attended by:
 - 88.1. DHSC Policy Lead;
 - 88.2. NHSBSA Senior Service Delivery Manager, Service Delivery Manager, Administrative Support.
- 89. There are no separate meetings for the annual reviews, as these reviews are incorporated within April's quarterly meeting.
- 90. Formal minutes are taken of the meetings. As mentioned above, DHSC have previously undertaken the secretariat function but NHSBSA now provide this role. Minutes would be shared with all invitees/attendees of the meetings.
- 91. The quarterly and monthly meetings provide governance of NHSBSA by DHSC and are the primary mechanism for DHSC's accountability of NHSBSA's administration of EIBSS. Reviews are not held outside of these scheduled meetings. There was a specific review undertaken at the early stages of EIBSS being formed i.e. the review of discretionary support; this has been previously explained to the Inquiry and the outcome was provided.
- 92. The only other review mechanism introduced is the JRG discussed above which was introduced in 2020.
- 93. Copies of the minutes of meetings between NHSBSA with DHSC and other documents relevant to the annual/performance reviews of NHSBSA have been provided to the Inquiry.
- 94. In addition to the above, there may be in person meetings, teleconferences or video conferences arranged by either DHSC or NHSBSA. Both NHSBSA and DHSC will feed into the agenda for these meetings, unless it is a specific meeting called for by an organisation, when that organisation will provide the supporting information.
- 95.DHSC will liaise with NHSBSA regarding responses to various requests, such as Parliamentary Questions, which are ad hoc in nature but require a quick turnaround. These mainly require both information (data) and supporting

administrative explanation. Due to the quick turnaround times, the information is discussed and worked on during the discussion and as such an ad hoc meeting will be arranged to discuss. NHSBSA aim to continuously improve our service, so we will need to discuss details of any proposed changes to forms of support with DHSC, to ensure this meets with policy. These meetings are unplanned and ad hoc in nature and as such we do not hold easily accessible records so it would require disproportionate time and effort to identify the dates of these ad hoc meetings.

- 96. The audience of these ad hoc meetings will vary depending on the topic and level of detail to be discussed. The DHSC Policy Lead will determine who is required from DHSC and either the Senior Service Delivery Manager or Service Delivery Manager will consider the matter from NHSBSA. Notes will be taken where required and shared with attendees.
- 97. EIBSS does not have any other funding. DHSC provide the only funding source to NHSBSA to administer the scheme.
- 98. EIBSS provide monthly financial year information to DHSC. This information includes the total amount paid out in-year and the breakdown of the related payments. If there are no expected significant policy changes where funding levels have been uplifted, then the previous year's spend will be used as the starting point for the following year and CPI appropriately applied. EIBSS provides discretionary support, so the number of applications within any year can vary and the best available information is the previous year(s). For non-discretionary spend, the beneficiary numbers have stabilised, so smaller numbers of new beneficiaries are applying to the scheme, which allows for more accurate forecasting based on previous year(s).
- 99. As explained above, the annual budget is based upon the known information, i.e. the previous year's financial details. If any additional changes are to be made to the funding support, DHSC undertake analysis which models the cost of the change(s) and the additional funding is supplied to NHSBSA
- 100. Funding is the overall availability of resource and cash to make the payments due under the scheme at the due time. In this respect, DHSC have fully funded all payments we were required to make since NHSBSA took over the scheme.
- 101. EIBSS does not maintain reserves. The defined process of quarterly drawdown requests against agreed yearly funding and tracking this against the forecasted

yearly spend allows for an early indication of any overspend. If this looked possible, NHSBSA would advise DHSC, who will invoke their standard internal processes to request additional funds, to ensure all payments can be made. NHSBSA reiterates that (as set out in more detail in my statement at paragraphs 80, 82 and 228), the lack of reserves has never led to circumstances where discretionary or additional support to beneficiaries has been refused where it was not previously budgeted.

- 102. Continuity of payment is a core requirement of the administration NHSBSA provide. The robust processes agreed between NHSBSA and DHSC are tried and tested resulting in consistent payments to beneficiaries. NHSBSA make payments at the levels set by DHSC.
- 103. The full budgeted amount is allocated to the infected/affected. The administrative support that NHSBSA provides for EIBSS is separately funded. EIBSS is a Directed Service, which NHSBSA administer on behalf of the Secretary of State for Health. NHSBSA administer several Directed Services, and these services are funded through a central allocation of funding from DHSC.
- 104. The NHSBSA operates under the Agenda for Change NHS Terms and Conditions. As part of these terms and conditions, any roles that are newly established go through a process of review to ensure that they are banded consistently with the wider NHS. This process involves independent input from HR representatives and staff side (i.e. trade unions). The process reviews the proposed job description and results in pay banding being established for the role. This is the process that was followed for staff/roles within the EIBSS service.

Section 6: Communication and engagement with the beneficiary community

105. The EIBSS service has recruited staff with customer service experience (which was required as part of the essential criteria for the person specification for those roles), as well as the ability to handle difficult calls and to be able to support vulnerable customers. Further, the staff on the EIBSS team have all had internal training on how to deal with vulnerable customers, which NHSBSA's training team has adapted especially for this area. The team have also been supported by the Samaritans, who have visited on two occasions to further advise on how to deal with any distressed beneficiaries.

- 106. EIBSS has not received any official complaints that relate to our customer service since its inception to-date. However, if a beneficiary were to report or complain about how they have been spoken to, this would be reviewed by a combination of the EIBSS Team Manager as well as the Customer Resolution Team and fed back to the team member involved to help improve their handling of future calls. If this became a regular issue, then the members of staff would be subject to performance improvement plans and ultimately a disciplinary procedure, should they not deal with contact with beneficiaries in an appropriate manner. Coaching sessions are also carried out by the EIBSS Team Manager on different topics based on real queries to ensure consistency of standards of communication across the EIBSS team when dealing with beneficiary queries and issues. There have been instances where a small number of beneficiaries have provided general feedback, commenting on the lack of empathy from staff and where this has happened the calls have been listened to or emails reviewed. In all instances, it was considered that staff have conducted themselves appropriately. Calls/emails can be emotive in nature but until EIBSS staff obtain a full understanding of how they can assist the beneficiary, this cannot be instantly gauged. EIBSS will always be courteous but it is difficult for EIBSS to be appropriately sympathetic to a caller before the caller has explained their reason for calling is because their partner has passed away. Once EIBSS are fully aware of the circumstances, they will always assist a beneficiary in the most appropriate way possible.
- 107. Application forms for non-discretionary support are generic to cover several types of support. This was intended to minimise the number of forms used to reduce confusion. Unfortunately, due to the form covering more than one form of support, the wording within the forms has been criticised as being insensitive. A case in point is the application for "Discretionary one-off payments" which covers all one-off payments. It originally included a question asking, "How would this benefit you?" Once this was brought to our attention, we promptly amended the form to avoid any potential future upset for others.
- 108. EIBSS has received and acted upon feedback to wording on our website. One instance was the wording relating to the Government payment changes in 2019. The wording appeared on the EIBSS landing page, but a beneficiary mentioned that this was disrespectful to those affected, as the 2019 changes were more for

- those infected rather than affected. As a result, we moved the information to a separate section of our website which focuses on those infected.
- 109. NHSBSA has attended the following meetings either regarding the background of the scheme and/or beneficiaries, regularly with beneficiaries present:
 - 109.1. Two meetings on All Party Parliamentary Groups on infected blood, where NHSBSA representatives spoke to some individual beneficiaries about concerns that they had and tried to answer any questions that were relevant to EIBSS:
 - 109.2. Surveys were issued to beneficiaries around discretionary support and customer satisfaction during the discretionary review (Dec 2017 to Apr 2018) as well as meetings with beneficiaries around possible changes to the discretionary payments policy;
 - 109.3. Ad-hoc focus groups with the beneficiary population, ensuring that these are rotated around all beneficiaries who are interested in attending (these groups have been spread across the country to try and ensure it is easier for beneficiaries to attend and are funded by NHSBSA, so no travel costs should be borne by beneficiaries);
 - 109.4. Ad hoc feedback from any beneficiaries that wish to provide it via any of our contact options, which are available on all printed materials sent to beneficiaries and are available on our website;
 - 109.5. Initial meetings with the Haemophilia Society and the Hepatitis C Trust as a general listening exercise to understand any concerns from beneficiaries.
- 110. With regard to contact with the Haemophilia Society and Hepatitis C Trust, before the inception of EIBSS, NHSBSA colleagues had several meetings and calls with both bodies and the DHSC, as well as individually, to understand any beneficiary concerns and to share when key communications had gone out to beneficiaries at the inception of the scheme. The purpose of this contact was to ensure there were no concerns from support organisations and ensure that both the Haemophilia Society and Hepatitis C Trust were aware of to whom they should signpost, in the event someone came to them who explained they had been infected with hepatitis C and/or HIV through a historical blood transplant.
- 111. NHSBSA has also previously invited feedback from both the Hepatitis C Trust and Haemophilia Society on any issues that have arisen with any beneficiaries who have contacted EIBSS or if they need support for a beneficiary or applicant. One

such example is a beneficiary who sought advance payments regularly. Ahead of the inception of EIBSS, the Haemophilia Society and Hepatitis C Trust visited the EIBSS team when originally based in London to explain their work as well as understanding what the EIBSS teamwork may involve. This helped ensure there was a shared understanding of the beneficiary community and their needs and concerns.

- 112. Several staff were also TUPE transferred across to NHSBSA from the AHOs and shared their extensive experience of working with beneficiaries and the previous schemes with newer team members to give them further understanding of the beneficiary community and their general queries, requirements and background.
- 113. As set out above, NHSBSA have attended several meetings with beneficiaries since the inception of the scheme. The EIBSS team are responsible for arranging and chairing ad-hoc focus groups with beneficiaries.
- 114. The purpose of the meetings is to understand any positive or constructive feedback from beneficiaries who attend to see if any improvements can be made to the administration of the scheme or to be able to collect suggested changes in policy to be able to feed these back to DHSC to review. Following initial feedback from beneficiaries, the groups also act as a medium for beneficiaries to be able to network with each other for support and information and to be able to speak to others who are in a similar situation to themselves. There are set lunches/food breaks where beneficiaries can talk to each other etc. and share contact details if they wish.
- 115. The meetings are arranged on an ad-hoc basis, with the aim that these should be booked in every two to three months subject to beneficiary availability and competing priorities (e.g. when Inquiry hearings are also taking place or when there is a particular peak time for applications or changes in the EIBSS service).
- 116. Meetings that have been arranged to date are:
 - 116.1. 20th February 2018 London;
 - 116.2. 21st February 2018 Manchester;
 - 116.3. 31st May 2018 Manchester;
 - 116.4. 28th June 2018 London;
 - 116.5. 11 September 2018 Birmingham cancelled due to beneficiaries cancelling;

- 116.6. 30 November 2018 Newcastle;
- 116.7. 24 January 2019 Manchester;
- 116.8. 04 April 2019 London;
- 116.9. 15 August 2019 Manchester;
- 116.10. 21 November 2019 Manchester;
- 116.11. 28 February 2020 London.
- 117. The agenda for these meetings is relatively open and is led by what beneficiaries have brought to discuss, although NHSBSA representatives should always ask for their feedback on EIBSS, either positive or constructive. If a recent change has taken place, beneficiaries will also be asked for their feedback on that change.
- 118. At the inception of the scheme, all beneficiaries were asked if they would like to register to give the EIBSS team feedback and potentially to attend future focus groups. This request has been repeated annually, usually as part of the annual payment schedule letters that are issued.
- 119. The EIBSS team collated details of all the people who expressed an interest in attending these groups and have added to it regularly as more people have expressed an interest in attending future groups. The attendance of the groups is rotated amongst this list depending on their availability, as is the geographical location of the meetings, as evidenced in the list of previous meetings set out above. At the latest focus group, a representative from the Haemophilia Society asked to attend and was invited to do so. However, this is the only occasion where someone who is not a beneficiary of the scheme has attended these meetings, other than where a beneficiary may need to bring a carer/support person to be able to attend. Usually the Service Delivery Manager of the EIBSS service and other representatives from the EIBSS team may also attend meetings.
- 120. The NHSBSA acts on any feedback received at these meetings and shares beneficiary policy change suggestions with DHSC. That feedback may then inform potential scheme or administrative changes.
- 121. Examples of changes/improvements that have been made to date are:
 - 121.1. Beneficiaries previously complained about the evidence burden to apply for income top ups and would prefer a flat rate payment. This has now been changed for infected beneficiaries following feedback to DHSC.

