

England Infected Blood Support Scheme (EIBSS) Focus Group

Summary Minutes

Meeting type: EIBSS Focus Groups
Meeting dates/time: 15th August, 16th August & 17th August 2022
Location: Online – Microsoft Teams

Attendees from EIBSS NHSBSA:

Hollie Edminson (HE) – Service Delivery Manager
 June Omadoye (JO) – Admin Support
 Mal Ross (MR) – Service Delivery Manager
 Sarah Thornton (ST) - Team Manager

1	Welcome
1	<p>The EIBSS focus group is a meeting between the NHSBSA who administer the scheme on behalf of the Department of Health and Social Care (DHSC) and the beneficiaries who the scheme supports. All beneficiaries are welcome to attend and those who do attend can provide feedback regarding the scheme.</p> <p>There were ten EIBSS Scheme beneficiaries who attended these EIBSS Focus Groups in total.</p> <p>Introductions were made and everyone was welcomed to the focus groups.</p>
2	Updates from EIBSS
	<p>Mal Ross, Service Delivery Manager gave an update on the EIBSS operational services.</p> <p>Current EIBSS scheme members:</p> <p>There are currently 3,196 EIBSS members as of the 1st August 2022.</p> <p>Below is the breakdown of the EIBSS scheme members:</p> <p> Hep C Stage 1 = 1198 Hep C Stage 2 = 562 SCM = 556 HIV = 62 Hep C stage 1 + HIV = 83 Hep C stage 2 + HIV = 57 SCM + HIV = 85 Carers & Dependants = 63 Bereaved Partners, not infected = 530 </p> <p>MR mentioned that EIBSS can be contacted at any time if there are any queries, not just during the focus groups.</p>

Between the first and last Focus Group meetings, an announcement was made by the Government on 17th August, confirming the intention to accept Sir Brian Langstaff's interim report to make compensation payments of £100,000 to existing scheme members.

Therefore, some of the responses were different for the final focus group as an announcement had been confirmed, instead of the speculative discussions in the earlier groups.

Updated answers are included below, where appropriate.

The intention is that compensation payments will be tax-free and will not affect any financial benefits support an individual is receiving. Infected individuals and bereaved partners who are registered with any of the four UK infected blood support schemes will receive the payment.

Therefore, work is ongoing across government departments including HM Treasury, HMRC, DWP and DHSC to ensure any compensation payments made are Tax-exempt and disregarded for benefit purposes, and appropriate legislation and guidelines are agreed in advance of payment being made.

NHSBSA will contact all eligible beneficiaries to confirm their bank account can accept this lump sum payment, as some bank accounts have an annual limit of how much can be deposited – and then write again, to confirm the actual payment date closer to the time.

NHSBSA will ensure that all payments will be made as directed by DHSC.

MR informed the focus group attendees that all queries received from the focus group meeting will be compiled and shared with DHSC, the responses to all questions will be uploaded on the EIBSS website, once received.

3 Comments and Questions from EIBSS Beneficiaries

Questions 1 – 7 received in advance from a beneficiary, and discussed in Focus Group:

1. Beneficiary question: In light of the report by Sir Robert Francis it is increasingly likely that the infected will be in line to receive significant levels of compensation. It is also quite likely that a number of the infected will die before the full compensation is paid. This makes the importance of good financial planning and legal support vital. I wondered whether EIBSS would consider adding an additional discretionary award to provide financial support to the infected in writing a will and financial planning?

EIBSS response: Referred to DHSC prior to the meeting. They advised information regarding financial advice is already available on the EIBSS website.

Annual payment under EIBBS were substantially increased in 2019, part of the intention in making this increase was to remove the need for beneficiaries to ask for smaller discretionary payments which were removed following a review of discretionary support.

Therefore, there are no plans to provide additional funding for financial planning.

EIBSS did also contact support groups including the Haemophilia Society, Hep C Trust, and Terence Higgins Trust, to understand if they offered any financial planning that EIBSS can promote on their behalf, but unfortunately, they do not.

