

Witness Name: William Vineall  
Statement No: WITN4688055  
Exhibits: WITN4688056 –  
4688058  
Dated: 23 April 2021

## INFECTED BLOOD INQUIRY

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### THIRD WRITTEN STATEMENT OF WILLIAM VINEALL

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

I, William Vineall, will say as follows:

#### **Section 1: Introduction**

1. My name is William Vineall. My professional address is 39 Victoria St, Westminster, London SW1H 0EU.
2. I am Director of NHS Quality, Safety and Investigations at the Department of Health and Social Care ("the Department"), since 2016. Part of my role includes oversight of on-going inquiries or investigations pertaining to the responsibilities of the Department, not just restricted to current NHS issues. I am duly authorised to make this Statement on behalf of the Department.
3. The team in the Department that provides evidence and information to the Infected Blood Inquiry has sat within my Directorate since late 2018. Since early

2019 the team responsible for policy and governance of the England Infected Blood Support Scheme (“EIBSS”) has sat within my directorate and so came within my area of responsibility. As a result, I have also provided a statement [WITN4688003, my Second Statement] about aspects of the working of EIBSS and in this Third Statement, I refer to my Second Statement. At the time of drafting this Statement, it remains in draft form, but I will refer to it as necessary, with the proviso that should the draft need to be changed for any reason (including as a result of further questions from the Inquiry), this Statement too will need to be changed, and that references here should be understood as references to the final version of my earlier Statement.

4. As I have previously explained, I was not in post when EIBSS was established or for the first 15 months afterwards. My evidence on more recent events is compiled from documents and from information provided to me by officials currently working on EIBSS. The contents of this Statement are true to the best of my knowledge, information and belief.

## **Section 2: Alleviating the suffering of those infected and affected by infected blood and blood products**

### **Questions 3 and 4: Alleviating the financial hardship of the infected and affected**

#### **Introduction**

5. I have been asked to describe what the Department has done to alleviate the financial hardship of those infected by NHS blood and blood products (the “infected”) and those whose relatives and loved ones have been infected by NHS blood and blood products (the “affected”). I have been asked these questions in relation to the period from 8 July 2018, when the Rt. Hon Matt Hancock MP was appointed Secretary of State for Health and Social Care.
6. As the Inquiry is aware, since 1988 successive governments have set up a number of schemes to provide ex-gratia financial and other support for those infected with HIV and/or Hepatitis C through NHS supplied blood or blood

products and other individuals affected as a result. By 2011 there were five separate schemes, collectively known as the Alliance House Organisations (“AHOs”). The AHOs provided support across the whole of the United Kingdom.

7. In 2016 and 2017 the Government undertook two public consultations with a view to reforming the support schemes provided by the AHOs. Each nation now has its own scheme. The England Infected Blood Support Scheme (“EIBSS”) operates for the benefit of individuals infected in England and their family members.
8. EIBSS has operated since 1 November 2017. Very simply put, the NHS Business Services Authority (“NHSBSA”) administers EIBSS on behalf of the Department. My second Witness Statement explained the division of responsibilities and the governance relationship between the Department and NHSBSA (my “Second Statement”) and I refer the Inquiry to that statement for further background information.
9. My response to the questions that are posed will focus on policy decisions made or implemented since 8 July 2018. I do not go into detail on policy before then. This Statement also does not cover NHSBSA’s administration of support through EIBSS.
10. The key actions taken by the Department since July 2018 to alleviate the financial hardship of the infected and affected are:
  - a. August 2018: Implementing changes to the EIBSS discretionary support scheme;
  - b. April 2019: Increasing the annual financial allocation to EIBSS from £46.3 million to approximately £76 million per annum, an increase of around 62%. This major uplift in financial support was announced on 30 April 2019 and payments were backdated to 1 April 2019; and
  - c. March 2021: Further changes announced to lump sum and annual payments to achieve broader parity across the four schemes.

11. Actions 'a' and 'b' were described in detail in my Second Statement. Action c is described in the accompanying statement of the Secretary of State. The announcement relating to parity will bring significant changes to the support provided by EIBSS and I wish to make clear that the information in this Statement represents the situation as at April 2021 and so before any such changes have been implemented. The full announcement made by Penny Mordaunt MP, Paymaster General, on 25 March 2021 is set out in the Secretary of State's witness statement.<sup>1</sup>

12. Between November 2017 and March 2021, the Department has allocated £213.1 million for the funding of EIBSS. In addition, since 2018/2019 the administrative costs associated with NHSBSA operating EIBSS have been funded separately.

### **August 2018 changes to discretionary support schemes**

13. EIBSS began to operate on 1 November 2017 and so, by July 2018, had administered support to the infected and affected for around 8 months. At paragraph 101 of my Second Statement, I explain that there were two stages to the reform of the AHO support schemes. The first stage, in place from 1 November 2017, was that EIBSS administered lump sum payments and annual non-discretionary payments made to new and existing beneficiaries. The second stage covered reform of the system for discretionary payments.

14. Between November 2017 and 31 July 2018 EIBSS administered discretionary payments by largely continuing with what the AHOs had done. When the Secretary of State was appointed in July 2018, NHSBSA had already reviewed the discretionary payments scheme and reported to the Department in the EIBSS Discretionary Support Review (the "Review").<sup>2</sup>

15. The elements of the discretionary scheme reviewed were:

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<sup>1</sup> Written ministerial statement by Penny Mordaunt MP, Paymaster General, on 25 March 2021: <https://questions-statements.parliament.uk/written-statements/detail/2021-03-25/hcws895>.

<sup>2</sup> The Review is exhibited to my Second Statement [WITN4688039].

- income top-up payments for the infected;
- income top-up payments for bereaved spouses/partners;
- child payments;
- one-off grants; and
- non-financial support.