- 121.2. Beneficiaries are now able to request to speak to staff they are comfortable with and who know their case, rather than just the advisor on the phone that day.
- 121.3. The policy rules around income top-ups for the bereaved have changed, so now only a small proportion of income of people living within applicant's households is considered, increasing likelihood of higher payments being made. The non-dependent contribution to household income calculation table is shown below.

Gro	Non-Dep Deduction		
nil	D	£142.99	£15.60
£143.00	4	£208.99	£35.85
£209.00	T	£271.99	£49.20
£272.00		£362.99	£80.55
£363.00	D	£450.99	£91.70
£451.00	&	above	£100.65

- 121.4. Arranging payments for counselling initial assessments to be paid in advance, based on beneficiary feedback, who raised this as a barrier to accessing services, if they did not have the money for the session up front.
- 121.5. Various web changes based on feedback, including making End of Year reports more prominent.
- 121.6. Creating and amending application forms to ensure correct evidence is supplied first time round.
- 122. Some beneficiaries have expressed unhappiness that they are not invited to every meeting or more regularly. However, this is not possible as the EIBSS team is trying to encourage and receive a wide range of feedback from different beneficiaries on their experiences. Beneficiaries in this instance are also asked if they would like to provide feedback at any time by any other means on any issues they are experiencing.
- 123. In focus groups themselves, the conversations can occasionally become heated given the emotive subject matter and disagreements between beneficiaries can arise. Beneficiaries who become heated are asked to be respectful of others. It is also outlined at the outset of all meetings to be respectful of one another. In one instance a beneficiary highlighted that they were unhappy that another beneficiary usually records all meetings they attend using a digital recording

- device. In this instance the recording was highlighted to EIBSS staff who asked the other beneficiary not to record the meeting, which they agreed to stop.
- 124. There has been one individual occasion where a threat of violence has been mentioned by a beneficiary towards EIBSS staff in a focus group. However, this was taken to be a heat of the moment comment by the staff involved, again due to discussing emotive subject matter and no further action was taken.
- 125. If threats are ever made by beneficiaries ahead of any focus groups and they ask to attend, then EIBSS may exclude them from attending future focus groups to ensure members of the EIBSS team are safeguarded. There has only ever been one such instance and we now exclude such beneficiaries from future meetings as the meetings are intended to be relaxed, respectful and collaborative; we would not want to have security at these groups. We explain at the start it is an open forum and we want to hear all views on suggestions for change from the representation of all groups so we can relay fully considered suggestions to DHSC.
- 126. There has been a disruption to the focus group schedule due to Covid-19 restrictions. We arranged online focus group meetings during November 2020 and December 2020 using Microsoft Teams which were well received by those beneficiaries who attended. This digital approach will allow us to seek the views of a larger number of beneficiaries compared to the usual face to face meetings, but we acknowledge this approach may not suit everyone.
- 127. EIBSS have assessed the suitability and success of this digital option, and it may be something that we use alongside face to face meetings once Covid-19 restrictions are lifted and it is safe to re-establish them. However, although focus groups are an extremely valuable source of feedback about EIBSS and any associated support, a beneficiary can provide their feedback at any time by contacting EIBSS by post, email or telephone. We intend to continue with the digital online focus groups quarterly, scheduling them in March, June, September and December to minimise any additional disruption where possible.
- 128. There is no contact between the senior management of NHSBSA and the beneficiary community. In this response, NHSBSA defines senior management as Head of Service roles and above. I trust the dedicated and knowledgeable support team to assist beneficiaries; they are best placed to liaise with the beneficiary community due to their first-hand awareness of beneficiary experiences and the assistance EIBSS can provide.

129. The EIBSS team attends focus groups directly so they can understand concerns and feedback provided by beneficiaries and relay this to NHSBSA senior management where required if changes are necessary. Attendance at focus groups is from middle and lower levels of management within the organisation at team level as they have a closer understanding of beneficiary backgrounds. This also ensures relationships can be built with those who beneficiaries are more likely to interact with on a regular basis.

Section 7: Eligibility requirements for EIBSS

beneficiaries.

130. The EIBSS specification is supplemented by appropriate guidance documents. These documents are accessible to beneficiaries on NHSBSA's EIBSS website. These guidance documents form the basis for internal work instructions on application processing.

Discretionary support guidance was sent out to all beneficiaries in June 2018,

- either via paper or e-mail depending on beneficiary preference. This guidance is also shared on the EIBSS website:

 https://www.nhsbsa.nhs.uk/sites/default/files/2020-11/Discretionary%20payments%20guidance%20November%202020%20%2800

 2%29.pdf. It is also shared on request by either e-mail or posting out to
- 132. Medical application guidance on how to complete the application form is supplied with the forms.
- 133. The eligibility criteria for the main types of support the scheme provides is defined within the specification. Any new/amended types of support will be worked on jointly, with DHSC outlining their requirements for the type of support and NHSBSA creating the related documentation and supporting internal processes. The process works and has been successfully used on several changes. NHSBSA therefore consider this adequate.
- 134. As part of the specification, NHSBSA is to establish and maintain a website which beneficiaries can access including information such as eligibility criteria and details of discretionary support and application forms. As set out elsewhere, NHSBSA also accommodate any beneficiary preferences as to communication methods. NHSBSA will also respond to any requests for information received,

- which could be providing details via telephone or post if someone did not wish to receive or access it electronically.
- 135. Since our response to the Inquiry's first rule 9 response dated 16 November 2018, the Government announced on Tuesday 30 April 2019 that additional funding will be made available to support those infected and affected by the infected blood tragedy. This resulted in changes to EIBSS. The main changes are:
 - 135.1. Increased and consolidated payments for all infected beneficiaries, removing the need for beneficiaries to apply separately for income topups as the new annual payment reflected that; and
 - 135.2. A larger number of bereaved beneficiaries will be eligible for income topup payments.
- 136. In the latest EIBSS focus group, the issue of particular cut-off dates of infection as an eligibility requirement was raised by beneficiaries to the EIBSS team as they felt that mistakes could have happened and batches of blood could have been stored and used past the cut off dates that are currently being used. This has been fed back to DHSC policy colleagues for their consideration as policy owners.
- 137. Requirements for medical evidence are given in guidance on the application forms themselves, and sections 5A to 9 on the application forms are also required to be completed by the medical professional. An example of the hepatitis Stage 1 application form is here:

https://www.nhsbsa.nhs.uk/sites/default/files/2019-07/EIBSS%20-%20Hepatitis%20Stage%20One%20%28V4%29%2007.2019 0.pdf

- 138. Where a beneficiary is unsure, they are advised to contact the EIBSS team who may be able to help explain in more detail, or access the EIBSS website to guide them to where full information is available;
 - https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-how-apply
- 139. If an application is declined, the EIBSS team advises that they can reapply if they obtain further evidence to support their application.
- 140. If a beneficiary would like to appeal and submits further evidence as part of their appeal, to avoid the wait for the next appeals panel (which may be up to eight weeks), their application can be reviewed with the additional evidence by a medical assessor to see if the additional evidence may change the outcome of the

- application. If this is still unsuccessful then the application can still be referred to the appeals panel.
- 141. In relation to the burden of proof on the applicant, EIBSS will examine all available information and evidence provided by an applicant. It is for the applicant to establish the facts that underpin their case for support, to the balance of probabilities. This means that EIBSS will consider all information and evidence that is provided by an applicant and whether it demonstrates that it is more probable than not (i.e. that there is 51% chance or higher) that certain events took place. If so, then those events are treated as having taken place and the applicant has succeeded in proving their case.
- 142. I can confirm that medical practitioners have previously contacted EIBSS regarding completing SCM applications. Where this happened, we can advise what evidence may be required to support applications and reiterate that they need to state on the form the likelihood of the condition(s) being caused by hepatitis C (in their medical opinion). The team would not offer an opinion on which likelihood should be indicated, as this is the medical professional's informed opinion to make.
- 143. Applications are considered in their entirety. As set out in an earlier Rule 9 response to the Inquiry, with regard to hepatitis applications, usually evidence from medical records is provided to confirm that someone has, or had, chronic hepatitis C, and evidence from medical records to confirm that a blood transfusion, treatment with blood products or a tissue transplant prior to September 1991 was received. Applications might still be successful if other forms of evidence can be provided. Examples are provided below.
 - 143.1. Medical records of the procedure that led to the need for treatment with blood, blood products or tissue but where this is not specifically mentioned;
 - 143.2. Witness statements from people who were witness to the treatment or were aware of it happening at the time;
 - 143.3. Personal statement giving as much information as possible regarding the procedure and the circumstances that led to the need for treatment with blood, blood products or tissue; or
 - 143.4. Physical evidence of the procedure that led to treatment with NHS blood, blood products or tissue.