Beneficiary comment: The reason that question (1) was mentioned was because the beneficiary was in a meeting where there was a discussion about how wide the recommendations might be for interim compensation payments. There is a lot of difficulties around dealing with a payment to an estate where a will might not have been left or where the estate was poorly planned.

EIBSS response: EIBSS do receive estate queries frequently, and the applicants are supported and advised on requirements for the regular EIBSS payments.

Compensation payments would be separate to EIBSS payments and if an announcement about compensation payments is made, NHSBSA would have to wait to understand the scope of the payment.

Update: Compensation payment announcement was made on 17th August [here](#)

2. **Beneficiary question:** I wondered whether EIBSS could drop the requirement for 2 quotes for car repairs. You were very amenable when I sent my request in for work that had already been completed and just felt asking people to get two quotes for a maximum pay-out of £500 GBP might be a tad OTT and put people off applying.

EIBSS response: As we are managing public funds, we need to ensure value for money is being achieved, and therefore it's not unreasonable to request a minimum of two quotes, prior to any work to be completed.

3. **Beneficiary question:** I've also applied for support with building repairs several times. I appreciate that the sums involved are significantly larger than for car repairs, but again, I wondered if the requirement for two quotes could be dropped. It is hard enough to find anyone to come and do work let alone get anyone to quote.

Beneficiary comment: Some people do not put in claims due to the hassle of getting 2 quotes and the administrative barrier to claim. The process of two financial quotes is very discouraging, difficult to do.

EIBSS response: Similar question - as we are managing public funds, we need to ensure value for money is being achieved, and therefore it's not unreasonable to request a minimum of two quotes, prior to any work to be completed.

However, if urgent help is required, then one quote can be submitted for consideration with a covering letter explaining the urgency.

4. **Beneficiary question:** Claims for travel and payments takes a long time to be processed. This is currently 30 days; can it be changed?

EIBSS response: The 30 day timescale is an agreed Service Level, however, the EIBSS team of assessors aim to process claims as quickly and efficiently as possible and have successfully processed all claims received within this timescale.

5. **Beneficiary question:** I would like to explore how much is paid to widows compared to people who are actually infected. Would it be possible to provide the meeting with some statistics on this?

I am very concerned to hear that some widows may be receiving more money than people who are actually infected with either hepatitis C or HIV. This cannot be right and needs addressing.

EIBSS response: EIBSS currently have 530 Bereaved Partners in receipt of payments, and payments made until 31.07.22 total £4,462,502.

Non-means tested annual payments to bereaved partners were announced in March 2021 as part of changes to all 4 UK infected blood support schemes intended to bring the schemes into broader parity.

The payment to a bereaved spouse or partner is based on the percentage of the infected person's annual payment, which was a well-established principle in Scotland, and was a model that was also in use in Northern Ireland and Wales.

When this was established in Scotland, it was considered to reflect the loss of income of the bereaved spouse or partner.

(Source: *Contaminated Blood: Financial Support: Conclusions and Recommendations* - <https://haemophiliascotland.files.wordpress.com/2015/11/contaminated-blood-financial-support-conclusions-and-recommendations.pdf>)

Payments were introduced from 1st December 2021, and new Bereaved Partner applications receive 100% equivalent payment for 12 months, which then reduces to 75% for each month after, to enable the bereaved partner to maintain their lifestyle.

- 6. Beneficiary comment: The Robert Francis report includes a recommendation to increase the annual payments to the median UK salary plus 5%. He also recommends replacing the discretionary payments with a single annual payment of £10K. (see page 26 points 2.52 - 2.55). I would like to discuss how we can take these recommendations forward and the role of EIBSS in helping. Perhaps, if this increase were applied only to the infected members, it would address the current anomaly of some widows receiving higher support payments than members that are actually infected.**

EIBSS Response: The interim compensation payments being made in response to Sir Brian Langstaff's interim report recognise the urgent need of infected people and bereaved partners, however, more work is being done by the UK Government to consider the recommendations made by Sir Robert Francis QC and they will consider any further recommendations from the Inquiry when it reports.

If NHSBSA are instructed to implement a compensation scheme, then we will work with DHSC to implement the scheme within the agreed timescales and guidelines.