16. The Department had instructed NHSBSA to undertake the Review in accordance with the principles for a reformed discretionary scheme set out in the “Government response to consultation on Special Category Mechanism and other support in England”, published in October 2017.<sup>3</sup> Payments from the new discretionary scheme began from August 2018 and were backdated to April 2018.

17. My Second Statement explains in detail the changes made to the discretionary scheme and the reasons behind these changes. It describes the application of the Department’s policy that existing beneficiaries should not be worse off after the reforms. It also explains the limitations of the Review (see paragraphs 99 – 115 of my Second Statement).

#### Income top-ups

18. One of the changes made in August 2018 was to income top-up payments. As explained in paragraph 109 of my Second Statement, income top-up payments are a discretionary monthly payment to increase a beneficiary’s household income to help with general living costs, where a household’s income is below a set threshold. As I understand it, they had been part of the discretionary support provided by the AHO charities. As part of its Review, NHSBSA worked up three options or models for providing income top-ups. Its analysis concluded that “all [of those three] models will result in an increase in beneficiary income overall once the 2018/19 uplift on regular payments is applied” (page 8 of the Review).

19. The model NHSBSA recommended, and the one accepted by Ministers, was that EIBSS should apply income assessments and income top-up payments

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<sup>3</sup> Also exhibited to my Second Statement [WITN4688038].

consistent with the Macfarlane Trust's practice. NHSBSA's view was that, if this was done, no one should receive less, because the Macfarlane Trust's income top-up scheme was more generous than the scheme operated by the Caxton Foundation. This meant some infected beneficiaries would receive more in income top-ups.

20. The analysis undertaken by NHSBSA in its Review does not neatly permit a comparison of income top-ups before and after the August 2018 changes to the discretionary income top-up payments. This is because the AHOs operated different schemes for income top-ups, applied different income thresholds and brackets, varying definitions of household income and different top-up amounts (indeed, in reforming the discretionary support system, the Department aimed to streamline and make it more transparent). Because of this I refer the Inquiry to the Review for more information. A further aim of the reform was that no one should be worse off financially. As stated above, some beneficiaries would be better off.<sup>4</sup>

21. Discretionary income top-ups are no longer part of the support scheme under EIBSS for the infected (see my Second Statement, paragraph 110 and paragraph 31 below). That change was announced in April 2019 and was implemented in July 2019 when the non-discretionary annual payments were increased. Therefore, the changes to income top-ups for the infected was a short-lived policy from August 2018 – April 2019.

22. However, income top-ups remain available for affected bereaved spouses/partners and, as a result of the uplift in funding in April 2019, higher income top-up payments are now available to more such beneficiaries. From paragraph 42 below I deal with the way in which benefits and other income are taken into account in assessing income for the purposes of discretionary income top-ups and other means-tested<sup>5</sup> discretionary payments.

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<sup>4</sup> I refer the Inquiry to paragraphs 116 – 119 of my Second Statement for an explanation of actions taken by the Department on learning that discretionary support payments for some beneficiaries had stopped when the scheme was changed in August 2018.

<sup>5</sup> Where I refer to means-testing in the context of EIBSS' assessments and payments, this is intended to mean means-testing based on household income.

23. NHSBSA also recommended that the reformed discretionary scheme should provide regular income top-ups to bereaved spouses/partners at the same level as the Macfarlane Trust had used, and based on the same income assessment. NHSBSA reported that “[t]his will ensure that all bereaved spouses/partners receive at least the same level of income top-up as from the old schemes and most will be better off” (page 20 of the Review and paragraph 110 of my Second Statement).

24. Bereaved spouses/partners who were previously registered with the Macfarlane Trust, whose income top-ups would otherwise remain the same, did benefit from the annual winter fuel payments made available. As the Review stated, “bereaved spouses and partners who were previously receiving income top-ups from the Macfarlane Trust will receive the same level of support through income top-ups but also receive the winter fuel allowance in addition. For those registered with Caxton previously, they will continue to receive the winter fuel allowance in addition to higher regular payments” (page 20 of the Review). The charts at pages 10 – 14 of the Review set out the overall anticipated gains for beneficiaries.

#### Child supplement payments

25. As part of its Review, NHSBSA also reviewed the payments that were available for children of infected EIBSS beneficiaries and the Department made changes to these. Child payments are payments to help with the costs of bringing up the children of an infected beneficiary up to age 18, or to age 21 if in full time education.

26. Prior to the Review, what was available depended on which AHO a beneficiary was registered with. For example, NHSBSA informed the Department that Caxton Foundation beneficiaries had not been eligible for a separate child payment at all, but were paid as part of the income top-ups which varied according to household composition (see pages 25 - 26 of the Review). Child supplements were available

through the Macfarlane Trust for infected beneficiaries but at a rate of £100/child/month.<sup>6</sup>

27. After the Review, child payments for beneficiaries were standardised:

- For the first child, a monthly payment of £250 was put in place (£3000/annum).
- For subsequent children, the monthly payment was £100 (£1200/annum).
- So, a family with two children could receive an additional £4200/annum.

The figures are the same today and eligibility is means-tested.

28. Bereaved spouses/partners who are EIBSS beneficiaries may also claim child payments at the same rates as above (£250/month for the first child and £100/month for each subsequent child). These child payments are only available for bereaved spouses/partners who are eligible for income top-ups.

29. In addition, where an individual is the primary care provider for a child or children of an infected beneficiary, but is not a beneficiary him or herself, that individual may still be entitled to the same child payments (again, depending on income).

30. To assist the Inquiry with the household income thresholds and brackets and the income top-up and child payments amounts after the scheme for discretionary payments was changed in August 2018, I exhibit a leaflet produced by NHSBSA for 2018/2019 [Exhibit WITN4688056].