- 144. NHSBSA look at all available evidence regarding the risks associated with certain types of blood products at the time treatment was received.
- 145. An application would not usually be approved based on one of these examples of evidence. One example may be where a beneficiary has supplied photographic evidence of a scar or injury. This alone would not mean an application would be approved. However if medical records indicated an injury or operation had occurred that support the photographic evidence and a medical expert determined that this is likely to have led to a blood transfusion at the time of the injury/operation, then this may lead to an application being approved.
- 146. Following discussions with managers and the EIBSS team, they are unaware of any instances where a prospective beneficiary has been approved using solely one of the examples of evidence provided above without using it in conjunction with other evidence. This is not to say that this is not possible but to-date the evidence provided in support of such cases has not been sufficiently robust to support an 'approved' decision.
- 147. One example where a combination of evidence led to a successful outcome when medical records confirming a blood transfusion were not available relates to a beneficiary that had an operation that would have required them to have a blood transfusion, as part of the treatment required. The supporting evidence confirmed that there was no medical evidence available due to retention periods and as such alternative evidence had been supplied. The evidence supplied was as follows:
 - 147.1. A medical report for a court case to state an operation took place but there is no reference to a transfusion; and
 - 147.2. Photographic evidence to show the extent of the injury.
- 148. Based on the type of injury and supporting information, the medical assessor was satisfied that the operation would have required a blood transfusion.
- 149. For the purposes of determining applications, the lack of evidence for whatever reason is not relevant. Medical assessors as part of EIBSS can only assess based on the evidence provided, in whatever form that may take.
- 150. I have been advised by the Inquiry that the Skipton Fund refused a large number of applications on the basis that the applicant could not prove that he or she had received a blood transfusion because the applicant's medical records had been lost or destroyed. EIBSS has not reviewed any applications previously refused by AHOs. This is not possible because NHSBSA was not provided with

any information (such as contact details and application forms) about unsuccessful applicants as part of the transition from AHOs. However, previously refused applicants could have contacted EIBSS themselves to apply for the scheme since its inception. Both the Haemophilia Society and the Hepatitis C Trust were made aware of the change from the AHOs to EIBSS so would have been able to signpost anyone who got in touch with them and provide details of the new scheme, and how to apply to EIBSS. DHSC also ran a public consultation with the infected and affected community regarding the support arrangements that led to the creation of EIBSS, including support groups such as the Haemophilia Society and Hepatitis C Trust. This had been communicated widely by DHSC within the community, so further wider communication about EIBSS beyond these three methods to previously refused applicants was not deemed necessary as public awareness of this new scheme should have been reasonably high. NHSBSA have not directly invited previously unsuccessful applicants of an AHO to re-apply but would welcome an application from anyone who chooses to do so. Please note that changing the scheme administrator does not increase the likelihood of a successful application, as the basis of a successful outcome is still dependent on providing supporting evidence and other information needed to determine eligibility. As the criteria used by EIBSS currently is consistent with that used by the AHOs, it is unlikely that a previously refused application to an AHO would result in a different outcome if they chose to apply to EIBSS without providing additional supporting information to what was supplied previously with their AHO application.

151. NHSBSA were unable to contact previously unsuccessful applicants to each AHO that did not have their data transferred by the AHOs as we did not have contact details. NHSBSA is unable to comment further on any other steps that might have been taken by the AHOs to contact beneficiaries. DHSC policy, as shared with the EIBSS team, dictates that in order to be eligible for a lump sum payment for a bereaved partner, the person who has passed away must have died from either hepatitis C and/or HIV (or causes arising from either). Therefore, to demonstrate their eligibility for this payment, the EIBSS team asks beneficiaries to provide a death certificate. This is the only application where a death certificate is required. However, a letter from a GP/consultant stating that hepatitis C and/or HIV was the likely substantive cause of death may also suffice. I have attached a

- copy of the DHSC policy document shared with NHSBSA for this policy as my **Exhibit BB5** (WITN4496006).
- 152. EIBSS does not provide for exemptions or waivers to documentary evidence requirements for any reason. Medical assessors (and the appeals panel where required) will consider all available evidence on a balance of probabilities to decide whether someone was eligible for payments under the scheme. Medical assessors would consider statements from applicants on their own but, to-date, the evidence provided in support of such cases has not been sufficiently robust to enable a medical assessor to reach an 'approved' decision, as set out above.
- 153. There is also signposting guidance available to beneficiaries on NHSBSA EIBSS website at:

https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-how-apply/requesting-medical-records

- 154. All documentation can be provided to beneficiaries via website, email or post. EIBSS also offer beneficiaries the option to complete forms on behalf of the beneficiary during a telephone consultation. The form will then be sent to the beneficiary for review and signature.
- 155. DHSC have requested that NHSBSA make the information to assist beneficiaries available in appropriate formats. Digital and non-digital options are available which provides applicants/beneficiaries with options for reasonable adjustment.
- 156. There are no defined review periods for these procedural requirements. A review is iterative based on a continuous improvement basis. When a beneficiary feeds back any suggested changes to the scheme, which result in a change to scheme support, all related internal and external documentation is updated.
- 157. The decision as to whether a person meets the eligibility criteria is that of an 'independent medical expert.' EIBSS have four medical consultants to assess medical based applications:
 - 157.1. Dr Margaret Bassendine;
 - 157.2. Dr Belinda Smith:
 - 157.3. Dr Leonie Grellier; and
 - 157.4. Dr Catherine Smith.

- 158. The first of these consultants has worked with EIBSS since May 2019. The other three were appointed during 2020 to replace existing consultants who decided to cease working with EIBSS.
- 159. A medical consultant's qualification and experience requirements are shown below:
 - 159.1. Basic medical qualification e.g. MB BS;
 - 159.2. Postgraduate Membership/Fellowship of Royal College of Physicians of London/Edinburgh;
 - 159.3. Specialist accreditation in either Gastroenterology or Infectious Diseases +/- General Internal Medicine;
 - 159.4. Experience of assessing/managing patients with chronic hepatitis C and/or HIV over a period of time the longer the better; and
 - 159.5. Evidence of undertaking research in the field of blood borne viruses over a period of time the longer the better.
- 160. To recruit or engage a medical expert, an advert is placed in the British Medical Journal. CVs are requested to be submitted and, based on the information provided, the applicants are shortlisted. Shortlisting is undertaken by a current medical consultant(s) and interviews are held with the shortlisted applicants. The interview panel consists of one current medical consultant and the EIBSS Service Delivery Manager.
- 161. All medical consultants are recruited as freelance contractors, whereby EIBSS is invoiced for the cases that each consultant assesses. A day rate is applied and the charging for the cases is not affected by the case outcome.
- 162. EIBSS medical consultants are provided with interactive induction training, which involves being introduced to the different types of applications, the related scheme criteria and any application guidance. The workshop style induction will allow all medical consultants to work through historic applications, to undertake mock assessments, which are then discussed with the supervising medical consultant.
- 163. Following their induction training, the medical consultants can commence EIBSS assessments. All assessments will be peer reviewed, so they are effectively assessed twice, once by two different medical consultants, to ensure consistency of outcome. Where the two consultants cannot reach consensus, a third consultant will conduct a third assessment to reach a majority outcome.

- 164. NHSBSA is aware of feedback from beneficiaries who are unhappy with the current substantive and procedural eligibility requirements for EIBSS. Examples of this are:
 - 164.1. Beneficiaries reluctant to provide evidence of their income for income topup applications.
 - 164.2. Beneficiaries reluctant to provide examples of different quotes when applying for a discretionary one-off payment.
 - 164.3. Beneficiaries unhappy that their application has been declined where they have been unable to provide medical evidence to demonstrate they qualify for the scheme, be that to initially qualify or to qualify for a higher level of payments through SCM or Stage 2 hepatitis C.
- 165. For beneficiaries who apply by income top-ups, the feedback from beneficiaries was passed to DHSC policy colleagues. DHSC policy colleagues then introduced changes applying from April 2019 that meant a significant number of beneficiaries no longer needed to apply for an income top-up as the monthly payments for all infected beneficiaries were increased significantly. This requirement for an application remains for the bereaved, who can apply for income top-up payments. The EIBSS service is responsible for the distribution of public monies to beneficiaries and has a duty to beneficiaries that this money (that is dedicated to their welfare and support) is distributed correctly and fairly. To do so, NHSBSA is required to formulate procedures that reduce the potential for fraud as well as making sure that payments and applications approved are done so consistently against set criteria. In this case EIBSS asks for evidence to demonstrate current income such as bank statements and is unable to reduce that requirement without lessening safeguards around the EIBSS monies. Due to this risk, evidence requirements have not been reduced.
- 166. For beneficiaries who apply for a discretionary one-off payment, there is a requirement to provide two different quotes, again to ensure that the payments made and products/services bought are more likely to be value for money, as well as ensuring that EIBSS funding is protected and fairly distributed.
- 167. For beneficiaries who are unhappy that their application has been declined because of a lack of evidence, the EIBSS team will give suggestions of what evidence could be obtained where relevant to help with the application. However, ultimately if there is not enough evidence to satisfy the independent medical

assessors and appeals panels, then the application will not be successful based on the current policy and procedures employed by EIBSS. Again, any reduction in requirement for evidence could significantly increase the risk of a person having an application incorrectly approved by the EIBSS team and being awarded a significant sum of public money that should be used to support beneficiaries in England who have been correctly assessed as being eligible for payments from the scheme. Due to this risk, evidence requirements have not been reduced.

Section 8: Decision on support applications within the EIBSS

- 168. Medical assessors have the ultimate authority in determining a successful application where medical criteria are concerned. EIBSS staff have the ultimate authority to determine income top-up and one-off applications within defined parameters and procedures.
- 169. In terms of the relationship between the EIBSS staff and medical assessors, the EIBSS team receive the applications from prospective beneficiaries, note the applicant details on the system and then share the application details with the medical assessors for them to assess. Once a decision has been made by medical assessors, this is then passed back to the EIBSS team to communicate the outcome to applicants.
- 170. For discretionary payments, individual EIBSS staff members follow procedures to determine whether an application will be successful or not. Where there is any gap in policy or something needs to be clarified, then this would be raised with DHSC for their consideration.
- 171. The EIBSS team construct outcome letters using information provided to them by medical assessors for medical applications. This may include information such as the reason for an application being declined or any potential further evidence that could support an application.
- 172. For one-off or income top up applications, the EIBSS team send out outcome letters without any other input.
- 173. The senior management of NHSBSA is not involved in individual decisions for applications.
- 174. The only 'committee' that is formed for the purposes of determination of applications is the appeals panel that reviews any appeals made relating to medical

applications. The appeal panel consists of several medical professionals and a legal chair as outlined elsewhere in this statement. The EIBSS team will contact the legal chair to convene an appeal meeting where cases are received, and these are generally held every 6-8 weeks. Again, the medical professionals have ultimate authority to decide and act independently of the EIBSS team. The EIBSS team are not medically trained in any way so do not have any input into the outcome.