Update: *Interim Compensation payment announcement was made on 17th August [here](#).*

- 7. Beneficiary question: Can we agree to have minutes of all three meetings circulated within say 1 week of the meetings rather than waiting months as we did last year?**

EIBSS response: Depending on workload, MR will work towards publishing the minutes by end of September, with an update to follow for any questions that may be referred to DHSC.

- 8. Beneficiary question: Has EIBSS received any information about the interim payment from the government?**

EIBSS response: There have been conversations with DHSC, but no announcement has been confirmed (15th August 2022).

Update: *Compensation payment announcement was made on 17th August [here](#).*

- 9. Beneficiary question: Will EIBSS continue with ongoing support after Sir Robert Francis recommendation to pay the compensation has been agreed?**

EIBSS response: EIBSS will continue to make regular payments until advised otherwise. We hope all beneficiaries have given their views to Sir Robert Francis, and also the Inquiry, on this matter.

If NHSBSA are instructed to implement a compensation scheme, then we will work with DHSC to implement the scheme within the agreed timescales and guidelines, alongside any ongoing support scheme.

- 10. Beneficiary question: Co-habits with partner, what happens when beneficiary dies, will payment be made to partner when beneficiary passes away?**

EIBSS response: We would encourage the partner to submit a Bereaved Partner application including supporting evidence of co-habiting, such as Bills, Rent or Mortgage agreement. Further details and criteria is available at <https://www.nhsbsa.nhs.uk/families-deceased-beneficiaries>

11. Beneficiary comment: EIBSS feedback method to beneficiaries is not good enough and does not add value to the group.

EIBSS response: We welcome all suggestions to improve communications and would encourage all beneficiaries to register their interest in attending future focus groups so a wider range of feedback can be received and discussed.

12. Beneficiary comment: A member of the policy team from DHSC should be part of the focus group meetings. If a member of the DHSC policy team is part of the meeting, there would be direct questions answered for all beneficiaries.

EIBSS response: NHSBSA operate the EIBSS 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, EIBSS has designed processes around the beneficiary's needs, through feedback, and has a commitment to continuously review and improve the service where opportunities are identified.

Through listening to beneficiaries, we will where possible, 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 present this to DHSC.

Any changes that are outside of the discretion that EIBSS can apply, will require a decision from DHSC. Such decisions may result in scheme changes, and this will likely affect scheme funding also. Scheme changes will always require analysis prior to a decision being made and will also need to be considered by the other UK infected blood support schemes, in the interests of parity.

13. Beneficiary comment: The focus group should be more structured with terms of reference and have an independent chair and held frequently. KPIs should be discussed, with operational and actual services, face to face meetings.

EIBSS response: The EIBSS are happy to investigate any improvements to our services, including the focus groups. We will create a draft terms of reference, which can be discussed at the next set of focus groups. The chair of the meeting will be an NHSBSA manager with knowledge of the EIBSS. The frequency and format of future focus groups is currently being considered, and once agreed, will be published to the EIBSS website.

Unfortunately, there was disruption to the focus group schedule due to Covid-19 restrictions, which is why we started online focus group meetings from November 2020.

The use of online focus groups allows us to seek the views of a larger number of beneficiaries compared to face to face meetings, as travel is not a barrier to attendance, but we acknowledge this approach may not suit everyone.

EIBSS is likely to offer a mixture of online and face to face focus groups in the future, however, beneficiaries can provide their feedback at any time by contacting the EIBSS by post, email or telephone.

14. Beneficiary question: Does EIBSS offer counselling and how do you apply?

EIBSS response: Yes, EIBSS is able to provide up to £900 per year, towards counselling and talking therapy costs for private treatments. This is for someone who has been infected by blood and/or blood products and is also available for their families. We have recently

updated the talking therapy section on our website here: <https://www.nhsbsa.nhs.uk/talking-therapy-support>

15. Beneficiary comment: Beneficiary would like to open a separate account so that the interim payment can be made in the account.

EIBSS response: Our systems only allow us to hold one set of bank details at a time, therefore, if you wish for your interim payment to go into a different account, you would need to complete a change of details form to change your account with us.

