

## England Infected Blood Support Scheme (EIBSS) Focus Group – Summary Minutes

**Meeting Type:** EIBSS Focus Group  
**Meeting Date:** 27 February 2025 & 5 March 2025  
**Location:** Crowne Plaza, Newcastle & Online (Microsoft Teams)

### Attendees from EIBSS NHSBSA:

Mal Ross (MR) – Senior Service Delivery Manager  
 Hollie Edminson (HE) – Service Delivery Manager  
 Joseph Helliwell (JH) – Service Delivery Manager (Online Session Only)  
 Sarah Patterson (SP) – Team Manager  
 Amy Gray (AG) – Assessor

<b>1</b>	<b>Welcome</b>																						
	<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 registered beneficiaries are welcome to attend, and those who do attend can provide feedback regarding the scheme.</p> <p>Everyone was welcomed to the focus group. A brief overview of the service was given.</p>																						
<b>2</b>	<b>Updates from EIBSS</b>																						
	<p>MR provided a breakdown of the number of beneficiaries on the scheme as of 31 January 2025.</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="background-color: #003366; color: white;">Infection Status</th> <th style="background-color: #003366; color: white;">Active Beneficiary Count</th> </tr> </thead> <tbody> <tr> <td>Hepatitis C Stage 1</td> <td style="text-align: center;">1,465</td> </tr> <tr> <td>Special Category Mechanism (SCM)</td> <td style="text-align: center;">528</td> </tr> <tr> <td>Hepatitis C Stage 2</td> <td style="text-align: center;">540</td> </tr> <tr> <td>HIV</td> <td style="text-align: center;">69</td> </tr> <tr> <td>Co-Infected (HIV &amp; Hepatitis C Stage 1)</td> <td style="text-align: center;">78</td> </tr> <tr> <td>Co-Infected (HIV &amp; SCM)</td> <td style="text-align: center;">83</td> </tr> <tr> <td>Co-Infected (HIV &amp; Hepatitis C Stage 2)</td> <td style="text-align: center;">54</td> </tr> <tr> <td>Carers / Dependants</td> <td style="text-align: center;">204</td> </tr> <tr> <td>Bereaved Partners</td> <td style="text-align: center;">835</td> </tr> <tr> <td style="background-color: #003366; color: white; text-align: center;"><b>Total</b></td> <td style="background-color: #003366; color: white; text-align: center;"><b>3,856</b></td> </tr> </tbody> </table>	Infection Status	Active Beneficiary Count	Hepatitis C Stage 1	1,465	Special Category Mechanism (SCM)	528	Hepatitis C Stage 2	540	HIV	69	Co-Infected (HIV & Hepatitis C Stage 1)	78	Co-Infected (HIV & SCM)	83	Co-Infected (HIV & Hepatitis C Stage 2)	54	Carers / Dependants	204	Bereaved Partners	835	<b>Total</b>	<b>3,856</b>
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MR also confirmed the annual payment amounts for 2025/26.

	CPI Increase - 1.7%	
Payment Type	2025/26 Annual Amount	75% Annual Amount
Hepatitis C Stage 1	£23,294.00	£17,471.00
SCM	£35,327.00	£26,495.00
Hepatitis C Stage 2	£35,327.00	£26,495.00
HIV	£35,327.00	£26,495.00
Co-Infected (HIV & Stage 1)	£47,952.00	£35,964.00
Co-Infected (HIV & SCM)	£55,518.00	£41,639.00
Co-Infected (HIV & Hepatitis C Stage 2)	£55,518.00	£41,639.00
Winter Fuel	£670.00	

MR confirmed that this will likely be the final in-person EIBSS focus group given that IBCA are now operational and that the existing supporting schemes will begin to close throughout the year. EIBSS will close on 23 March 2026. We may potentially hold an online focus group later this year if there are any communications or updates to share.

Any beneficiary who is due a payment on 27 March 2026 will instead receive their final payment by EIBSS on 20 March 2026.

EIBSS will stop accepting medical applications on 31 March 2025. This includes applications from existing beneficiaries with a change to condition type (e.g. Hepatitis C Stage 1 to SCM or Stage 2). Bereaved partners will have until 30 June 2025 for an application for bereavement payments to be received by EIBSS.