- 175. For medical assessments, the policy for determining applications is in the scheme specification that was provided by DHSC and administered by NHSBSA. For discretionary applications, the policy as to what would be covered by the discretionary payments scheme, including payment levels to beneficiaries, was determined by DHSC.
- 176. NHSBSA's input into both policies are purely administrative. However, as previously explained, NHSBSA did review the previous discretionary scheme and report back findings including spending levels, types of payments and beneficiary feedback to DHSC. DHSC then determined the discretionary policy and co-wrote the webpage and other guidance that is in place for beneficiaries when the scheme was reformed in June 2018.
- 177. For the EIBSS service, there has been no medical input (except for the JRG formed in January 2020) into any of their policies and procedures as they are administrative matters. All administrative policies have been provided to the Inquiry previously. For the actual policy of what the scheme will cover in terms of payments, this policy is determined by DHSC and we are unable to comment on what expert advice they may have sought.
- 178. During the review of the discretionary payments within EIBSS, the beneficiary community opinion was sought by EIBSS to understand what they may require from a discretionary payments scheme. This took the form of surveys and two focus groups for their feedback. The outcome of the review was shared with DHSC.
- 179. DHSC ran a consultation on the entire scheme prior to the inception of EIBSS, which also included a section on discretionary support. This included consultation with beneficiaries on what they believed was important for this element of the scheme. However, NHSBSA is unable to comment on what other input DHSC

- sought when considering policy changes other than the information that has been provided by NHSBSA.
- 180. Applications for hepatitis C stage 1 payments or HIV payments request historic medical records, which aid the medical assessors in reaching an outcome, based on the balance of probabilities, that the applicant received infected NHS blood or blood products or not. If successful, they would then be registered as an EIBSS beneficiary.
- 181. If a beneficiary expresses difficulty obtaining records of a blood transfusion to support their hepatitis C stage 1 or HIV application, we signpost them to all relevant sources to enable them to gather information which could provide as many facts as possible to the EIBSS medical assessors to come to a decision on the probability the applicant received infected NHS blood or blood products.
- 182. Supporting letters, notes and other documentation from GPs and/or specialist consultations may also be required for applications. For example, the SCM application form requires completion by a doctor or viral hepatitis nurse to confirm the beneficiary has one of the qualifying diseases listed within the application, as a result of hepatitis C.
- 183. If the beneficiary does not have a listed qualifying disease, the application provides another section for completion, where the doctor or viral hepatitis nurse are asked to confirm that the beneficiary's infection, or its treatment or complications, are causing mental health problems or tiredness that affect what they can do, day to day.
- 184. Their doctor or viral hepatitis nurse will also be asked to provide a statement assessing how likely it is that any problems they have are caused by their infection (and not something else).
- 185. The application also asks a doctor or nurse to provide an overall clinical assessment of their condition and its impact on their ability to carry out daily activities. Evidence from their medical records is also requested. The doctor or nurse is being asked to assist with this process because they will know the status of the applicant's health best and will have access to the evidence required.
- 186. The evaluation made by the treating doctor/nurse is important. However, we recognise that it may not always be possible for them to provide factual evidence from the medical records available. In such cases, their clinical judgement may

- be enough to allow the EIBSS medical assessors to determine the outcome of the application based on a balance of probabilities approach.
- 187. Applications for discretionary payments may ask for the input of a medical specialist. An example being an application for a specialist bed or mattress, as there is a requirement that a specialist bed or mattress would best support the beneficiary's health concerns.
- 188. An application for a discretionary payment towards counselling requires confirmation that the person providing the counselling is a registered professional to ensure they are both qualified and insured, to ensure the wellbeing of beneficiaries.
- 189. A respite break must be recommended by a medical professional, following a period of ill-health as a direct result of the HIV and/or hepatitis C infection or its treatment. A beneficiary must detail the reason for the break and if the break is required following treatment for hepatitis C. The treatment start and end dates should be included in the supporting medical letter. This is to confirm that a respite break is needed.
- 190. AHOs previously assessed household income to determine what level of support was available for both elements of the discretionary support scheme income top-ups and discretionary one-off payments. We adopted their ways of working until we were able to complete a review of the discretionary scheme within EIBSS, which was revised from 20 June 2018. The outcome of the review was that:
 - 190.1. discretionary one-off payments were no longer subject to income assessments and these types of payments could be applied for when needed and all eligible beneficiaries would receive the full payment after submitting a complete application form; and
 - 190.2. income top up applications currently require supporting information to determine the appropriate level of payment for each beneficiary, which will vary from person to person based upon their household earnings. The information is required to ensure that the applicant receives the right level supported by evidence, as opposed to a self-declared approach. This approach is to help reduce any potentially fraudulent claims.
- 191. Income top-up payments are means-tested assessments and based on household income. As such, they require fully itemised details of monthly income

and expenditure. The household income is calculated using all income received by the household, including earnings and benefits, which are listed within the "Income top-up and Child Payment Support leaflet" which can be found on our website at: https://www.nhsbsa.nhs.uk/sites/default/files/2019-12/EIBSS%20-%20Income%20top-

<u>up%20payments%20and%20child%20payments%20application%20form%20%28V5%29%2011%202019.pdf</u> Income top up payments were carried over from the AHO schemes and although their use was reduced when the Government increased EIBSS funding in April 2019, they currently remain in place for assessing bereaved beneficiary payments. The beneficiary household income thresholds are shown in the guidance document referenced above. The calculation of household income will take account of a certain amount of weekly income for any non-dependent person within the household other than partner or spouse.

- 192. Multiple quotes for a particular product of service are required for the following discretionary payments:
 - 192.1. Respite breaks;
 - 192.2. Accommodation adaptations;
 - 192.3. Accommodation repairs;
 - 192.4. Mobility aids;
 - 192.5. Car repairs; and
 - 192.6. Specialist beds & mattresses.
- 193. The reason for two quotes being required is to ensure that there are appropriate controls on payments made using public funds. A high quote without any comparisons could result in disproportionate expenditure.
- 194. The application for a bereavement lump sum requires proof of marital status or cohabitation, as this payment is available for spouses or long-term partners only. Cohabitation of children may be questioned when it is indicated children do not live with the beneficiary. Recognised carers of children who do not live with registered beneficiaries can also apply for the support payments directly.
- 195. The application for income top-up and child payments is income assessed, so a bank statement showing the last three months' income can be sent as evidence of incomes.
- 196. When EIBSS took over administrative responsibilities from the AHOs, we followed instruction from DHSC and broadly based the initial operating processes

and eligibility criteria upon those used by the Skipton Fund. We ensured the processes we adopted aligned to the DHSC specification for the scheme. I am aware from the Inquiry that the Skipton Fund did not consider treatment by intramuscular anti-D immunoglobulin as a route of probable infection for an award of payment under their scheme. The Inquiry has also provided me with a copy of a letter between the Skipton Fund and Dr Patricia Hewitt dated 24 February 2005 (SKIP0000031_071, which is discussed in Dr Hewitt's statement WITN3101004). This letter provides one explanation as to why this position may have been adopted by the Skipton Fund, which is expected to have been based upon medical opinion.

- 197. EIBSS intended to carry forward the criterion not to include intra-muscular anti-D immunoglobulin as a probable route of infection based upon the criterion previously set by the Skipton Fund. However, in the course of preparing this statement during February/March 2021, NHSBSA reviewed EIBSS' current exclusion criteria with Dr Hewitt, who is now an assessor for EIBSS, forming part of the EIBSS Appeal Panel. In doing so, it was identified that intravenous (rather than intra-muscular) anti-D immunoglobulin was excluded as a potential route of hepatitis C infection in error. As a result, and noting that Dr Hewitt has recently reconfirmed her previous view that hepatitis C infection through intra-muscular anti-D immunoglobulin is improbable (as set out in her statement WITN3101004), DHSC has agreed that NHSBSA should correct the exclusion criteria on its website to only exclude intra-muscular anti-D immunoglobulin. This means that intravenous anti-D immunoglobulin could now be considered as a potential source of hepatitis C infection, as it was within the Skipton Fund.
- 198. Following a review of its records, NHSBSA have been able to confirm that no applications to EIBSS to date have been refused on the basis of anti-D immunoglobulin. However, as a result of incorrectly applying a holistic exclusion criterion, NHSBSA may have potentially deterred or prevented potential beneficiaries from applying to EIBSS. Medical opinion from Dr Hewitt suggests that any such number of individuals would be low. However, nevertheless. NHSBSA will prepare a communication to share with appropriate beneficiary support groups such as the Hepatitis C Trust and the Haemophilia Society about the change. Usually any successful applications for support from EIBSS is dated from the date of application. However, in this situation, if EIBSS receives a successful application based on intravenous anti-D immunoglobulin, that will be

- backdated to the start of EIBSS on 1 November 2017, as it is likely the delay in application was due to the incorrect exclusion criterion, rather than a delay by the beneficiary.
- 199. Given the issues identified with this aspect of the EIBSS criteria, NHSBSA are putting a plan in place to review the remaining aspects of the scheme with medical expert opinion as necessary, to ensure that the scheme remains appropriate and reflective of current medical opinion.
- 200. NHSBSA performance is measured against key performance indicators which have been agreed with DHSC. These are reviewed monthly as part of the Accountability Review meetings. There are two indicators relating to application processing times (from date of receipt to payment made). These are shown below: 200.1. 90% of new applications processed to completion within 30 working days; and
 - 200.2. 90% of applications through the SCM processed and payments made to individuals within 120 working days.
- 201. Within the financial years 2017/18 and 2018/19, EIBSS has achieved at least 99% for both indicators. The performance of our service against all agreed measures is reflected within our annual report published on NHSBSA EIBSS website.
- 202. Please note that although EIBSS has a separate indicator for SCM applications, we regularly process these within the 30-working day period. This indicator was originally set at 120 working days due to the initial influx of SCM applications, when SCM was introduced. This indicator will be amended in the next financial year and reduced to 30-working days to be aligned to other application types.
- 203. EIBSS has received 5,199 applications in total since its inception (as at 18/09/2020).
- 204. 549 applicants have been refused because they do not meet the eligibility criteria. Of those, 139 are medical cases in which a transfusion would be checked as part of the application process. Of these 139, 115 have claimed to have been infected via a transfusion (as at 18/09/2020).
- 205. 4,458 applications have been granted (as at 18/09/2020).
- 206. A table is provided below showing the breakdown of these cases together with those in which further information was requested.

Status	Applications	%
Approved	4458	86%
Declined	549	11%
Further Information	192	4%
Grand Total	5199	100%

Notes/Caveats:

- Data is valid as of 18.09.2020.
- Applications involved are those received between 1st November 2017 and COB 31st March 2020.
- "Approved" and "Declined" numbers include those applications that have had a decision recorded following an appeal.
- Further information includes those cases which are currently going through the appeals process.
- Transfusion Only hepatitis C stage 1 and HIV cases are checked for transfusion evidence as part of the application process.
- 207. Previous outcome/decision letters sent to applicants where their applications were refused did not contain any details of why the application was unsuccessful other than a general reason. However, acting on feedback from these applicants, the letters now contain a more detailed summary of why the medical assessors refused the application. Medical assessors, based on their qualifications and experience, can determine outcomes and may refer to several sources of information to assist in their decision making. EIBSS has no requirement for these sources to be documented and this would not be shared with individual beneficiaries. If this were identified as a service improvement by further feedback, we would look to document the sources of referenced information. Only a general summary would be shared as part of communicating the outcome.
- 208. All applications are assessed as soon as possible depending on current resource and application levels coming into the team.
- 209. The EIBSS team operates within a 30-day assessment Service Level Agreement ("SLA") for medical-based applications as this can take time to assess.
- 210. Discretionary payments also operate within a 30-day assessment SLA; however, they are generally completed within five working days. Where a beneficiary states that their need is urgent, for example for items such as boiler

- and car repairs, or where they may have issues with hardship, a 'faster payment' can be authorised for the same day following approval of their application.
- 211. Beneficiaries can request that a member of the EIBSS team completes their application form/s on their behalf and then send the application to the beneficiary to check, sign and supply relevant evidence. This applies to non-medical applications, such as one-off or income top-up.
- 212. NHSBSA are also able to contact beneficiaries at a convenient time for them, to assist with the completion of an application form/s and they can request to deal with the same member of the team each time they call for continuity.
- 213. Where assistance is required around medical-based applications, the EIBSS team can consult with medical assessors to seek their advice on what evidence may be required and relay that to the applicant.
- 214. Changes to the discretionary payment scheme from June 2018 meant that the way that assessments of beneficiary income had been conducted in the past were not consistent. The two previous income top up payment schemes from Macfarlane and Caxton were assessed differently and had entirely different income brackets for deciding levels of payments. Also, the current levels of income had been assessed approximately 18 months ago by both Macfarlane and Caxton and were previously assessed annually. In order to establish current levels of income and to ensure that people did not miss out on potentially increased levels of payments with the new income top up payments, NHSBSA (in consultation with DHSC) requested a further application from beneficiaries for the scheme from June 2018.
- 215. NHSBSA did suggest to DHSC looking at calculating the best-case payment for beneficiaries where we were unsure of their payment levels and asking beneficiaries to re-apply in April 2019 to let the changes to the scheme bed in. However, DHSC were keen to implement the changes to the discretionary payments as soon as possible.
- 216. DHSC, as owners of the policy in this area, prescribed the details of the decision to award payments to those suffering from hepatitis C based on staging of their disease to NHSBSA in the scheme specification. This was in place with the AHOs and NHSBSA is unable to comment on how this came about or its rationale as it was not involved.