Some UK bank accounts, such as an ISA will not accept annual payments over £30,000 and would be rejected. We can then revert back to the previous bank details once the interim payment is made and would be discussed on an individual basis.

16. Beneficiary question: Would payments be backdated as arrears from when the scheme started after application has been made to EIBSS?

EIBSS response: NHSBSA were directed to administer EIBSS from 1st November 2017. Payment will start from the date an approved application is received.

17. Beneficiary question: Can EIBSS payments be backdated to the date beneficiaries were infected instead of the date of application?

EIBSS Response: This was previously referred to DHSC, and request was declined. NHSBSA were directed to administer EIBSS from 1st November 2017. EIBSS continued with the pre-established decision to backdate approved payment start dates, to the date of receipt on an application. This decision is also consistent with the other Devolved Administration infected blood schemes.

18. Beneficiary question: Can payments be backdated as arrears to when the scheme started, after an application has been made to EIBSS?

EIBSS Response: All applications are assessed based upon all evidence provided, and EIBSS payments will be backdated to the date of receipt of an approved application. If an application is declined, and a subsequent appeal is successful, payments would be backdated to the date of the receipt of the initial application. This decision is consistent with the other Devolved Administration infected blood schemes.

19. Beneficiary question: Why doesn't EIBSS just pay all beneficiaries a flat payment of 10k yearly to cover discretionary payments instead of having to apply and wait 30 calendar days when they require something fixed?

EIBSS response: This was a recommendation in Sir Robert Francis' recent report, however, is not a current scheme guideline in any of the Infected Blood Support Schemes.

EIBSS discretionary payments can be applied for on a rolling 12-month basis, so if you applied for car repairs in April 2021, you could apply again from April 2022, if your car required repairs again.

20. Beneficiary comment: EIBSS should email to all beneficiaries to inform them about the focus groups and ensure that accurate details are held.

EIBSS response: Some EIBSS beneficiaries have advised they wish to be contacted as little as possible; therefore, we are arranging for a sign-up sheet to be added to our website so any registered scheme member can register their interest in attending future focus groups – then we will contact those interested via their preferred contact method.

21. Beneficiary comment: Service to beneficiary on the website is not really helpful.

EIBSS response: We would need more detail to understand which areas you would like to improve. We add as much information as we can to support applicants and scheme members, however, we are happy to receive suggestions for improvements.

22. Beneficiary question: Due to the cost of living rise and increased energy bills, will the winter fuel payment be increasing?

EIBSS response: DHSC and the Devolved Administrations agreed to increase annual payments and winter fuel payments across all the UK Infected Blood Support Schemes in line with the Consumer Price Index (September 2021 rate), with a 3.1% increase for 2022/23 financial year. This was to ensure that these payment rates across the Schemes remain consistent and that new disparities do not emerge. No further changes will be made to payment rates for 2022/23.

23. Beneficiary question: Why was an application rejected due to the lack of a chronic PCR test result?

EIBSS response: Without commenting on a specific application, EIBSS guidance explains what evidence to include, in support of an application. All applications are assessed based upon all evidence provided. The team would contact the applicant informing them of further information to include to help strengthen their application.

24. Beneficiary question: Any information about end of life after care?

EIBSS response: This type of support is not currently offered by the UK infected blood support schemes, the Inquiry may include recommendations regarding this type of support, at their conclusion. Further information about end of life care under the NHS can be found at <https://www.nhs.uk/conditions/end-of-life-care/>

25. Beneficiary comment: Newsletter should be published on the EIBSS website for information.

EIBSS response: An initial newsletter was sent with a questionnaire asking for feedback/interest and offering people to 'opt in'. Unfortunately, the low number of responses received back, indicated a newsletter was not wanted, therefore a second newsletter was not published. We are happy to revisit at any time, if there is enough interest, and could simply create a newsletter and add this to the website without sending this out separately.

26. Beneficiary question: Can EIBSS be part of any contaminated blood group?

EIBSS response: No, NHSBSA operate the EIBSS as directed and within policy determined by DHSC; with a focus on delivering a fair and transparent scheme to beneficiaries. Therefore, EIBSS remain impartial to any groups. We are of course open to receiving feedback through focus groups, post, email or telephone.

