Witness Name: Brendan Brown
Statement No.: WITN4496013
Exhibits: WITN4496014 to WITN4496016
Dated: 26 August 2021

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF BRENDAN BROWN
ON BEHALF OF NHS BUSINESS SERVICES AUTHORITY

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

1. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 June 2021. As with my first and second statement, this 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. Details of my professional background and career is set out in my first statement.

Section 2: EIBSS focus groups

3. Attendance at EIBSS focus groups is not limited to certain categories of beneficiaries. A beneficiary of any category of support from EIBSS may attend.

EIBSS did hold an additional online focus group for beneficiaries infected with HIV only in November 2020, as HIV beneficiaries requested a separate meeting to address specific HIV related feedback about the scheme. This HIV beneficiary focus group was attended by a Terence Higgins Trust representative, as they also are a beneficiary of the scheme. However, EIBSS' general approach is to treat all beneficiaries equally in terms of access to and attendance at Focus Groups; an additional focus group for a certain group could be arranged if there was a requirement to do so.

4. The purpose of the EIBSS focus group is to enable the NHSBSA team responsible for EIBSS to meet with beneficiaries who receive support from the EIBSS scheme it administers and to receive feedback on EIBSS from those beneficiaries. The only non-beneficiaries who attend are carers and support workers of the attending beneficiaries. EIBSS does not extend attendance further because the purpose of the focus groups is to obtain feedback on the administration of the scheme, so scheme recipients (who are the recipients of such administration) are the focus group's target audience.

5. Each year, EIBSS seeks expressions of interest from beneficiaries who would like to attend a focus group. This communication is part of the annual payment notification sent to all primary and secondary beneficiaries who receive regular payments, as EIBSS is aware unnecessary mailings can cause distress to beneficiaries. Details of the forthcoming focus groups and how to be invited to attend will be added to the EIBSS website shortly. Details will also be included in future EIBSS newsletters that any beneficiary who has chosen to subscribe to the EIBSS mailing list can receive.

6. Any beneficiary who has registered their interest will be contacted by NHSBSA through their preferred method of contact and invited to attend the next focus group and advised of its proposed date, time and location. Beneficiaries are asked to confirm their attendance by a certain date and beneficiaries who have not been to a focus group before will be given priority over those who have, to ensure that NHSBSA capture as much feedback to represent as wide as pool of beneficiaries as possible. There are a few beneficiaries that want to be

present at every focus group so NHSBSA will extend the invite to these beneficiaries if, closer to the time, the number of attendees is not at capacity.

7. Any beneficiaries who could not attend on a particular occasion are reminded that they can provide their feedback directly to the EIBSS team by telephone and/or via email at any time.

8. Initial focus group sessions were held to introduce members of the EIBSS team to beneficiaries, understand beneficiary concerns and receive any feedback on how the service was running. The groups were also used to discuss any changes to the scheme, such as the review of discretionary payments explained in my first witness statement. Minutes were not taken at these earlier meetings. The meetings subsequently evolved into the focus groups that EIBSS holds today. As set out in paragraphs 116 and 126 of my first witness statement, focus groups have been held on the following dates and at the following locations:
    a. 20 February 2018 - London;
    b. 21 February 2018 - Manchester;
    c. 31 May 2018 - Manchester;
    d. 28 June 2018 - London;
    e. 11 September 2018 - Birmingham – cancelled due to beneficiaries cancelling;
    f. 30 November 2018 - Newcastle;
    g. 24 January 2019 - Manchester;
    h. 04 April 2019 - London;
    i. 15 August 2019 - Manchester;
    j. 21 November 2019 - Manchester;
    k. 28 February 2020 - London;
    l. 30 November 2020 - virtual meeting via Microsoft Teams;
    m. 3 December 2020 - virtual meeting via Microsoft Teams;
    n. 4 December 2020 - virtual meeting via Microsoft Teams.