All payments made after 1 April 2025 will be deducted from final compensation paid by IBCA, except for pre-payment certificates (PPC) and talking therapy.

MR explained that there is no set agenda for the meeting. EIBSS beneficiaries were then invited to ask any questions.

### 3 Comments and Questions from EIBSS Beneficiaries

**1. Beneficiary Question – If the government decide to start charging people over the age of 60 for prescriptions, what will happen there in terms of people who don't currently have a PPC because it's not needed now?**

**EIBSS Response** – If that was to happen in the next 12 months, you would just contact EIBSS, and we can arrange to set up a PPC for you. If it's after EIBSS have closed, we are unable to advise and would have to contact IBCA directly.

**2. Beneficiary Question – Will IBCA be issuing PPC’s after EIBSS has closed?**

**EIBSS Response** – We’re currently working with IBCA and DHSC with regards to this, but unable to confirm at this stage. The NHSBSA runs the PPC scheme for England, which is why it’s currently easy for us to do this now.

**3. Beneficiary Question – So will we continue to receive exemption from prescriptions when IBCA take over?**

**EIBSS Response** –  
As above.

**4. Beneficiary Question – Will discretionary payments be deducted from final compensation paid by IBCA?**

**EIBSS Response** – For applications made after 31 March 2025, any discretionary one-off payments will be deducted from final compensation.

**Addendum** – The Infected Blood Compensation Scheme Regulations 2025 were updated on 31 March 2025 to advise that any discretionary payments made after 31 March will be deducted from final compensation.

<https://www.legislation.gov.uk/ukdsi/2025/9780348268843/regulation/6>

**5. Beneficiary Question – You mentioned that you had already shared files with IBCA. Can you firstly confirm when that happened, and further to that if people have since had a change to condition type or applied for discretionary one-off payments since, how is that then passed over to IBCA?**

**EIBSS Response** – When the Victims and Prisoners Act came into effect in October 2024, this gave IBCA the right to request everyone’s information. We’ve set up a central SharePoint drive which holds all our beneficiary’s information which IBCA has access to, as well as the EIBSS system which holds payment information and notes made by the EIBSS team. We were then able to set up a monthly refresh, which happens on the 1<sup>st</sup> of each month and provides IBCA with the most up to date information i.e. change to condition types, contact information, bank details, etc.

**6. Beneficiary Question – Do EIBSS have a copy of IBCA’s SCM criteria as it does not appear to be the same?**

**EIBSS Response** – No, we don’t have this as IBCA are a different organisation.

**7. Beneficiary Question – Have EIBSS had any experience of dishonest people trying to contact beneficiaries?**

**Beneficiary Comment** – I know of somebody who has received several phishing type calls from people where they might not speak for example, and it has unnerved them.

**EIBSS Response** – Because of the nature of the scheme and the publicity it has received, especially within the last few years, the media often release information regarding payments beneficiaries will receive and the amounts. This means that family members or neighbours for example of beneficiaries will know that they are about to come into some money. We are aware of some vulnerable beneficiaries who have been approached by family members and asked if money can be paid into a different bank account. We always try to protect beneficiaries against these kinds of instances. We have warned IBCA of this. IBCA are very keen on using social media, and their channels are public rather than private. For people using Twitter/ X, this isn't usually an issue as you don't necessarily use your name as your handle. However, a lot of Facebook users will display their full name meaning it is very easy for people to go through IBCA's page and find names of beneficiaries who might innocently be asking questions. We've asked IBCA to make their channel private to try and protect people against this, or to not use it at all. When beneficiaries are contacted by IBCA, they should make themselves known because they will already be in possession of your name, address, etc.

**8. Beneficiary Question – Will IBCA contact beneficiaries using the same contact preferences currently held by EIBSS?**

**EIBSS Response** – We have provided IBCA with everybody's contact preferences. If beneficiaries have all contact preferences selected with EIBSS (email, post and telephone), we will always use post as first choice as beneficiaries have previously advised us that they prefer to have physical copies of any paperwork. However, if email is one of your preferences this is how IBCA will contact you due to the urgency.