27. Beneficiary question: Focus group frequency?

EIBSS response: As mentioned in question 13. The frequency was disrupted due to Covid-19, and subsequent focus groups were moved online. EIBSS are hoping to return to regular focus groups in the future, with at least one per year being face-to-face.

28. Beneficiary question: Does the EIBSS team have counselling due to the nature of the role?

EIBSS response: The EIBSS team have access to a dedicated line to speak with professionals should they need such support. The team's main priority is to support our beneficiaries in any way they can, and we have found having that at the forefront of our minds helps everyone to perform as best they can.

29. Beneficiary comment: Beneficiary sent a letter to the House of Commons and also visited about payments to be made asap, and to also request support to continue after any interim payment is made regardless of the policy.

EIBSS response: Please see question 9 response.

30. Beneficiary question: Matt Hancock made a statement about continual payments to beneficiaries for the rest of their lives. Beneficiaries would like the payments to continue. What is EIBSS thoughts on this as most beneficiaries rely on the payments due to their inability to work and what is the government stand on what Matt Hancock said on camera?

EIBSS response: This was raised in a previous focus group, and also referred to DHSC for their response:

During the Infected Blood Inquiry hearing in May 2021, the previous Secretary of State of Health and Social Care, Matt Hancock, was asked about the Government's future intention regarding the support provided to those infected and affected.

Mr Hancock provided a few related responses within his statement, details of where these can be found are included below. The most relevant response from Matt Hancock's statement is shown below for clarity.

"Yes, I would absolutely give a commitment to anybody receiving a payment, any of the beneficiaries infected or affected, that I would expect that to continue for their lifetime, absolutely. That's my expectation. I would say it goes without saying but sometimes these things need to be said".

The related points to this question can also be found on the [Infected Blood Inquiry website](#), evidence section within Transcript – London - Friday 21 May 2021.

Page 133 section 22- 25 & page 134 section 1- 3
Page 194 section 21- 25 & page 195 section 1- 4

DHSC are awaiting the findings of the Infected Blood Inquiry (IBI) and any recommendations they make, and as a result, are unable to confirm 'payments would continue for life' as the IBI may recommend different options.

Beneficiary comment: The compensation payment took almost 40 years to be agreed. Hopefully beneficiaries' continuous payment will not be stopped as this will be destitute for beneficiaries.

31. Beneficiary comment: Sir Robert Francis report suggests support continues after the compensation is paid, as the compensation payments are different issues.

EIBSS response: Please see question 9 response.

32. Beneficiary question: Due to the amount given to beneficiaries, will a financial adviser be available and be provided to help them with investing their payment?

EIBSS response: EIBSS are unable to recommend or appoint financial advisors. It is at the discretion of the beneficiary who they wish to choose, and we do signpost to various financial services on the EIBSS website. Please also see the response to question 1 above.

33. Beneficiary question: Applied for PIP and not heard anything from DWP. What is the advice from EIBSS?

EIBSS response: We have Benefits Advisors available to EIBSS beneficiaries, who can support with benefit applications. Please contact the EIBSS team and they can put you in touch with them.

34. Beneficiary question: Can EIBSS provide the percentage of beneficiaries who would like to be paid and not want the continuous support from EIBSS?

EIBSS response: Unfortunately, we are unable to provide the information as Individual beneficiaries and campaign groups have shared their opinions with EIBSS, as well as the Infected Blood Inquiry, on their preferred outcomes of the Inquiry.

35. Beneficiary question: If a parent lost their job or are deceased, will dependants be supported?

EIBSS response: Dependents would be entitled to apply for counselling or other talking therapies and may be able to claim on behalf of an estate as executor in the scenario of a beneficiary passing away. However, any specific scenario should be discussed with the EIBSS team for advice.

All focus group questions and answers will be collated and shared with DHSC and beneficiaries.

Minutes finalised and published on 30 September 2022.

Minutes updated and published on 03 October 2022.