9. EIBSS attempts to hold these focus groups regularly wherever possible, in order to continually receive first-hand feedback from those the scheme supports

and to discuss forthcoming developments/changes. As can be seen from the dates above, the meetings were held every 2 – 4 months until March 2020 when COVID-19 restrictions made it impossible to meet face-to-face. The meetings were then trialled online when they re-started from November 2020. The meetings are useful to allow us to meet some of the beneficiaries we support and allows us to identify any opportunities for improvement. Face-to-face meetings can also be used to give beneficiaries face-to-face assistance with their applications with prior agreement. EIBSS is currently in the process of planning the next set of sessions, which is expected to take place once the parity changes (discussed at paragraphs 259 – 260 and 310 in my first statement) have taken effect, so EIBSS can discuss and deal with any feedback on those changes with beneficiaries, and once there is a clearer understanding of COVID-19 restrictions.

10. Minutes of the meetings listed in paragraph 8 above that were held on or after 31 May 2018 have been provided to the Inquiry. Minutes of meetings held prior to that date were not minuted. There are no formal, set agendas for these meetings; the meetings are an open forum where attendees can provide feedback on anything scheme related. One such example is the removal of disability related elements of state benefits from the Income Top Up ("ITU") assessment.

11. Minutes of each focus group are usually circulated to the attendees of that meeting by their preferred contact method so that they can be checked for accuracy. Due to an oversight on EIBSS' behalf, the minutes of the latest focus groups in November and December 2020 were not shared with beneficiaries and EIBSS will shortly correct that by publishing all focus group minutes on the EIBSS website. EIBSS will communicate this update to all those who attended and all other beneficiaries through regular communications and support groups. The minutes of each focus group have also been shared with Department of Health and Social Care ("DHSC").

12. Where a focus group raises a policy issue, that is taken away and brought to the attention of DHSC policy officials responsible for EIBSS. Initially, the DHSC

officials may have been informed via email, face-to-face meetings, telephone or a combination of all of these channels. The EIBSS Joint Review Group ("JRG") that was established in January 2020 (and described in my first statement in more detail starting at paragraph 48) is now the default mechanism used to review any focus group matters that require policy consideration.

13. Paragraph 50 of my first witness statement explains one example where the JRG approved an EIBSS change as a result of improvements suggested by beneficiaries relating to application processes for a respite break. Other examples include:
    a. A request by a beneficiary that a payment for moving costs and redecoration costs be implemented. A beneficiary raised that they were moving to somewhere with a more accessible bathroom to meet their mobility needs and other beneficiary feedback has been that moving/redecorating would help them forget painful memories. This request was approved. The JRG recognised that due to certain circumstances beneficiaries may be unable to adapt their current property, due to medical conditions related to them being infected with hepatitis C and/or HIV from NHS blood or blood products. The group therefore deemed it appropriate that a beneficiary could claim the cost for removals, as part of the adaption allowance. The maximum allowance within 10 years remains at £2,500.
    b. A beneficiary queried that they have to prove they were a wheelchair user to go to hospital appointments and needed someone to push them. The beneficiary also raised having to pay for associated costs going to hospital such as food, clothing and heating. The JRG approved the use of a common sense 'self-declared' approach where a partner/carer is required to accompany a beneficiary to their hospital appointment, although the decision applied to the travel costs only and not any associated costs going to hospital such as food, clothing and heating.
    c. Beneficiaries with childcare issues have requested payments to allow them to take their children on a respite break. In some cases beneficiaries have children with severe disabilities and have no option to take them, leaving them in a position where they are unable to go or, if

they do, they will not benefit from the break due to having to care for their children. This request was approved. EIBSS fully considered the sensitive and emotive reasons behind this situation i.e. the beneficiary and their partner/carer would not be able to access a respite break without either taking their severely mentally/physically disabled child with them or placing them in temporary respite care. It was also agreed that where a partner is also the carer for the beneficiary and their severely mentally/physically disabled child, the child should also be entitled to the respite care payment. Entitlement to the payment will be dependent on the provision of evidence to show that a child is severely mentally/physically disabled. The beneficiary and/or partner/carer is able to opt for either the respite payment to cover a break away or to cover placing the child in temporary respite care.