#### One-off payments

31. Changes were also made to the discretionary one-off payments available as a result of the Review.<sup>7</sup> The AHO charities had provided one-off payments for

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<sup>6</sup> The rate for bereaved spouses/partners was different, see page 27 of the Review.

<sup>7</sup> Although before the Review NHSBSA, after discussions with the Department, had already streamlined the discretionary one-off payments available through EIBSS (see Table D at pages 17 - 19 of the Review).



different items or needs and these were available in different circumstances. This led to inconsistencies in awards being made, depending on which charity a beneficiary was registered with. The Department wanted to remove such inconsistencies.

32. The types of discretionary one-off payments available to the infected from August 2018, and the payment that was available for each, is set out at Table 4 of the EIBSS leaflet [Exhibit WITN4688056] and so I do not list each payment type.

33. The Inquiry will also be able to compare NHSBSA's recommendations in the Review with what was implemented. For example:

- a. The Review suggested a payment of up to £300/year for counselling to help address short term mental health issues, with the possibility of reviewing individual cases if more support was needed. As explained below at paragraph 62, up to £900/year was put in place.
- b. The Review suggested up to £3000/year for up to three years for employment training costs. There is no maximum amount that can be claimed.
- c. The Review suggested up to £5,000 for home adaptations. Instead infected beneficiaries can receive up to £2,500 every 10 years for adaptations and £2,500/ year for accommodation repairs.

34. Other examples of one-off payments available to infected beneficiaries are:

- a. Up to £750/year for a respite break for the beneficiary and £750 for a carer.
- b. Hospital travel costs of up to £1,800/year for a beneficiary and travel costs of up to £250/month for family members during a period of hospitalisation.
- c. Up to £4,500 for a funeral pre-payment plan.
- d. Prescription pre-payment certificates.

35. In its Review NHSBSA also recommended that one-off payments should be available for bereaved spouses/partners. The Department made available up to

£900/year for counselling services, £4500 for funeral costs and an unlimited amount for employment training.

36. I explain further below:

- a. The current discretionary payments scheme, as this changed after the funding uplift announced in April 2019 (from paragraph 47);
- b. The non-financial support that EIBSS assists with (from paragraph 76); and
- c. Psychological support for the infected and affected (from paragraph 56).

#### **April 2019 uplift and further changes to scheme**

37. When EIBSS was established the Department's intention was to review the scheme at the end of the spending review period, i.e. 2020/2021. However, after taking on board feedback from beneficiaries and the Inquiry, including during a meeting on 21 January 2019, a major financial uplift was announced on 30 April 2019 by then-Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention, Jackie Doyle-Price MP. Funding for EIBSS was increased from £46.3 million/year to approximately £76 million. By this stage EIBSS' operating costs were also funded separately so this sum was exclusively for the benefit of the beneficiaries.

38. As explained in my Second Statement (paragraph 120), the main changes that resulted from this funding uplift were:

- a. Increased annual payments for infected beneficiaries. This increase also removed the need for this group to apply to EIBSS for income top-ups – that support became part of the non-discretionary scheme of annual payments; paragraphs 39–41 below.
- b. The upper level of household income used to means-test support for bereaved spouses/partners was raised, (meaning that more such bereaved beneficiaries were eligible for both income top-ups); paragraphs 42–44.
- c. These income top-ups for bereaved spouses/ partners were also increased; paragraphs 42–44.

- d. The income threshold to receive additional financial support for dependent children was increased (for both the infected and the affected), so that those with higher incomes could receive these payments; paragraphs 45-46.

Increased annual payments for infected beneficiaries

39. The Table below compares the annual payments for infected beneficiaries before and after the funding uplift in April 2019. It also includes the level of annual payments in 2020/2021. These annual payments increase annually in line with the Consumer Price Index.

**Table 1**

<b>Beneficiary type</b>	<b>Infected beneficiaries</b>		
	<b>Payments before April 2019</b>	<b>Annual payments after April 2019 uplift (2019/2020)</b>	<b>Annual payments (2020/2021)</b>
Hepatitis C stage 1	£4,000	£18,458	£18,772
Hepatitis C stage 1 + SCM	£18,000	£28,000	£28,476
Hepatitis C stage 2	£18,000	£28,000	£28,476
HIV	£18,000	£28,000	£28,476
Co-infected stage 1	£22,000	£38,000	£38,646
Co-infected SCM	£35,000	£44,000	£44,748
Co-infected stage 2	£35,000	£44,000	£44,748

40. In addition, all infected beneficiaries received/receive a winter fuel payment. This was £531/year in 2019/2020 and £540/year in 2020/2021.

41. It is apparent from Table 1 that the April 2019 uplift led to a significant increase in the annual payments for each category of infected beneficiary, most particularly those with Hepatitis C stage 1. As explained in my Second Statement (paragraph 120), a principle behind the changes made was that no beneficiary should be worse off as a result of the changes.

#### Changes to income top-up thresholds and amounts for bereaved spouses/partners

42. Table 2 below provides figures for income top-ups for bereaved spouses/ partners before and after the April 2019 uplift. To assist with comparing the income top-up amounts, the household income brackets used before April 2019 are in the first column. The income brackets now used by EIBSS are in the third column. The income top-up available did not and does not depend on which category the deceased beneficiary fell into while alive, but rather on the household income of the bereaved spouse/partner.