- 217. DHSC, as owners of the policy in this area, prescribed the policy to NHSBSA in the scheme specification, including the different lump sum payments to those with HIV compared to hepatitis C and the different lump sum payments given depending on when they apply to EIBSS. This was in place with the AHOs and NHSBSA is unable to comment on how these differences came about or their rationale as it was not involved.
- 218. I can confirm that the following comments in relation to the assessment of support and assistance payment levels by EIBSS, which have been extracted and provided here from our first rule 9 response dated 16 November 2018, remain accurate:
 - 218.1. NHSBSA operate the scheme as directed and within policy determined by DHSC; with a focus on delivering a fair and transparent scheme to beneficiaries who rely on the support provided. In this regard, NHSBSA has designed processes around the beneficiary's needs, through engagement activities, and has a commitment to continuously review and improve the service where opportunities are identified.
 - 218.2. As DHSC set the policy for the scheme, it will be for DHSC to respond on any influence the devolved administration schemes may have or have had on their policy listed below:
 - 218.2.1. The level of payment provided to infected beneficiaries relating to their infection.
 - 218.2.2. The level of payment provided to bereaved partners of the scheme (one-off bereavement payments).
 - 218.2.3. The level of discretionary income top-up support provided to beneficiaries*.
 - 218.2.4. The types of one-off discretionary payments and other support provided to beneficiaries*.

*As set out in more detail above, DHSC instructed NHSBSA to review payments in these categories by the previous administrators in order to combine them under one framework for consistency and fairness, with an aim that no beneficiaries would be worse off. The review was then shared with DHSC to determine the revised DHSC policy for this aspect of the scheme. This formed the revised discretionary scheme for EIBSS.

- 219. I can confirm that the policy regarding regular payments and discretionary payments is owned by DHSC. NHSBSA will be asked for up to date information on beneficiary numbers and related payment levels to help DHSC inform their decision. NHSBSA cannot comment on whether regular payments are based on a principle of not reducing previous AHO support levels, rather than an assessment of present day needs and living costs.
- 220. As per the consultation on the development of SCM, it is NHSBSA's understanding that the rationale for introducing SCM is to recognise the long term effects that hepatitis C (or treatment related to it) has had on beneficiaries without meeting the criteria for Stage 2 support. NHSBSA is unable to comment on all the expert advice and consultations that DHSC may have sought during the consultation process around the SCM policy development.
- 221. The EIBSS team always advises that beneficiaries should apply for a payment for a specific expense or item to ensure that beneficiaries do not commit to paying for something and then find a later application to EIBSS to be unsuccessful. However, this does not mean that the EIBSS team will not reimburse for items already paid for. An example of this may be car repairs, where the need is urgent, therefore it may not be feasible for a beneficiary to apply before committing to pay.
- 222. As previously stated, the EIBSS team acts as a guardian of public funds and must ensure that these are distributed correctly to those beneficiaries in need of support as well as providing value for money for the taxpayer. To ensure value for money, the EIBSS team requests two quotes where beneficiaries can find items or services that support them in the same way. In these cases, the EIBSS team does always grant the lower of the two sums.
- 223. EIBSS backdates payments for hepatitis C and HIV, or income top-up and child payments, from the date the application was made. An exception will apply to any hepatitis C application related to intravenous anti-D immunoglobulin, for the reasons set out above.
- 224. EIBSS are aware that the Skipton Fund had not been able to make contact with approximately 460 infected beneficiaries, where they were unable to provide them with the regular monthly payments that were introduced in April 2016 and in some cases the hepatitis C stage 2 top-up payment of £25,000, ensuring stage 2 beneficiaries received a total of £50,000 as their lump sum. As a result of the Skipton Fund being unable to contact these beneficiaries to advise of further

payments they should receive, this also meant they may not have been aware of the transition to EIBSS, although as set out elsewhere in this statement, since November 2017, 67 beneficiaries have independently contacted and joined EIBSS even though their details had not been passed over to EIBSS by the Skipton Fund prior to its closure.

- 225. If EIBSS received queries from beneficiaries of the AHO schemes, EIBSS direct them to Russell-Cooke to send EIBSS a copy of their historical records. EIBSS will register the beneficiaries to ensure payments can be made from the point the data is received, but also check the files and pay any of the regular payments or lump sums that they would have been due. If a beneficiary has sadly passed away since the payments were introduced, EIBSS would arrange the amount the beneficiary should have received to be paid to the executor of their estate.
- 226. Consistent decision making is ensured by multiple sign offs (like peer to peer review) for each application. For medical assessments, applications are now signed off by two separate medical assessors to ensure there is an agreement. Where an application is unsuccessful, beneficiaries are also able to appeal the decision to the appeals panel.
- 227. Following the introduction of the SCM policy, all initial assessments were carried out by two medical assessors. After discussions with the medical assessors involved, this was reduced following successful calibration of their assessments to a single assessor with a 10% sample being quality checked for decision consistency. Single assessment with 10% quality checking was in place for approximately a year before the reintroduction of dual assessment across all types of medical based applications.
- 228. Each application is considered on its own merits and is not impacted by overall demand. EIBSS is a demand led service and DHSC are committed to fund all successful applications received. There is no capped limit on the number of applications that can be funded in any year. As stated in NHSBSA's previous responses to the Inquiry, the DHSC have processes in place to request additional funding to ensure all successful applications are funded.
- 229. Previous payments from EIBSS and/or the previous AHOs are not considered when determining each application.
- 230. Income from benefits is considered when determining income top-up applications only. The purpose of the income top-up payments is to top up the

- levels of beneficiary income; therefore, income from benefits is considered for these purposes. This is as per policy agreed with DHSC.
- 231. EIBSS does not means test for regular payments, lump sum payments or grants/one off payments.
- 232. The income brackets that applied previously and currently apply are shown below.

The income brackets EIBSS used for income top-ups from 1st July 2018 to 31 March 2019 were as follows:

Income top-up payments for beneficiaries with HIV and/or hepatitis C Household income bracket	Monthly top-up	Yearly top-up
£0 - £7,600	£479	£5,744
£7,601- £15,200	£362	£4,348
£15,201-£22,750	£245	£2,939
£22,751-£30,000	£134	£1,603
£30,001-£37,900	£64	£765

Income top-up payments for bereaved spouses/partners Household income bracket	Monthly top-up	Yearly top-up
£3,000 or less	£1,417	£17,004
£3,001-£4,000	£1,333	£15,996
£4,001-£5,000	£1,250	£15,000
£5,001-£6,000	£1,167	£14,004
£6,001-£7,000	£1,083	£12,996
£7,001-£8,000	£1,000	£12,000
£8,001-£9,000	£917	£11,004
£9,001-£10,000	£833	£9,996
£10,001-£11,000	£750	£9,000
£11,001-£12,000	£667	£8,004
£12,001-£13,000	£583	£6,996
£13,001-£14,000	£500	£6,000
£14,001-£15,000	£417	£5,004
£15,001-£16,000	£333	£3,996
£16,001-£17,000	£250	£3,000
£17,001-£18,000	£167	£2,004
£18,001-£19,000	£83	£996
£19,001 or more	£0	£0

Since 2019/20, the income brackets for a bereaved beneficiary to qualify for an income-top payment are:

Household income (£)	Annual income top-up (£)
£0 - £10,000	£18,000
£10,001 - £15,000	£10,421
£15,001 - £20,000	£5,412
£20,001 - £28,400	£1,412
£28,401+	£0

Non-dependent income contribution thresholds to household income calculation:

Gross Income		Non-Dep Deduction	
nil	T	£142.99	£15.60
£143.00	4	£208.99	£35.85
£209.00	4	£271.99	£49.20
£272.00	0	£362.99	£80.55
£363.00	D	£450.99	£91.70
£451.00	&	above	£100.65

The brackets and payments remain the same for 2020/21.

- 233. Please note infected beneficiaries no longer needed to reapply for an income top-up as from 2019/20 as their regular payments were increased.
- 234. For child payments, beneficiaries had to qualify for an income top-up to get a child payment. The previous income bracket of £37,900 still applies for infected beneficiaries wishing to claim a child payment.
- 235. The policy rules around income top-ups for the bereaved have changed, so, as set out elsewhere in my statement, only a small proportion of income of people living within an applicant's households is taken into account, increasing likelihood of higher payments being made. The calculation of household income will take account of a certain amount of weekly income for any non-dependent person within the household other than partner or spouse.
- 236. Income top-ups are a discretionary monthly payment to increase a beneficiary's household income to help with general living costs. If a beneficiary has non-dependent people living within the household, a proportion of their income is used within the assessment as they are contributing to the general living costs of the household.
- 237. The income brackets set out above are published within the guidance document "Income top-up and Child Payment Support leaflet" which can be found on our website at:

https://www.nhsbsa.nhs.uk/sites/default/files/2019-07/Income%20top-up%20and%20Child%20Payment%20Support%20leaflet.pdf

Currently the non-dependent income contribution thresholds are not publicly available as these only apply to a small number of applicants' income top-ups but would be provided if requested. A full breakdown of each beneficiary's income top-up calculation can be provided to any beneficiary on request. There is also an ongoing exercise to review current and previous income top-up applications, due to a change in criteria to now exclude any disability related elements from household income totals. This will result in some beneficiaries receiving an additional backdated payment, with interest included, to the start of the EIBSS income top-up process in April 2018.