14. Prior to the JRG, examples of actions taken, and changes made include:
    a. A beneficiary stated they found it difficult to complete application forms and did not like to speak to different staff members when they call for help, as they feel they have to repeat their experiences. As a result, NHSBSA confirmed that any beneficiary can request that they deal with the same member of the team each time they call and then confirmed to staff that they should take this approach.
    b. A beneficiary asked if they could claim the cost of counselling assessments, so we introduced that.
    c. At one focus group, it was asked if the cost of a psychological assessment can be claimed in advance, so we adapted our procedures for that, to enable beneficiaries to attend and get the further support, if needed.
    d. In relation to ITU, it was raised that we use the full income of people living within the household, we therefore reduced the amount considered, so used a small proportion of their weekly income instead. (The Inquiry should note that in my oral evidence, I was asked about the use of household income at page 66 of my transcript and I have since identified that, as set in this paragraph, EIBSS did subsequently change to only use a proportion of weekly income in ITU assessments.)

e. A beneficiary asked if we could publish an email address and telephone number for Russell Cooke online rather than simply an address, so we updated that information. Such information can be found on the NHSBSA website "Member of previous schemes" accessible via the following hyperlink: https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-how-apply/people-infected-hepatitis-c-stage-1-payment

f. We were asked if we could introduce an annual newsletter, which we have now introduced, and which is discussed elsewhere in this statement.

g. We were asked if beneficiaries can receive travel costs in advance, to attend focus groups, we agreed that we would book the train tickets if someone did not have the funds to claim a reimbursement.

h. We were asked if end of year reports can be made more prominent on the website, so we created a section directly on the EIBSS homepage.

i. Beneficiaries told us that when applying for discretionary payments, often doctors do not provide the correct evidence, meaning there is a delay for us to process and provide a payment. EIBSS created individual forms for each payment with explicit guidance on the cover sheet and as part of the questions on the form for doctors to try to deal with this issue.

15. The way in which EIBSS communicates the outcome of a matter raised at a focus group is dictated by the matter itself. It may be a specific issue unique to a single beneficiary or it may be a scheme wide matter. Generally, EIBSS will feedback the outcome of any focus group matters put to the DHSC/JRG for a decision by sharing directly with the individual who initially raised the issue (where known, as feedback can be fed in anonymously). Where outcomes may affect all or a wider potential group of beneficiaries, EIBSS will share any updates with beneficiaries via the next newsletter, bespoke communications and/or the EIBSS website.

16. With regard to newsletters, a 'pilot' newsletter was sent out to all EIBSS beneficiaries between September and October 2020 along with a feedback questionnaire to understand what our scheme members would want to see in a newsletter. The newsletter also included an 'opt in' form for future newsletters

to be completed, as we have had feedback in the past from beneficiaries that they do not like to be contacted by EIBSS.

17. A total of 2,941 newsletters were sent by email and post and subsequently 1,371 completed survey responses were received. These survey responses showed that beneficiaries' frequency preferences were as follows:
    a. 57% quarterly;
    b. 23% six-monthly;
    c. 13% when changes are made;
    d. 6% annually; and
    e. 1% did not want further newsletters.

18. A second newsletter was drafted to promote free prescriptions, attendance at focus groups, advise of changes to the website and promote ITU applications. However, this newsletter was put on hold due to the parity changes being announced and subsequently resource being re-prioritised to focus on the changes required.

19. I attach copies of the two EIBSS newsletters as my **Exhibit BB11** (WITN4496014).

20. Whilst we are keen to relaunch the newsletter, we are conscious of less than half of beneficiaries wanting to receive it, and also the desire of beneficiaries not to receive additional communications from EIBSS, so we will be prioritising updates via the website in the short term and the sending of parity payment letters to all affected beneficiaries.

Section 3: Communication

21. In my first witness statement and in my oral evidence to the Inquiry on 21 May 2021, I explained that, in March 2021, it was agreed at a meeting between DHSC and NHSBSA that a communication campaign to publicise EIBSS and what the scheme covers was sensible to raise awareness and particularly to reach out to beneficiaries registered with the Alliance House Organisations

("AHOs") whose details were not transferred by the AHOs to EIBSS when EIBSS was established.