Table 2

Income top-up payments for bereaved spouses/partners under EIBSS			
Before April 2019		From April 2019 to date	
Household income bracket (these were the brackets used by the Macfarlane Trust)	Annual top-up amount	Household income bracket (these are the brackets used by EIBSS)	Annual top-up amount
£3000 or less	£17,004	£0 - £10,000	£18,000
£3001 - £4000	£15,996		
£4001 - £5000	£15,000		
£5001 - £6000	£14,004		
£6001 - £7000	£12,996		
£7001 - £8000	£12,000		
£8001 - £9000	£11,004		
£9001 - £10,000	£9,996		
£10,001 - £11,000	£9,000	£10,001 - £15,000	£10,421
£11,001 - £12,000	£8,004		
£12,001 - £13,000	£6,996		
£13,001 - £14,000	£6,000		
£14,001 - £15,000	£5,004		
£15,001 - £16,000	£3,996	£15,001 - £20,000	£5,412
£16,001 - £17,000	£3,000		
£17,001 - £18,000	£2,004		
£18,001 - £19,000	£996		
£19,001 - £20,000 <sup>8</sup>	£0		
£20,001 - £28,400 <sup>7</sup>	£0	£20,001 - £28,400	£1,412
£28,401 or more <sup>7</sup>	£0	£28,401 or more	£0

<sup>8</sup> The original bracket used was "£19,001 or more". This has been split in this table for ease of comparison.

43. As can be seen from the above, the threshold for income top-ups was significantly raised in April 2019, from £19,000 to £28,400, meaning that more bereaved spouses/partners became eligible for top-up payments. The income top-up amounts also increased (although the amount of increase for an individual depended on where his/her income fell in the relevant bracket). Payments remained unchanged in 2020/21.

44. Again, all bereaved spouses/partners are entitled to a winter fuel payment. As with infected beneficiaries, this was £531/year in 2019/2020 and £540/year in 2020/2021.

#### Income threshold for child payments increased

45. As explained above (paragraph 42 onwards) child payments were still in place after the April 2019 uplift, at the same rates as set out in paragraph 27.

46. Infected beneficiaries can still qualify for child payments if the household income is under £37,900. Bereaved beneficiaries who are primary care providers and entitled to income top-ups (i.e. with a household income under £28,401) may also claim child payments. Primary care providers of a child or children of an infected beneficiary, but who are not beneficiaries themselves, may also be entitled to child payments, subject to the same income levels. Details for 2020/21 are set out in the leaflet attached ("EIBSS income top-up and child payment support information") [Exhibit WITN4688057]. Again, the increased upper thresholds for income mean that more people became eligible for child payments.

47. Discretionary one-off payments can still be claimed by all infected beneficiaries and bereaved spouses/partners. The Inquiry will find a list of potential one-off payments in the document, "EIBSS discretionary one-off payments – guidance document" [Exhibit WITN4688058].

## Payments under EIBSS: taxation and benefits

48. It is important to understand how EIBSS payments relate to income tax and benefits payments and equally, how benefits payments and other income impact on means tested EIBSS payments.
49. Any lump sum or regular payments from the scheme (annual payments or income top-ups) are not taxable for the purposes of income tax. A beneficiary also does not need to declare the payments for income tax purposes to Her Majesty's Revenue and Customs.
50. Payments from EIBSS also do not count towards certain means tested benefits paid by the Department of Work and Pensions ("DWP"), namely income support, jobseeker's allowance, state pension credit, housing benefit, employment and support allowance and universal credit. DWP may be able to provide more information, including in relation to how payments made by other infected blood schemes are taken into account in England, and the obligation to declare payments nonetheless. I understand that a beneficiary does not need to include details of EIBSS payments when applying to his/her local authority for a reduction in his/her council tax.
51. In addition, EIBSS payments are disregarded for the purposes of calculating the 'disposable capital' of an individual when applying for civil legal aid.
52. As explained above (paragraph 42 onwards), income top-ups for bereaved spouses/partners are means tested using the household's income which includes earnings and certain, but not all, social security benefits. Some benefits are excluded entirely (e.g. attendance allowance, personal independence payments, disability living allowance), while disability-related elements of some benefits are also excluded (e.g. any disability-related element of universal credit).
53. As explained in my Second Statement (paragraph 140), in 2020 NHSBSA conducted a review of income top-up payments previously made to ensure that social security benefits were to have the disability-related elements disregarded

in calculating an applicant's income (as an error was identified, which the Department advised should be rectified and back payments made). This is an important exercise, which has begun but which I understand has not yet been completed by NHSBSA.

#### Other decisions since July 2018

54. I will now summarise a number of policy decisions that Ministers have made since July 2018 that impact on the financial support available to EIBSS beneficiaries. These are described in my Second Statement and I refer the Inquiry to that document for more detail:

- a. There is small group of EIBSS beneficiaries who are, sadly, both secondary infectees (i.e. beneficiaries who were infected by someone who was infected through NHS supplied blood or blood products) and bereaved spouses/ partners. Ministers decided that beneficiaries should continue to be treated flexibly so that each individual was able to receive the payments that were optimal for him/her (see paragraphs 162 – 163 of my Second Statement).
- b. Ministers instructed NHSBSA to apply a tapered support scheme to a relatively small number of beneficiaries, so that support from discretionary payments was gradually reduced, rather than abruptly stopped (see paragraphs 116 – 119 of my Second Statement).

#### HIV payments

55. The Department also provides funding for HIV payments to the Devolved Administrations, supplying payments that are equivalent to the EIBSS HIV payments to each beneficiary resident in the Devolved Administrations. I have explained this in my Second Statement and refer the Inquiry to paragraphs 95 - 98. The Department entered into this arrangement with the Devolved Administrations for the period 2015/2016 – 2020/2021, and the Department has committed to continuing these payments for 2021/2022. These payments were agreed to correct a payments miscalculation that had been made in the Spending



Review 2015 and so the Department has continued to make these payments to the other three administrations to address the miscalculation, rather than devolve them.

**Question 5: Psychological and other support for the infected and affected**

**Psychological support**

56. I have been asked what the Department has done to alleviate the suffering of the infected and affected and in particular, what psychological support it has made available since July 2018. I am also asked whether consideration has been given to the need for specialist psychological support and whether any ring-fenced funds for such a service have been provided. I will first deal with psychological support and then turn to other support made available by the Department, through EIBSS.