- 238. DHSC decide on the scheme funding each financial year, which is based on previous year's expenditure, scheme feedback and any potential policy changes. Income top-ups and their associated income brackets are considered in this yearly funding review process.
- 239. To ensure consistency and fairness of decision-making, NHSBSA has implemented the following improvements since the inception of EIBSS:
 - 239.1. Medical assessments require two medical assessor sign-offs to ensure consistency of decision-making;
 - 239.2. Discretionary framework is simplified to ensure what support is available to beneficiaries is clearer and more consistent. Anecdotal evidence from the AHOs suggests that some payments were made to beneficiaries for nominal items, such as a dress and a holiday for a wedding anniversary. The criteria for payments was not clear and this could lead to payments being made for some things for some beneficiaries that would not have been made public for all to be able to apply for.
 - 239.3. Discretionary payments reviewed by the EIBSS team are signed off by more than one EIBSS team member to ensure correctness and consistency.
- 240. NHSBSA believes that the current system of decision-making eliminates the potential for a 'rogue' or individual decision to be made by either a medical assessor or a member of the EIBSS team. Where any of these safeguards are believed to have failed, beneficiaries are able to ask for an appeal in the case of

- medical applications, or raise a complaint and ask for their application to be reviewed in the case of a discretionary application.
- 241. Medical assessors apply their knowledge and experience to each case individually. As mentioned above, NHSBSA believes its processes provide for consistency of decision-making. EIBSS does not have a process of filing and retrieving all applications separately for all medical assessors to reference when considering an application as this would be a disproportionate administrative burden. NHSBSA also does not have all historical applications as everything prior to the inception of EIBSS in November 2017 is still held by the AHOs/their legal representatives. The assessors can ask for previous cases, however they are not expected to review hundreds of previous cases looking for similarities that may or may not exist. There is set criteria for the EIBSS assessors to assess an application against, each application is assessed by two medical assessors and if a decision was challenged and went to appeal the appeals panel consisting of three medical consultants would also assess the application, so in total an application may have been assessed by five medical consultants to reach a final appealed outcome.
- 242. EIBSS only considers certain benefit payments in income top up and child payment applications as it is an income assessed application. EIBSS would expect other funding sources to be exhausted for some discretionary payments, such as Motability payments. Information on what other sources of support, including benefits and charitable support, can be considered when determining eligibility and levels of support from EIBSS can be accessed on its website or by calling and requesting the guidance notes.
- 243. Initial work was carried out by DHSC, working in conjunction with policy teams at DWP and HMRC, to ensure that EIBSS payments were added to legislation to grant them non-exempt status from tax. The EIBSS team responds to individual beneficiaries who may contact us where they have encountered issues where either DWP or HMRC are taking the payments into account and should not. Here, the EIBSS team will send a letter out for beneficiaries to share with DWP/HMRC in the event of any issues or disagreements. The EIBSS team may also be able to refer to a welfare advisor to help in cases where there are issues that have been unable to be resolved.

- 244. There is a 'Financial and Support services' section on the EIBSS website with information for beneficiaries if their EIBSS income is questioned, and a letter can be provided advising authorities to disregard any payments from EIBSS. https://www.nhsbsa.nhs.uk/financial-and-support-services.
- 245. This issue has recently been raised at an EIBSS focus group and subsequently relayed to DHSC to pick up with their Cabinet Office and DWP counterparts to ensure that the message is made clear to all DWP and HMRC offices.
- 246. EIBSS can also signpost beneficiaries to Neil Bateman, an independent "Specialist advisor in welfare rights and social policy," who provides contracted advice and whose time is invoiced to EIBSS, or to another welfare adviser to represent beneficiaries where there is a dispute over their payments attracting tax or being taken into account for benefits calculations.
- 247. Although EIBSS provides discretionary one-off payments for a range of services, the EIBSS team look to signpost and assist beneficiaries with their applications for these payments.
- 248. EIBSS refers beneficiaries to a range of counselling and psychological support organisations either online or by providing contact numbers. EIBSS often signposts beneficiaries to their local specialist as they are usually aware of local services that they would find useful. EIBSS also signposts beneficiaries to support organisations such as the Hepatitis C Trust or Terrence Higgins Trust.
- 249. EIBSS are currently working with the Terrence Higgins Trust to promote access to free counselling sessions for HIV infected beneficiaries. EIBSS signpost to the Hepatitis C Trust or Terrence Higgins Trust via phone, website, and printed materials such as direct scheme updates and recently through the EIBSS Newsletter.
- 250. From May 2020, EIBSS changed the process for beneficiaries to be able to obtain counselling without the need to go via the NHS first. EIBSS received feedback at focus groups and from working with a haemophilia social worker on the journey of beneficiaries accessing services and identified that the support available on the NHS was not always suitable for beneficiaries. EIBSS fed this back to DHSC who agreed the change, also ensuring that services could be accessed for beneficiaries that need to shield during the Covid-19 pandemic. EIBSS also created a specific application for counselling support for beneficiaries to ensure all

- the information required would be clear on the form to enable the team to process the application as swiftly as possible.
- 251. From beneficiary feedback, EIBSS understands it is important for a beneficiary to feel comfortable with the person providing them with psychological support and that they may have had a range of counsellors they feel were unable to support them previously. EIBSS amended the process and application to give beneficiaries the opportunity to claim back for initial counselling assessments until they find someone, they feel comfortable with. EIBSS communicated the change in process in May 2020 to beneficiaries.
- 252. EIBSS also signposts beneficiaries to a range of services for further advice where EIBSS are unable to provide a discretionary support payment, whether this is by researching support or signposting to organisations such as the Hepatitis C Trust, Haemophilia Society, the Terrence Higgins Trust and/or the Citizen's Advice Bureau.
- 253. EIBSS looks to provide discretionary payments to beneficiaries who would like to claim back their travel costs to hospital appointments. We understand beneficiaries do not like to make applications to EIBSS, so looked to signpost beneficiaries to claim travel costs via other means. A lot of beneficiaries are already covered under income-based benefits for their travel costs and can often claim costs back from the hospital on the day of their appointment, saving completing forms and waiting to be reimbursed. EIBSS signposts beneficiaries to this option via online guidance and if we get queries via the telephone. EIBSS have also tried to suggest alternatives for beneficiaries who may be on a low income but do not receive an income-based benefit, encouraging them to apply for the NHS Low Income Scheme. If successful, beneficiaries would have received a 12-month certificate entitling them to claim back travel costs on the day, again reducing the amount of applications they would need to make to EIBSS. EIBSS initially asked beneficiaries to apply for the Low Income Scheme in the first instance but based on feedback from a small number of beneficiaries who did not agree with that, we removed the need to follow this route, but advertised it for people who may have found it beneficial.
- 254. EIBSS also signpost beneficiaries to external services relating to money management advice, benefits advice, and careers advice however if an advisor's fee is required, we would look to supply a discretionary payment.

- 255. The discretionary support scheme was reviewed and communicated to all beneficiaries on 20 June 2018. The information is currently on the website, with a guidance booklet for anyone looking online.
- 256. The EIBSS team advise what support beneficiaries in England can apply for and guide them through the application process and what evidence is required over the telephone, email or via written correspondence.

Section 9: Disparities between support under the Devolved Schemes

- 257. I am aware that there are differences between EIBSS and the other devolved schemes. NHSBSA are unable to comment on the differences, as we administer EIBSS in adherence to the specification determined by DHSC. Any differences should be put to DHSC for comment.
- 258. The devolved schemes have occasionally contacted EIBSS to ask how things are operated in EIBSS, but this has been very limited since the inception of EIBSS. EIBSS is aware that DHSC meets with representatives of the devolved administrations to discuss policy in this area but is unaware of the regularity or content of these meetings.
- 259. On 25 March 2021, the paymaster general provided an update on parity of financial support across the infected blood support schemes administered within each of the four nations. The announcement is available at https://questions-statements.parliament.uk/written-statements/detail/2021-03-25/hcws895. It explains that changes are planned which are aimed at bringing greater parity between the different schemes operated throughout the UK. NHSBSA is fully in support of these changes, as they will deliver very positive additional support for EIBSS scheme members. In particular, the planned change to support for bereaved partners (to increase annual payments for bereaved partners to an automatic 100% of their partner's annual payment in year 1 and 75% in year 2 and subsequent years, in line with the Scottish model) is very welcome indeed, and is one that the NHSBSA knows will be extremely well received by beneficiaries.
- 260. All changes will realise additional financial support and will help current and future beneficiaries. We are keen to work with DHSC to deliver these changes to EIBSS. Beneficiaries will be kept up to date with the development of these changes

through broad updates on our website until we are able to update individual beneficiaries on what these changes mean for each of them.

Section 10: Appeals and complaints process

- 261. Medical condition-based applications are all applications that require supporting medical information to be provided as evidence and will be assessed by an EIBSS medical expert. Appeals on decisions in respect of those applications lies to NHSBSA to reconsider the decision. All appeals are heard by a panel of three medical consultants retained from the AHOs, with a legal chairperson to chair any appeal meetings. A medical consultant's qualification and experience requirements are set out earlier in my statement.
- 262. Further to the details in NHSBSA's response to the fourth rule 9 letter dated 18 October 2019, the legal chairperson for the EIBSS appeals panel has changed. The chairperson is now Megan Larrinaga. Megan Larrinaga is a Legally Qualified Chair/Legal Assessor for the Medical Practitioners Tribunal Service and a Senior Legal Advisor at the Oil and Gas Authority. She qualified as a solicitor in 2008 and since that time has acted on behalf of the Police, Legal Ombudsman and Parliamentary and Health Service Ombudsman. As Legally Qualified Chair, she has extensive experience in chairing fitness to practise proceedings brought by the GMC against doctors and ensuring the smooth and fair running of the hearing and as a Legal Assessor providing legal advice to the Tribunal at each stage of the hearing and providing guidance on law, guidance and procedure.
- 263. The chairperson arranges and chairs all appeal panel hearings. Prior to the panel hearings, they will review the information provided by the applicant including the application form, any medical records provided and any support provided in respect of the appeal. Where appropriate, the chair also advises the panel of any matters which may require further direction. At the hearing, the chair will facilitate discussions and seek views from each of the medical members, canvassing views as to the merits of the application and the evidence in support of the appeal. The chair will also ask questions, where relevant and appropriate, particularly in cases where there is little in the way of evidence to support the application or where the prima facie case appears to be weak. These questions and discussions can often lead to discussions around the prevailing circumstances of practices at the time

relevant to the application which the applicant often will not know themselves. During discussions, the chair will provide legal and procedural guidance ensuring that the final decision is fair (both from a procedural and evidence-based perspective) and legally defensible in the event of further challenge. In addition to fully participating in the decision-making process, the chair is also responsible for drafting the decision letter sent to the appellant ensuring that letter is sufficiently clear to assist the applicant in understanding the basis on which the decision was made.