22. The option of contacting applicants to these previous AHOs (through somehow using the information held by the AHOs but not shared with EIBSS) was also considered as part of the options for identifying the missing beneficiaries. However, the option was discounted due to the age of the contact information. It was considered that even if it could be accessed using this historic information to advertise the existence and possible support from EIBSS could unintentionally divulge a person's medical condition to a third party, as the age of the data increases the likelihood that the person has moved to a new address. The option of utilising an external third-party commercial organisation to trace any missing beneficiaries was considered between the DHSC, Russell-Cooke Solicitors and NHSBSA. However, the third-party organisation requested that they be provided with information regarding the purpose of the exercise and the identity of the AHO behind the search. DHSC made the decision that such information should not be shared with the external third-party organisation and so this option was not progressed. Contacting these previous AHO applicants could be explored again, as part of the associated activity of the communications campaign but would need to be something DHSC led on, as they are responsible for the support work Russell Cooke provide in relation to the former AHOs.

23. The details of any communications campaign and its target audience have yet to be agreed. EIBSS will be working with DHSC to understand the details of what the communications campaign will include and the options involved to make this campaign effective at reaching the appropriate audience. The audience could include those attending support organisations, treatment centres, hospitals or GP Practices where targeted messaging is required but, as I say, the intended audience and communications options to target them are still to be defined. At this stage, the proposal for a communications campaign has been put to DHSC and I understand that DHSC have submitted the communication proposal to their Minister. The Minister felt that more detail on

the communication options is required so NHSBSA is working with DHSC to pull together some potential communication options.

24. I am not able to clarify why such a communication campaign to publicise EIBSS has not taken place previously. NHSBSA administer EIBSS in accordance with the specification between DHSC and NHSBSA and there has not previously been a requirement for NHSBSA to undertake an EIBSS communication campaign. As explained in my first witness statement, NHSBSA administers EIBSS on direction from the Secretary of State for Health and Social Care in compliance with that specification and any changes to that specification (including its funding requirements) need to be agreed by DHSC. NHSBSA has undertaken all other communication activities in the current specification, including establishing a dedicated section of its website to EIBSS. As I said in my first witness statement, DHSC had also explained the scheme was moving to NHSBSA in their consultation with people who were affected by infected blood. NHSBSA representatives also had discussions with both the Hepatitis C Trust and Haemophilia Society ahead of the scheme transfer, to ensure that both organisations were aware of EIBSS and that they had relevant contact details of the scheme in order to be able to signpost to EIBSS. NHSBSA continue to work with such organisations to make people aware of EIBSS through their networks. This Inquiry may also have raised awareness of EIBSS too.

25. EIBSS does not collect data on its beneficiaries to try and identify where there may be gaps in the beneficiary cohort. This is because EIBSS applies the data minimisation principle enshrined in the UK General Data Protection Regulation, which requires that NHSBSA identifies and only processes the minimum amount of personal data necessary to fulfil its obligations under its Memorandum of Understanding and specification with DHSC and no more. EIBSS' primary function is to assess applications against certain criteria and make payments to successful applicants. Any other information outside of this purpose is not required to fulfil our stated purpose.

Section 4: Staff

26. 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. The scheme specification is introduced to staff as part of their induction training, so they are fully aware of the scheme's aims and objectives.

27. Initial training for staff at the inception of EIBSS was training on the background of the scheme, details of payment types etc. followed by one to one mentoring and support from established staff TUPE'd from the AHOs. This was followed by training from the Samaritans to support staff to best manage difficult conversations with beneficiaries. Support was also provided by medical professionals in the scheme around what to expect, details around HIV/Hepatitis C and difficulties beneficiaries might face etc. EIBSS are currently looking at some new training with the Terrance Higgins Trust too.

28. All staff selected for EIBSS are recruited from an experienced pool of people and are required to demonstrate their capabilities during the recruitment process. All EIBSS staff have a background in dealing with vulnerable callers, as other services in the NHSBSA have customers who fall into this category. In addition, there is specific training for assisting vulnerable customers available to staff, which is specifically tailored for EIBSS. During training, staff also review some of the statements that have been published by the Inquiry to raise awareness of some of the difficulties faced by beneficiaries.