57. I am aware that Claire Foreman of the NHS Commissioning Board (NHS England) has provided written evidence to the Inquiry about the commissioning and funding of psychological services in the NHS generally, and specifically in relation to those who have been infected and affected with a chronic and serious disease such as HIV or Hepatitis C or B. She explained that many patients requiring specialised services for a disease or condition (like HIV or Hepatitis C or B) will also have psychological support needs at some point in their care or treatment and that the patient's overall care package in the NHS should include referral and access to psychological care, as determined by the treating clinical team (see Claire Foreman's Second Witness Statement, WITN3953053, at paragraph 16).

58. As explained in Claire Foreman's evidence, eligibility for NHS treatment is most typically determined based on clinical need and not by the reasons a patient needs the treatment. This is in accordance with NHS England's duty to act in a way that promotes the NHS Constitution (s13C of the National Health Service Act 2006, the "NHS Act").

59. The Secretary of State is under a similar duty, in that he must have regard to the NHS Constitution in the exercise of his duty to promote a comprehensive health service for all in England, with equal access for all that is based on clinical need (see s1 and s1B of the NHS Act). The NHS Constitution promotes the principle of equal access to services, based on clinical need: see generally principles 1, 2 and 4, for example.

60. I draw attention to this as the issue of prioritisation for treatment for Hepatitis C was raised in (for example) the 2016 consultation, “Infected blood: reform of financial and other support”. This discussed the proposal of an offer of priority access to new Hepatitis C treatments for those infected via NHS blood or blood products. NHS England responded that it could do this via a Department-funded programme, but noted significant concerns about prioritising treatment based on how individuals had become infected. The proposal did not proceed. The consultation response, published in July 2016, stated that it was not taken forward on account of the need for fairness towards all those in need of NHS treatment.<sup>9</sup>

61. My response covers different ground, namely support available through EIBSS. Additional funding for psychological counselling via EIBSS, as described below, has enabled provision for counselling to be made outside of NHS-provided psychological services, by accessing privately-funded therapies.

#### Simpler access to support via EIBSS

62. There has been a change made recently in how the infected and affected (including family members) are able to access funding for counselling, with the goal of making it easier and quicker to have counselling. This change was made in May 2020. Before this, infected beneficiaries, bereaved spouses/partners and

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<sup>9</sup> “In line with the consultation responses, and on account of the need for fairness towards all those in need of this NHS treatment, access to Hepatitis C treatment for scheme beneficiaries will be provided by the NHS on the basis of clinical need in line with NICE guidelines. We have decided not to use funding available for the scheme to provide enhanced access to the new treatments. However, we will ensure the new scheme administrator works with the NHS to ensure that beneficiaries are signposted to, and made aware of, treatment services and the treatments available. We will also review how many beneficiaries are being treated and/or have already completed their treatment” exhibited to my Second Statement, at paragraph 3.32 [WITN3953052].

their families were entitled to up to £900 per year, per applicant, to fund counselling. That money could be used to access treatment in the private sector. To support an application, the applicant needed to obtain a letter from his/ her GP and be on an NHS waiting list. This was part of the wider scheme of discretionary support available.

63. Since 1 May 2020, the process of applying for and obtaining psychological support has changed. This coincided with the Covid-19 pandemic which, it was recognised, could put extra pressure on already vulnerable groups. A change in policy was agreed between the Department and NHSBSA so that beneficiaries would be able to receive funding for counselling without GP approval or the need to access waiting lists. As stated, the aim was to make accessing psychological support easier. I am informed that NHSBSA sent a letter to beneficiaries about this change on or around 1 May 2020. I also understand that the EIBSS website was updated on 7 September 2020 to communicate the change and the EIBSS newsletter in September 2020 (Issue 1) also included information about the change.

64. The experience of take-up of the EIBSS grant for psychological support described above is also important, not least as take-up prior to May 2020 was limited. Figures received from EIBSS indicate that from April 2018 – April 2020 (i.e. over 2 years), EIBSS made 48 payments for counselling. Between May 2020 – January 2021, EIBSS made 75 payments for counselling, (i.e. there has been a higher uptake since access was made easier in May 2020). The Department also understands that the Wales Infected Blood Support Scheme (“WIBSS”) is preparing a survey of beneficiary experience of its services, including this, and this is likely to provide further useful information.

65. Now an applicant should send to EIBSS either:

- a. A completed application form and a letter from a registered counsellor confirming the cost of an assessment; or

- b. A letter from a registered counsellor confirming the cost, number of counselling sessions required and confirmation of which approved register for counsellors the practitioner is on.

66. Beneficiaries and their families can, of course, also access available NHS services if they wish.

#### Ring-fencing of funding

67. The Department provides funding for this psychological support through EIBSS. It is not ring-fenced as such but forms part of the overall EIBSS funding which stood at approximately £76.1m per year in 2020/2021. I am informed that EIBSS' expenditure on counselling from May 2020 – January 2021 has been £51,532. There has been no suggestion that this has been causing any strains or shortfall on budgets.

#### Alternative models for psychological support

68. Alongside this change, the Department has been investigating the provision of additional psychological support and how best to achieve this.

69. On 28 January 2020 a meeting took place between the then-Chancellor of the Duchy of Lancaster, Oliver Dowden, and the then-Parliamentary Under Secretary of State for Patient Safety, Suicide Prevention and Mental Health, Nadine Dorries ("PS(PSM)"), and a number of infected and affected individuals. Psychological support was one of the issues discussed at this meeting and PS(PSM) undertook to seek expert input and advice from Claire Murdoch, NHS England/Improvement's ("NHSE/I") National Mental Health Director, on bespoke counselling and mental health support for the infected and affected.