- 264. An advert for the legal chair position was placed in the British Medical Journal. CVs were requested to be submitted and based on the information provided, the applicants were shortlisted. Shortlisting was undertaken by Nicola Richardson (outgoing Chairperson) and interviews were held with the shortlisted applicants. The interview panel consisted of the Nicola Richardson and Service Delivery Manager, Hollie Edminson. The Chairperson is required to be a qualified solicitor, so as a minimum NHSBSA required them to have completed the following qualifications and training and to have chairperson and/or appeals panel experience:
 - 264.1. Three-year undergraduate degree (+ 1-year GDL conversion course if required);
 - 264.2. One-year Legal Practice Course (LPC);
 - 264.3. Two-year Professional Skills Course;
 - 264.4. Two-year law training contract in a law firm.
- 265. The Chair will lead the appeals panel and draft the outcome letters, separate from any involvement from the EIBSS support team. They have autonomy in their decision-making capability.
- 266. All appeals panel members are contractors, who provide a chargeable service based on throughput of cases. The legal chair is recruited on the same basis as the medical consultants, which is as a freelance contractor, whereby EIBSS is invoiced for the cases that are reviewed as part of the appeals panel.
- 267. Someone who has been involved in considering the decision under appeal cannot sit on the appeal panel at NHSBSA. In any event, the EIBSS appeals panel medical consultants are a separate group of medical experts to those who initially assess medical related applications.

- 268. I can confirm that the description of the separate appeals procedures in respect of "medical-condition based applications" in NHSBSA's first and fourth rule 9 responses remain accurate. The appeals panel composition is mainly unchanged i.e. the three medical Consultants are unchanged but there is a new Chairperson, who has been identified and explained above. The timescales and approach to determining appeals is unchanged from our previous response.
- 269. The appeals process is available on the EIBISS website at: https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-how-apply/how-appeal. We also inform each declined applicant of their right to appeal and the appeals process.
- 270. Non-medical based applications are effectively discretionary support applications. A decision letter is provided to every applicant (using their preferred contact route i.e. email/post). If an applicant disagrees with the discretionary payment decision, it can be escalated to an independent Customer Resolution Team within NHSBSA as a complaint and will be reviewed in line with the NHSBSA complaints process and timescales.
- 271. There is currently no process in place for an appellant to give evidence or make representations in person. EIBSS has to carefully consider how the scheme can meet the requirements it has been asked to fulfil by DHSC within the specification, but in a way that provides a cost efficient service. The number of beneficiaries that the scheme supports is an important factor in deciding the format of appeals meetings. EIBSS had 3,058 beneficiaries and reviewed 130 appeals up to 31 March 2020. The practicalities of arranging in person evidence/attendance was considered to be too costly to administer for England.
- 272. One of the appeal outcomes is 'More Information Required.' This means the appeals panel feels the applicant needs to provide further information for the panel to reach an outcome. The decision letter from the appeals panel states this outcome and asks for specific information to be sourced by the applicant and/or requested directly by the panel themselves. On receipt of this new information, the appeals panel will re-assess the appeal to reach a definitive outcome.
- 273. Where the appeal outcome is either 'Unsuccessful' or 'More Information Required,' the decision letter from the appeals panel will include information on what other information is required or why the appeal was unsuccessful.

- 274. However, if at a later stage the applicant can locate further information, they are able to re-apply to the scheme as a new applicant. There is no waiting time following a previous outcome; the applicant can re-apply as soon as they have new information to provide to EIBSS.
- 275. Currently for medical based applications there is no ability to escalate a decision beyond the appeals panel outcome. EIBSS' hope is that by providing a thorough description of why the appeal was not successful and what other information would be useful in supporting any future application, the appellant would source this additional information and reapply to the scheme. If they do wish to escalate further, then they are advised to seek their own legal advice to discuss their available options.
- 276. Non-medical based applications would escalate through NHSBSA complaints process until conclusion at stage 2 (appeal to the NHSBSA Chief Executive). Following that, an applicant could take the matter to the Parliamentary and Health Service Ombudsman. The complaints process is accessible on NHSBSA website at: https://www.nhsbsa.nhs.uk/contact-us/complaints
- 277. On appeal, the appeals panel will examine all available information and evidence provided by an applicant, and it is this information and evidence that is used to determine whether the burden of proof of the application (the balance of probability) is met.
- 278. To calculate probability, the appeal panel needs to establish whether a case is more likely than not. This means that panel will consider all information and evidence that is provided by an applicant and whether it demonstrates that it is more probable than not (i.e. that there is 51% chance or higher) that certain events took place. If so, then those events are treated as having taken place and the applicant has succeeded in proving their case.
- 279. All discretionary applications are assessed by members of the EIBSS team against clear, objective criteria. A beneficiary may not agree with the outcome of an application where this has either been rejected or not fully approved. At this point the EIBSS Team Manager would review how the application had been assessed and whether it followed procedures and met with our policy obligations. If the Team Manager has been involved in the original application assessment, the appeal would initially be reviewed by the EIBSS Senior Delivery Manager. If a

- beneficiary is still unhappy following speaking to the EIBSS Team Manager/Senior Delivery Manager about their review, they are advised to raise a complaint.
- 280. The Customer Resolution Team (CRT) will review the complaint, which may include speaking to the EIBSS Team Manager or other areas of the team for information around the application/complaint. The Customer Resolution Team are independent of this service. The Head of Service for Health & Community Services will review the CRT investigation outcome to determine whether correct procedures have been followed and the beneficiary has been treated correctly, this will conclude stage 1 of NHSBSA complaints process.
- 281. Where a beneficiary is still unhappy, they can proceed to Stage 2 of the complaint process, where the Chief Executive or an independent representative will investigate. The final stage if the beneficiary is still unhappy is to proceed to the Parliamentary and Health Services Ombudsman.
- 282. All cases are assessed based on their own merits and using the experience and knowledge of the medical assessors involved. There are double-checks in place for all assessments so two medical assessors review each form for continuity as well as further review from the appeals panel. It would be a disproportionate administrative burden to file each case based on particular characteristics. The Customer Resolution Team do not decide whether a grant or income top-up is paid to a beneficiary. Their role is to investigate whether the relevant processes and procedures have been followed by the team. In this case they may refer to several members of the EIBSS team for their technical input in their investigations to ensure that the application has been assessed correctly. They are experienced staff dealing with written and verbal correspondence with customers over several different service areas.
- 283. The Customer Resolution Team are all NVQ level 3 qualified or have equivalent work experience to this level. All Customer Resolution Team staff have a contact centre background and have been internally recruited and were successful based on matching the skills and attributes for the role which include:
 - 283.1. Possessing high levels of communication and customer service skills, and the ability to handle contentious complaints in an empathetic manner.
 - 283.2. Working as part of a team, they must be flexible, adaptable, and prepared to move quickly between competing tasks and duties.

- 283.3. Their experience involves using their technical and investigative skills to examine information to make decisions in line with policy to respond to complaints.
- 283.4. Working with confidentiality and with an eye for detail, to ensure complaints are handled in accordance with agreed policies and procedures.
- 283.5. All have full knowledge of NHSBSA complaints policy.
- 284. All staff have received training (provided by NHSBSA training team) in letter writing, adhering to NHSBSA's writing guidelines and training in the effective handling of customer calls. They have also done various customer service courses and more specialist training like autism and suicide awareness.
- 285. Medical professionals do review a previously refused application where supplementary evidence has been provided, as this is hoped to avoid the need for an application to go to appeal and be unduly delayed. The case application could be reviewed by the same medical assessor incorporating the new evidence but as all applications are dual assessed, the independence is upheld. The applicant is then able to appeal if a successful outcome is not reached.
- 286. There are no time limits or fees for bringing an appeal to EIBSS for a medical condition-based application. There is however a time limit (but still no fee) for a non-medical based applications, as these are aligned to our complaints policy, which states no more than 90 calendar days after the incident you wish to complain about occurred. After this time, an applicant would need to raise a new application.
- 287. There is no longer a requirement to wait six months (from the date of the original application) where an appeal against a SCM decision has failed. The specification is currently under review but in the spirit of the new revision, the EIBSS processes have been updated to reflect that there is no waiting time following a previous outcome; the applicant can re-apply as soon as they have new information to provide to EIBSS, given without new information the outcome is unlikely to be different. The six month period is historic; this related to an earlier period within EIBSS where application volumes were high, and the expectation was that an applicant required this additional time to source new supporting information.
- 288. As explained elsewhere in my statement, it would be a disproportionate burden if EIBSS were to file all applications according to their characteristics for medical assessors to review and consider each time they considered a new application.

There is set criteria for the EIBSS assessors to assess an application against. Each application is assessed by two medical assessors and if a decision were challenged and went to appeal, the appeals panel consisting of three medical consultants would also assess the application

- 289. The EIBSS process is required to maintain an appeals panel as per the DHSC service specification. As the substantive requirements of the service have not changed, therefore neither have the appeals processes as this is believed to be working correctly. The complaint process that is followed is regularly reviewed by NHSBSA, as the process is applied consistently across all NHSBSA services.
- 290. The figures for how many have applied for non-discretionary support and the associated appeal volumes are shown in the tables below:

Status	Applications	%
Approved	4458	86%
Declined	549	11%
Further Information	192	4%
Grand Total	5199	100%

Notes/Caveats

- Data is valid as of 18.09.2020.
- Applications involved are those received between 1st November 2017 and COB 31st March 2020.
- Approved and Declined numbers include those applications that have had a decision recorded following an appeal.
- Further information includes those cases which are currently going through the appeals process.

All figures provided are annual figures as reflected in the EIBSS annual report.

291. The information relating to appeals volumes and their associated success percentage is shown in the table below:

Status	Applications	%
Approved	17	13.08%
Declined	105	80.77%
Further	8	6.15%
Information		
Grand Total	130	100.00%

Based on the information provided in the two tables above, 3% of applications are appealed.

Applications	Appeals	%
5199	130	3%

- 292. Since the 1 November 2017, there have been 130 appeals reviewed by the EIBSS appeal panel. 17 appeals have been approved, eight have requested further medical evidence and 105 appeals have been declined. The reason for an unsuccessful appeal will differ between application types. Some examples of those reasons are supplied below:
 - 292.1. Hepatitis C stage 1:
 - 292.1.1. IV drug use;
 - 292.1.2. no evidence of treatment with NHS blood/blood products;
 - 292.1.3. no evidence of treatment with NHS blood/blood productstreatment unlikely to require transfusion;
 - 292.1.4. no evidence of chronic hepatitis C (natural clearer i.e. individual showed no symptoms of hepatitis C after the acute phase of infection (the first 6 months) was over);
 - 292.1.5. no evidence of chronic hepatitis C;
 - 292.1.6. Transfusion was after September 1991
 - 292.2. Hepatitis C Stage 2:
 - 292.2.1. no evidence of stage 2 conditions;
 - 292.2.2. not enough evidence to suggest liver problems linked to hepatitis

 C instead of Non-alcoholic fatty liver disease (NAFLD);
 - 292.3. SCM
 - 292.3.1. conditions not caused by hepatitis C;
 - 292.3.2. not enough evidence to suggest mental health problems linked to hepatitis C.
 - 292.4. HIV
 - 292.4.1. no evidence of treatment with NHS blood/blood products;
 - 292.4.2. no evidence of HIV or treatment with NHS blood/blood products;
 - 292.4.3. treatment in Turkey more likely source of infection.
- 293. A beneficiary is able to raise a complaint about the service (e.g. service standards or other matters not directly related to their applications), which they can

do via NHSBSA complaints process, which is available on our website at: https://www.nhsbsa.nhs.uk/contact-us/complaints. If the beneficiary advises EIBSS of their dissatisfaction and their request to raise a complaint, we will either direct them to this website page, provide written details upon request if they were unable to access the internet, or escalate internally to the independent Customer Resolutions Team.