29. EIBSS calls are evaluated to ensure the sensitivity and accuracy of conversations with EIBSS staff remain at the required standard. If any need for improvement is identified, feedback is given, and re-training provided.

Section 5: Decisions by DHSC

30. DHSC is best placed to describe how it makes decisions that impact EIBSS. EIBSS is asked to feed into policy decisions that DHSC make. DHSC's reliance on NHSBSA's expertise and experience in the detail of EIBSS , how the scheme is administered or proposed scheme changes will affect beneficiaries has grown over time, as EIBSS became established and in light of turnover of DHSC policy staff. EIBSS will provide an informed opinion regarding proposed DHSC policy decisions and their ability to impact on beneficiaries and the support EIBSS provides. The recent parity change was one such case. Just prior to the announcement, NHSBSA became aware that the majority of existing beneficiaries would not receive the increased lump sum payments proposed as the new change would apply to new applicants only. EIBSS immediately voiced their strong feelings against this intention, which we stated would negatively impact upon many beneficiaries when the parity changes should be a financially positive policy decision for all those that should be entitled.

31. Following the initial conversation, a subsequent email exchange and meeting took place between NHSBSA and DHSC Senior Policy staff, so NHSBSA could explain why they believed the intended direction by DHSC was incorrect. Following the meeting, I put NHSBSA's concerns in writing to DHSC, hoping that they would take these into account as part of their final decision. I attach relevant email correspondence from 24 March 2021 as my **Exhibit BB12** (WITN4496015). After I sent this email, I received a call from William Vineall at DHSC that evening. He confirmed that DHSC accepted our concerns and would amend the new rules, taking into account my feedback, so existing beneficiaries benefited from the parity changes in the final announcement.

Section 6: Application process

32. EIBSS provides a supportive service to applicants and to beneficiaries of the scheme. That support is based upon the requirements within the scheme specification. EIBSS has based its service design i.e. the processes and its staffing to deliver the scheme as defined within the specification. EIBSS does not obtain medical records on behalf of applicants as explained in my first witness statement. However, EIBSS is always open to feedback and

suggestions of service improvement. If support to obtain medical records on an applicant's behalf is something that has been requested of EIBSS, it would require a change to be made to the EIBSS service specification by DHSC. If DHSC made such a change, EIBSS would need to plan how it would build that support into its service delivery and explore/manage the likely impacts, such as the likely increase in the administrative cost of the scheme.

33. I have been asked how EIBSS clinicians take steps to obtain any information/evidence about historic medical practises that may be used in particular parts of the country or in particular procedures at a specific time when considering whether it is clinically plausible that blood or blood products would have been required. Following discussions with my team, I confirm that assessors consider the likelihood of use of blood and blood products within context e.g. the likelihood of contracting an infection from a transfusion in a particular intervention is considered against the likelihood that an individual was infected from another source in light of other potential risk factors to which they may be exposed.

34. I am aware that many EIBSS clinicians have lengthy clinical/academic training/experience which means that they will be aware of historic medical practices. For example, all medical members of the EIBSS Appeal Panel are clinicians who were working within the NHS from the 1970s onwards. Clinicians will also conduct relevant research and/or consult relevant published literature such as via https://pubmed.ncbi.nlm.nih.gov/ which comprises more than 32 million citations for biomedical literature.

35. I understand from the EIBSS assessors that it is more difficult to obtain evidence on medical practices in different parts of the country but as voluntary blood donations were used for routine blood transfusions, the applicability of practice across the country should be reasonable.

36. I have been asked about the term "good cause" which I mentioned during my oral evidence to the Inquiry on Friday 21 May 2021 (at page 49 of my transcript). Thank you for the opportunity to comment on my use of this term which I now

realise was incorrect. I sincerely apologise for any confusion caused; I am responsible for several areas in the NHSBSA and "good cause" is a feature of another of one of my service areas. Entitlement to Special Category Mechanism ("SCM") payments is assessed using a combination of clinical judgment (as to whether certain criteria have been met) and consideration of whether, on the balance of probabilities, the medical assessor believes the reported symptoms to be due to Hepatitis C infection. The application is assessed by the independent medical assessors by taking into account the likelihood indicator that has been ticked and the supporting medical explanation and/or information provided, as set out in the NHSBSA's medical assessor guidance on assessment of SCM applications attached as my **Exhibit BB13** (WITN4496016).