70. On 4 February 2020 PS(PSM) had a meeting with Claire Murdoch and then requested NHSE/I to investigate options for the provision of psychological support. NHSE/I reported back to the Department, and using this information, Departmental officials prepared advice for PS(PSM) on mental health support for

the infected and affected. The preferred option, accepted by PS(PSM), involved creating a bespoke psychological support service for people under EIBSS's jurisdiction.

NHSE/I England's work suggested that this service could include:

- a. Psychological assessment and formulation;
- b. Signposting to existing local services, for example the NHS's Improving Access to Psychological Therapies ("IAPT"). NHSE/I expected that this would be the outcome for the majority of service users; and
- c. A specific psychological therapy service for some service users. This would be for more complex adjustment and mental health issues unlikely to be met by specific local services.

71. At the time of preparing this advice (March 2020), the scale of demand for such a bespoke service was not known. It was recognised that more work was needed to understand the likely demand or clinical need for this service, what existing services can offer and how this service would sit alongside existing pathways. In April 2020, officials agreed that there was a need to work with the support schemes across the UK to get a more detailed understanding of prevalence of mental needs among beneficiaries and use this as a basis for developing clinical support.

72. NHSBSA was asked to investigate options for providing this kind of support service within EIBSS. I am told that NHSBSA has discussed with WIBSS the bespoke service it provides and that NHSBSA intends to prepare a paper for the Department on how that might apply to EIBSS.

73. Some further discussions between NHSE/I and officials at the Department have taken place, examining potential models and how they might fit into existing services as well providing additional support for more complex needs. In particular, a remote meeting held on 14 August 2020 discussed whether a potential model could be based on directing beneficiaries to the 'talking therapies' offered by NHSE/I's 'Long Term Conditions IAPT' service, where there is

experience in dealing with the overlap between mental health and physical health conditions. There would be a need to explore whether additional training for those providing the service would be needed, and also whether additional bespoke provision would be needed for more complex needs. Further discussion would also be needed, in due course, as to whether any additional service was to be funded from NHSE/I budgets or additional Department resources.

74. It is important to recognise the complexities of strengthening bespoke psychological support services within existing NHS services in England. The pool of beneficiaries served by EIBSS is very different to that of any of the devolved schemes both in terms of size and need. The infected access ongoing care and treatment in a number of centres across England, through a variety of clinical pathways and with many care teams involved. Their families and others affected may seek help from the NHS via numerous entry points including GPs. These multiple clinical pathways need to be considered, ensuring that there is signposting to relevant support services, with regard to geographical accessibility.

75. In summary, an important change was made in May 2020 to ensure ease of access to psychological support for all EIBSS beneficiaries and their families. The Department plans further work with EIBSS and NHSE/I to understand uptake of this service and what else might be needed.

#### **Other non-financial support**

76. I will now turn to other means of support available to the infected and affected, primarily through EIBSS. With the exception of paragraph 80, my understanding is that these kinds of support were available before July 2018, but I include these examples as they are additional sources of support for the infected and affected.

77. First, I have explained above that EIBSS payment are not taxable and disregarded when applying for certain means-tested benefits from the DWP (paragraphs 49, 50).

78. Second, EIBSS assists with welfare advice. This is done either through an EIBSS welfare advisor or by beneficiaries choosing to source their own welfare advice which is then funded by EIBSS.<sup>10</sup> EIBSS can also assist beneficiaries in locating welfare advice.

79. Third, NHSBSA assists by 'signposting' the infected and affected to other services that may provide additional support in areas such as finances, careers or employment, health and bereavement (e.g. Citizens Advice, the National Careers Service, relevant healthcare charities and Bereavement UK). This kind of support is required by the Service Specification between the Department and NHSBSA (signed August 2018) [WITN4688006]. Under the Service Specification NHSBSA must provide non-financial support and advice:

*"NHSBSA shall provide support/ advice/ signposting services to the Beneficiaries. Given the age range of the Beneficiaries, this support should be tailored as far as possible to accommodate individual needs and preferences for receiving information (e.g. website/ email/ telephone). NHSBSA shall be capable of advising individuals of what they can and cannot apply for (under the ex-gratia payment Scheme). Beyond that, the Service should include provision or signposting to health advice/financial management/ debt advice/ counselling and support in dealing with Her Majesty's Revenue and Customs (HMRC) and Department for Work and Pensions (DWP)" (paragraph 3.3.1, see also paragraphs 1.5 and 3.2.5).*

80. Fourth, as part of the discretionary support available through NHSBSA, infected beneficiaries and bereaved spouses and partners can apply once per year for financial support for employment training costs, aimed at improving employment opportunities.

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<sup>10</sup> See page 19 of the Review [WITN4688044]: "NHSBSA will provide a dedicated welfare support professional. Currently, NHSBSA signpost towards Neil Bateman, who has worked as part of the previous schemes and with beneficiaries, however beneficiaries are also advised that they can source their own welfare support professional to help with any ongoing issues and NHSBSA will fund this."

## **Question 6: Differences between the support schemes across the UK**

81. I have been asked (question 6(a)) to explain my understanding of differences in how the four United Kingdom governments have addressed the hardship and suffering experienced by the infected and affected. My response focusses on the support currently provided by the four schemes operating in the four nations, i.e. via EIBSS, the Scottish Infected Blood Support Scheme (“SIBSS”), the Wales Infected Blood Support Scheme (“WIBSS”) and the Infected Blood Payment Scheme for Northern Ireland (the “NI Scheme”). It reflects the position before any changes to the four schemes have been made following on from the announcement of 25<sup>th</sup> March 2021.<sup>11</sup> In answering this question, I have relied upon the information supplied to me by officials in my team. It has been checked against information from the other four nations’ schemes, but the administrations of those nations will have the most detailed understanding of the operation of their schemes.

82. To explain the Department’s understanding of the support offered by the three schemes operated by the Devolved Administrations, I annex to this Statement a Table that summarises the main elements of each of the schemes, and so highlights the differences (the “Comparison Table”). It is not exhaustive, but is rather intended to highlight the main features in a reasonably accessible form.