Section 11: Mechanisms for ongoing review and improvement

- 294. As aforementioned, EIBSS' service performance is reviewed throughout the year via the monthly and quarterly accountability meetings. EIBSS strive to deliver excellent customer service, as with all NHSBSA services. Any feedback to the contrary will be used as an opportunity to learn how we can improve our services to customers.
- 295. The only review of EIBSS that has been carried out to my knowledge is the discretionary review from December 2017 to April 2018 onwards. It is unlikely that the full costs of the review are available now. Most of the cost would have been NHSBSA internal resource and the likely external costs of that review would involve booking venues for meetings and the costs of the third-party company collating the report. The funds for those costs were from NHSBSA administration main budget and did not affect the beneficiary funding budget. The SCM review had already been decided by DHSC but was administered by us from November 2017 onwards.
- 296. Other policy reform and changes, including changes in payment levels since the scheme inception, have all been carried out following instructions from DHSC. Examples of this were in the consolidation of income top ups with regular payments from July 2019 for infected beneficiaries and the changes of payment brackets for bereaved beneficiaries in receipt of income top-ups to increase payment levels.

Section 12: Relationships with other organisations

297. Initial involvement with the Haemophilia Society is set out above in relation to the transition to EIBSS to explain who NHSBSA are and what we do. At the inception of EIBSS, as set out above, there was regular interaction on the setup of the scheme and sharing of correspondence etc. was maintained with the

- Haemophilia Society. The Haemophilia Society also attended Skipton House to meet the EIBSS team at the early stages after inception.
- 298. Other than that, interaction has been limited other than individual queries from the Haemophilia Society to support beneficiaries. Recently a representative GRO-D has also attended a focus group with beneficiaries in February 2020. Following this focus group, the EIBSS team has asked the Society for further information about their services, so we are able to update signposting on our website.
- 299. NHSBSA is unaware of any difficulties in the working relationship with the Haemophilia Society and is happy to continue working with Haemophilia Society more in the future where appropriate.
- 300. NHSBSA has not been involved or interacted with the UK Haemophilia Centre Directors Organisation ("UKHCDO"). As such, NHSBSA does not have a current working relationship with the UKHCDO, however we are happy and open to working with the organisation when relevant.
- 301. Other than the medical assessors and appeals panel, the EIBSS team has been in contact with Karen Gray, Haemophilia Social Worker. This involved the EIBSS Team Manager meeting with her as she had been involved in supporting beneficiaries making applications to EIBSS. This was mutually beneficial as it gave her more background into what was required for applications but also for the EIBSS team to understand the work of Haemophilia Social Workers and what support beneficiaries may have from Haemophilia Social Workers in general.
- 302. With regard to the Hepatitis C Trust, as set out elsewhere in this statement and as described above in relation to the Haemophilia Society, there was initial involvement and feedback between NHSBSA with their teams on issues that beneficiaries were experiencing. NHSBSA also shared initial letters going to beneficiaries so the Hepatitis C Trust and Haemophilia Society were aware what questions they might get asked etc.

Section 13: Criticisms or observations

303. NHSBSA and the EIBSS team welcome any feedback from the beneficiary population and are open to change things that will help improve beneficiary experience from an administrative perspective.

- 304. As mentioned elsewhere within this statement, NHSBSA was unable to contact all beneficiaries registered with the AHOs to inform them of the EIBSS service start-up as the AHOs had adopted a policy of explicit consent around transferring their data to NHSBSA and NHSBSA did not hold their data to contact them itself. However, the setup of the EIBSS scheme was originally announced in the DHSC consultation response in this area, which involved consultation with the beneficiary community as well as several support groups. Where someone did not consent to sending their data to the EIBSS service originally, NHSBSA worked with the AHOs by allowing staff to be seconded back to the AHOs to support them with the process of seeking consent and on-going data transfer and close down activities. For anyone where payments were affected, the EIBSS team always looked to make payments as quickly as possible, often within 24 hours, to ensure continuity of payment.
- 305. The EIBSS team attempts to engage with beneficiaries through an open dialogue. All beneficiaries have regularly been asked if they would like to be part of focus groups and attend meetings with members of the EIBSS team to build relationships and give feedback on the service. Ultimately some beneficiaries may want to be part of these groups, but most registered beneficiaries have not registered an interest in engaging with the service.
- 306. It would also require a lot of staff resource for the EIBSS team to get to build significant and close relationships with all EIBSS beneficiaries when it has a registered beneficiary population of approximately 3,000. Therefore, a more pragmatic approach is taken through focus groups with interested parties to ensure that those who would like to engage with the EIBSS team are given the opportunity to do so. The team also has to have continuity considerations for when staff are sick or on leave, so specific case contacts is impractical from a staffing perspective without requiring a larger team to support it (at greater cost) and even then there would have to be several staff allocated to a beneficiary for the continuity points already mentioned.
- 307. The EIBSS team would welcome further detail around these criticisms to review and see if there is anything that can be changed or improved immediately if appropriate.
- 308. Application forms for non-discretionary support were generic to cover several types of support. This was intended to minimise the number of forms used to

reduce confusion. Unfortunately due to the form covering more than one form of support, the wording within the forms has been criticised as being insensitive, a case in point being the application for "Discretionary one-off payments" which covers all one-off payments, which originally included a question asking "How would this benefit you?" Once this was brought our attention, we promptly amended the form to avoid any potential future upset for others. EIBSS have now reviewed the discretionary application form, and have created a specific form for each support request. This is intended to improve clarity and consistency within each application, and a dedicated area on the website has been created https://www.nhsbsa.nhs.uk/discretionary-support.

- 309. EIBSS has been setup to provide primarily financial support for those infected and affected. The support that can be provided is based upon the agreed specification with DHSC. The funds available are to be used for the criteria described within the specification document. EIBSS has an obligation to not only support scheme beneficiaries, but to act as guardians of public funds and to ensure that these funds are distributed correctly to those beneficiaries in need of support, as well as providing value for money for the taxpayer. If the support is available from other available sources, EIBSS is required to first direct a beneficiary to those sources, as those sources are funded separately for a specific purpose. There is also the potential for a beneficiary to claim twice if EIBSS was to provide financial support and it was available from another source, which could result in double funding for the same thing from two separate Government sources.
- 310. I am aware that there are differences between EIBSS and the other devolved schemes. NHSBSA are unable to comment on the differences, as we administer EIBSS in adherence to the specification. DHSC should be asked for comment. However, as set out above, on 25 March 2021, the paymaster general provided an update on improving parity of financial support across the infected blood support schemes administered within each of the four nations, which NHSBSA fully supports, as the planned changes will deliver very positive additional support for EIBSS scheme members.
- 311. As previously stated within this response, the EIBSS service is responsible for the distribution of public monies to beneficiaries and has a duty to beneficiaries that this money is dedicated to their welfare and support and is distributed correctly and fairly. To do so, NHSBSA is required to formulate procedures that reduce the

- potential for fraud as well as making sure that payments and applications approved are done so consistently against set criteria. Therefore, EIBSS has eligibility requirements and asks for evidence to demonstrate eligibility for the different areas of support.
- 312. Having said that, the EIBSS team is open to working with beneficiaries where supplying any of the evidence is difficult to see if there are any alternatives. The EIBSS team would welcome further detail around these criticisms to review and see if there is anything that can be changed or improved immediately, if appropriate.
- 313. The policy around income top-ups and how these are assessed has been agreed with DHSC as part of their overall policy. Following feedback from beneficiaries shared with EIBSS and subsequently DHSC, means testing and the evidence requirements for infected beneficiaries was removed, as of 1st April 2019.
- 314. Bereaved income top-up currently remains but support increased 1st April 2019.
- 315. EIBSS are unable to comment on the 1991 cut-off date for hepatitis C infection used by the Skipton fund. This is the date defined within the DHSC EIBSS specification, and we administer the scheme in adherence to that specification. However, any concerns on the cut-off date should be directed to DHSC as a policy matter.
- 316. New applicants to EIBSS are paid from the date their application is received, although an exception will apply to any hepatitis C application related to intravenous anti-D immunoglobulin, for the reasons set out above. There have been a number of beneficiaries that either fell out of touch with the AHO schemes therefore missing out on support available or where their details were not passed across at commencement of EIBSS due to explicit consent not having been provided. Where a beneficiary contacts EIBSS who was registered with an AHO scheme, we work with them and Russell Cooke to identify any historic payments they are entitled to. The backdating policy is defined within the DHSC EIBSS specification under which we administer the scheme. Please direct any concerns on the backdating criteria to DHSC directly. Since November 2017, 67 beneficiaries have made contact with EIBSS and subsequently transferred to this scheme after their details were not previously passed over to EIBSS when the Skipton Fund closed.

317. I do consider EIBSS is well run. EIBSS looks beyond its service performance and strives to provide the best possible service for the beneficiaries it supports. Our decision-making capacity is bound by the criteria defined with the EIBSS specification document and this is often perceived as EIBSS being unwilling to help. EIBSS listens to beneficiaries and where possible will apply discretion to specific scenarios, where a beneficiary has presented appropriate supporting information for doing so. Where we are unable to apply discretion, we will capture all beneficiary feedback and will include this within the next JRG. Through telephone, email, postal and most importantly the Focus Groups, we have the opportunity to listen and learn about what works and does not work and how this has affected beneficiaries and we are able to stress the emotive reasoning behind the feedback we receive when discussing this with DHSC.

Section 14: Other

318. Thank you for the offer to provide further information relevant to the Inquiry Terms of Reference. I do not believe there is anything further I can provide in addition to the previous five rule 9 requests NHSBSA have responded to and my statement provided here. For the Inquiry's convenience, I have attached these responses as my **Exhibits BB6** (WITN4496007) **to BB10** (WITN4496011).

Statement of Truth

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

GRO-C Signed

Dated 22 April 2021

Table of exhibits:

Exhibit number	Date	Notes/ Description
Exhibit BB1 (WITN44960 02)	September 2017	Example letter to beneficiaries by the Caxton Foundation shared with the NHSBSA
Exhibit BB2 (WITN44960 03).	Undated	Template 'welcome letter' to beneficiaries sent by NHSBSA that gave contact details and information about EIBSS
Exhibit BB3 (WITN44960 04).	January 2020	Terms of Reference for the JRG
Exhibit BB4 (WITN44960 05).	January 2020 and July 2020	Notes from JRG meetings
Exhibit BB5 (WITN44960 06)	December 2016	Infected blood: Reform of Financial and Other Support in England policy document by DHSC
Exhibit BB6 (WITN44960 07)	16 November 2018	First rule 9 request response on behalf of NHSBSA
Exhibit BB7(WITN44 96008)	24 January 2019	Second rule 9 request response on behalf of NHSBSA
Exhibit BB8 (WITN44960	10 May 2019	Third rule 9 request response on behalf of NHSBSA

09)		
Exhibit BB9 (WITN44960 10)	18 October 2019	Fourth rule 9 request response on behalf of NHSBSA
Exhibit BB10 (WITN44960 11)	23 March 2020	Fifth rule 9 request response on behalf of NHSBSA