37. I have been asked whether ITU payment rates are reviewed every year at EIBSS. I confirm that EIBSS will review the income top-up payment rates annually, which is a requirement on NHSBSA in the EIBSS specification. The amount paid may vary each year if a person's earnings changes year to year. In my oral evidence (at page 69 of my transcript) I was asked whether changes to payments should be made this year, given the parity statement changes announced on 25 March 2021. However, I have since discussed with my team and understand that changes are still being made to ensure people get the right amount, including increasing the amounts paid where applicable.

38. In order to ascertain whether or not infection with HIV/AIDS and/or Hepatitis C contributed to death, prior to 25 March 2021, EIBSS would look at the reason on the death certificate. If one of the above infections was not mentioned, the matter would be referred to a medical assessor to review to see if, based on the evidence, they agreed the listed conditions were caused by HIV or Hepatitis C. In one such example, a beneficiary died by suicide. We tried to ascertain if the reason behind the suicide was linked to their medical condition and how they were impacted, and we were able to approve the bereavement payment on that basis.

39. I would like to take this opportunity to also correct another issue that arose in my oral evidence. I stated that I was not aware of any situations where EIBSS allowed the monthly/quarterly payments that a bereaved individual would usually receive to continue to their bereaved partner, which could then later be taken out of the bereaved payment lump sum, if the bereaved partner wished us to do so to alleviate initial financial hardship. I have since been made aware of a situation where this exact process was applied to a bereaved partner's situation by EIBSS.

40. Since the parity changes were announced on 25 March 2021, the criteria requiring that death is related to HIV or Hepatitis C infection before a bereavement payment can be made has been removed. A payment from this date will be payable upon death regardless of the cause of death.

41. Historic bereavement applications are being revisited as part of the parity changes. Where we have up-to-date contact information, the payment will be made to applicants previously declined. For those where we do not have up to date confirmation, we will communicate the update through the aforementioned routes such as on our website etc.

42. I have been asked whether EIBSS has received and/or used any information about subcutaneous anti-D procedures in decision making. Following enquiries with my team, I can confirm that Dr Patricia Hewitt has informed EIBSS that, in current guidelines, it is recommended that anti-Rh(D) immunoglobulin should be administered by the sub-cutaneous route in the rare circumstance where a patient who requires an injection has severe thrombocytopenia (platelet deficiency). Administration by this route would be with the standard anti-Rh(D) preparations used for intramuscular administration and, as such, there would be no difference in the decision-making process used by EIBSS.

Section 7: Other Issues

43. I would like to take this opportunity to correct some other points that I made in my oral evidence to the Inquiry on Friday 21 May 2021. The first point appears

at page 80 of my transcript. I stated that to my knowledge a HIV specialist sits on the EIBSS Appeal Panel. However, having since spoken to my team, the HIV specialist that I was thinking of is an EIBSS medical assessor, not an EIBSS Appeal Panel member. Also, I confirm that the names of the independent Appeal Panel members are not published, contrary to what I said in oral evidence (at page 78 of my transcript). Finally, at page 85 of my transcript, I state that the number of beneficiaries who have died is not reported to the DHSC but I have since identified that it is reported by EIBSS to the DHSC monthly.

Statement of Truth

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

Signed GRO-C

Dated: 26 August 2021

Table of exhibits:

Exhibit number	**Date**	**Notes/ Description**
Exhibit BB11 (WITN4496014).	Various	EIBSS newsletters
Exhibit BB12 (WITN4496015).	24 March 2021	Email from Brendan Brown to William Vineall
Exhibit BB13	17 February	NHSBSA Assessment of Special Category

(WITN4496016).	2021	(SCM) applications Medical Assessor Guidance