83. In addition to the information in the Comparison Table, I discuss in more detail below some of the differences between the four schemes.

### **Description of differences between the schemes**

#### **Hepatitis C payments**

##### **Differences in provision of enhanced support for Hepatitis C Stage 1 beneficiaries**

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<sup>11</sup> Written ministerial statement by Penny Mordaunt MP, Paymaster General, on 25 March 2021: <https://questions-statements.parliament.uk/written-statements/detail/2021-03-25/hcws895>



## EIBSS

84. The Inquiry is aware that EIBSS uses the special category mechanism ("SCM") to provide additional financial support for beneficiaries who suffer from Hepatitis C and who are at stage 1, but whose infection, its treatment, complications or associated conditions have a long term negative impact on their ability to carry out daily activities.
85. An applicant who wishes to apply to EIBSS for the SCM completes an application form which seeks information from the applicant about the impact of Hepatitis C on his/her ability to carry out daily activities, and also from an applicant's treating healthcare practitioner. The questions in the application form focus on (a) whether the applicant has one of the specified conditions/diagnoses; and (b) mental health problems and fatigue that have an impact on the applicant's ability to carry out daily activities. The application is then assessed by specialist medical assessors. If the EIBSS medical assessors decide an applicant is eligible for the SCM then there is a single level of enhanced annual payment, which is currently £28,476/year.
86. WIBSS and SIBSS provide additional support for beneficiaries in a similar position but I am aware there are differences in the assessment processes and eligibility criteria. The NI Scheme does not provide this kind of additional financial support.

## WIBSS

87. Under WIBSS there is a single level of enhanced annual payment, currently £19,172 year. An applicant is only eligible for the enhanced Hepatitis C stage 1+ annual payment under WIBSS if he/she is suffering from mental health issues. An applicant self-assesses and self-certifies that he/she is suffering from mental health issues (including post-traumatic stress), that these are related to being infected and that the symptoms are affecting his/her ability to carry out day to day activities.

88. By contrast, under EIBSS, SCM payments can be made on the basis of mental health issues or fatigue resulting from Hepatitis C infection when signed off by a healthcare professional.

### SIBSS

89. Under SIBSS I understand there are two levels of regular annual payments for beneficiaries with chronic Hepatitis C (what EIBSS refers to as Hepatitis C stage 1). Current levels of payment are £6,407 where the applicant's life is moderately impacted by Hepatitis C and £19,221 where the applicant's life is severely impacted by Hepatitis C. An applicant self-assesses and self-certifies the impact of his/ her Hepatitis C infection on his/ her ability to carry out routine activities.

90. I understand there is also a living costs supplement payment of £1,000 where Hepatitis C does not have a noticeable day to day impact on the applicant's life.

91. Therefore, there are two differences between EIBSS and SIBSS in relation to Hepatitis C regular payments:

- the method of assessment (EIBSS has medical assessors to determine eligibility for the SCM, while SIBSS uses self-assessment); and
- the structure of payments (EIBSS has Hepatitis C stage 1 payments and SCM payments, while SIBSS has three payment levels, namely 'no impact', 'moderate impact' and 'severe impact').

### NI Scheme

92. The NI Scheme provides an annual payment for Hepatitis C stage 1 and a higher payment for Hepatitis C stage 2. Currently, there is no 'equivalent' to the SCM, to enhanced stage 1+ payments, or to SIBSS' 'severe impact' category.

### Differences in qualifying conditions for Hepatitis C Stage 2 payments

93. I am also informed that there are some differences between the schemes in the health conditions that qualify a beneficiary for Hepatitis C stage 2 or advanced payments. For example, WIBSS has four qualifying conditions, whereas EIBSS, SIBSS and the NI Scheme have five.

### Payments when an infected beneficiary dies

94. It is my understanding that there are differences between the schemes relating to eligibility for payments when an infected beneficiary sadly dies.

### Lump sum bereavement payments and cause of death

#### EIBSS

95. Under EIBSS, a lump sum payment of £10,000 is available for bereaved spouses/partners when an infected beneficiary dies. There should be evidence that Hepatitis C and/or HIV contributed to the death to become eligible for the bereavement payment.

#### WIBSS

96. WIBSS makes available £10,000 as a lump sum payment for bereaved spouses/partners or the estate when an infected beneficiary dies. The bereavement payment can be made even if there is no evidence of a link between Hepatitis C and/or HIV and the cause of death.

#### SIBSS

97. SIBSS does not have an equivalent bereavement payment and instead makes regular payments to bereaved spouses/partners.

## NI Scheme

98. The NI Scheme provides a £10,000 bereavement payment for spouses/ partners, but not to the estate. The bereavement payment can be made even if there is no evidence of a link between Hepatitis C and/or HIV and the cause of death.

99. Therefore, EIBSS, WIBSS and the NI Scheme are similar but not the same. SIBSS does not make a bereavement lump-sum payment.

## Regular payments for bereaved spouses/partners

100. I am also aware of differences between the availability of annual regular payments for bereaved spouses/partners. These differences are summarised in the Comparison Table but I set out their essence below.

## EIBSS

101. EIBSS does not provide regular annual payments for bereaved spouses/ partners. However, discretionary income top-ups are available as explained at paragraphs 42 - 44 above.

## WIBBS

102. WIBSS provides bereaved spouses/partners with 75% of the deceased's entitlement to annual payments for the 3 years following death.

## SIBBS

103. SIBSS provides to bereaved spouses/partners, in most cases, 100% of the annual payment the deceased would have received in the first year after death, with 75% of the annual payment in subsequent years.

## NI Scheme

104. On 1 March 2021, Robin Swann, the Northern Ireland Health Minister, announced that the NI Scheme would provide tax-free annual payments to bereaved spouses/partners, calculated at 75% of the payment their deceased spouse/partner was receiving or would have been entitled to, had he/she lived. These payments are to be backdated to April 2020. For those infected beneficiaries who passed away since April 2020, payments to the bereaved will be backdated to the date of death. Prior to this announcement, the NI Scheme did not provide regular annual payments for bereaved spouses/partners. I understand this means that income top-ups for non-infected bereaved beneficiaries will cease from 1 April 2021.

105. Therefore, WIBSS, SIBSS and the NI Scheme now provide regular payments for bereaved spouses/ partners, while EIBSS does not.

## Section 5: Other

106. I have been asked if there is anything else relevant to the Terms of Reference that I should add. At present, there is nothing further that I wish to add, but I am of course willing to help with any further matters that the Inquiry may wish to pursue.

## Statement of Truth

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

Signed

GRO-C

Dated 23.04.2021

**Table of exhibits:**

<b>Date</b>	<b>Notes/ Description</b>	<b>Exhibit number</b>
2018/2019	EIBSS: income top-up and discretionary support leaflet 2018/19	WITN4688056
2020/2021	EIBSS: income top-up and child payment support information	WITN4688057
2019	EIBSS discretionary one-off payments – guidance document	WITN4688058

Comparison Table Summarising the Four Infected Blood Support Schemes (as at 18 March 2021)

- Annual rates given are for 2020/21 financial year.
- This table seeks only to record the main elements of the Schemes. More detailed information can be obtained from each Scheme.

Beneficiary	Payment Type	EIBSS	SIBSS	WIBSS	NI Scheme
<b>Hepatitis C stage 1/ chronic</b>	One-off lump sum payment	£20,000	£50,000	£20,000	£20,000
	Annual payment	£18,772	Where life is moderately affected by hepatitis C:£6407	£4790	£18,772
<b>Hepatitis C stage 1 'plus':</b>	One-off lump sum payment	No additional payment – £20,000 paid for hepatitis C stage 1	No additional payment - £50,000 paid for hepatitis C stage 1	No additional payment – £20,000 paid for hepatitis C stage 1	N/A
	Annual payment	Special category mechanism ('SCM'): £28,476	Where life is severely affected by hepatitis C: £19,221	Enhanced stage 1+: £19,172	N/A
<b>Hepatitis C stage 2/ advanced</b>	One-off lump sum payment	£50,000 (on moving from stage 1 to stage 2)  £70,000 for a new beneficiary with hepatitis C stage 2	£20,000 (on moving from chronic to advanced)  £70,000 for a new beneficiary with hepatitis C stage 2	£50,000 (on moving from stage 1 to stage 2)  £70,000 for a new beneficiary with hepatitis C stage 2	£50,000 (on moving from stage 1 to stage 2)  £70,000 for a new beneficiary with hepatitis C stage 2
	Annual payment	£28,476	£27,459	£19,172	£28,476
<b>HIV</b>	One-off lump sum payment	£23,500 - £80,500 depending on	£70,000	£20,000	£23,500 - £80,500 depending on circumstances of

Beneficiary	Payment Type	EIBSS	SIBSS	WIBSS	NI Scheme
		circumstances of infection and status of beneficiary			infection and status of beneficiary
	Annual payment	£28,476	£27,459	£19,172	£28,476
<b>Co-infected: hepatitis C stage 1 and HIV</b>	One-off lump sum payment	Both hepatitis C stage 1 and HIV one-off payments	Both hepatitis C stage 2 and HIV one-off payments	Both hepatitis C stage 1 and HIV one-off payments	Both hepatitis C stage 1 and HIV one-off payments
	Annual payment	£38,646	£37,629	£23,317	£38,646
<b>Co-infected: hepatitis C 'plus' and HIV</b>	One-off lump sum payment	No additional payment	No additional payment	No additional payment	N/A
	Annual payment	£44,748	£37,629	£37,826	N/A
<b>Co-infected: hepatitis C stage 2 and HIV</b>	One-off lump sum payment	Both hepatitis C stage 2 and HIV one-off payments	Both hepatitis C stage2 and HIV one-off payments	Both hepatitis C stage 1 and HIV one-off payments	Both hepatitis C stage2 and HIV one-off payments
	Annual payment	£44,748	£37,629	£37,826	£44,748
<b>Bereaved partners/ spouses</b>	One-off lump sum payment	£10,000	N/A	£10,000	£10,000
	Annual payments	N/A  Discretionary income top-ups available.	In year 1: 100% of the deceased spouse's/ partner's annual entitlement	75% of deceased spouse's/ partner's annual entitlement for 3 years	75% of deceased spouse's/ partner's annual entitlement



Beneficiary	Payment Type	EIBSS	SIBSS	WIBSS	NI Scheme
<b>Discretionary income top-ups</b>		Available for bereaved spouses/partners	Available to bereaved spouses/ partners and also to beneficiaries in some circumstances	Only provided to small number of beneficiaries	Means tested income top-ups available for bereaved spouses/ partners(will cease from 1 April 2021)
<b>Discretionary one-off grants</b>		One-off grants available for beneficiaries and bereaved spouses/ partners	One-off grants available, which are means tested	One-off grants available	Discretionary one-off grants available in line with EIBSS policy
<b>Psychological support</b>		£900/ yr support available to seek support via non-NHS services	SIBSS can arrange referral for support or discretionary grant available to seek support via non-NHS services.	Bespoke mental health support service attached to WIBSS	Psychology services provided by Belfast Health and Social Care Trust (not directly through the NI Scheme)
<b>Cost of Living / Winter Fuel Payments</b>		Available to Infected beneficiaries and bereaved spouses/ partners: £540/yr	Included in £1000 Living Costs Supplement	Included in regular payments	Winter Fuel Payment available: £540/ yr