**9. Beneficiary Question – Does compensation have any impact on benefits?**

**EIBSS Response** – No, initial payments do not have any impact on benefits. However, any money made from payments i.e. interest will have an impact. Everybody should be able to provide an audit trail to the relevant authorities confirming where the money has come from to prove that it will not impact benefits.

**10. Beneficiary Question – Is there any update on the psychological support service that was supposed to be being set up for EIBSS beneficiaries and their families?**

**EIBSS Response** – There are no updates or changes that we are aware of. You can approach NHS England directly for therapy services and can still obtain funding support for talking therapies through EIBSS.

**11. Beneficiary Question – Will talking therapy funding paid by EIBSS be deducted from final compensation paid by IBCA?**

**EIBSS Response** – No. There are 3 types of support paid by EIBSS that will not be deducted: PPC's, talking therapy and child payments. We would advise getting any discretionary one-off payment applications in before 31 March 2025 so that if they are approved, they will not be deducted.

**Addendum** – The Infected Blood Compensation Scheme Regulations 2025 were updated on 31 March 2025 to advise that and discretionary payments made after 31 March will be deducted from final compensation. The only payments not subject to deductions are talking therapy and PPC's, and therefore Child Payments would be deducted.

<https://www.legislation.gov.uk/ukdsi/2025/9780348268843/regulation/6>

**12. Beneficiary Question – Can applications be sent in by email?**

**EIBSS Response** – We can't accept medical applications by email, but we can accept discretionary one-off payment applications and supporting evidence by email unless they include bank details.

**13. Beneficiary Question – Have there been any changes to the cut-off dates?**

**EIBSS Response** – No. The cut-off dates may be less stringent with IBCA, although this has not been confirmed yet.

**14. Beneficiary Question – Is there a rough date as to when compensation will be finalised?**

**EIBSS Response** – The lifespan of IBCA as far as we're aware will be around 7 years. However, for people who choose to receive ongoing payments for life will require some sort of support team in place for this to be managed.

**15. Beneficiary Question – For beneficiaries who first applied through an AHO organisation e.g. Caxton or Skipton, was the information provided to the AHO's passed over to EIBSS?**

**EIBSS Response** – When EIBSS was established in 2017, we were provided with the necessary information required to continue making payments i.e. name, address, contact details, bank details and condition type. As Russell-Cooke became the data controllers, all the information not passed over to EIBSS was held by them. As part of the Victims and Prisoners Act, IBCA became the data controllers. So, where EIBSS may not hold all the files from the AHO's, IBCA can now access these files.

**16. Beneficiary Question – Will discretionary applications received on or before 31 March 2025 but approved on or after 1 April 2025 be deducted from final compensation?**

**EIBSS Response** – No. As long as we receive the application on or before 31 March 2025 it will not be deducted.

**Addendum – The Infected Blood Compensation Scheme Regulations 2025 were updated on 31 March 2025 to advise that any discretionary payments made after 31 March will be deducted from final compensation (excluding PPC and Talking therapy/Counselling).**

<https://www.legislation.gov.uk/ukdsi/2025/9780348268843/regulation/6>

**17. Beneficiary Question – Why were we not asked for signed consent in order for our information to be shared with IBCA?**

**EIBSS Response** – The Victims and Prisoners Act gave IBCA the right to request the information without signed consent being needed. We sent a letter out to all beneficiaries in 2024 confirming that information will be shared and should anybody not wish for IBCA to use their information it provided the necessary contact details.

**18. Beneficiary Question – What will happen to the existing EIBSS benefits advisors?**

**EIBSS Response** – We can't comment on what will happen beyond 23 March 2026, but both benefits advisors currently part of the EIBSS team will still be here to assist beneficiaries up to this date. If you, however, choose to accept a compensation offer from IBCA and de-register from the scheme, this support will also cease.

**19. Beneficiary Question – How do we contact / request contact from the benefits advisors?**

**EIBSS Response** – You would get in touch with EIBSS and ask for a callback from one of the benefits advisors. An EIBSS assessor will take your details and a brief reason for the callback request, and they will contact the benefits advisors on your behalf to request the callback. You will usually be contacted by one of the benefits advisors within 3 working days. They can also assist with form-filling.

**20. Beneficiary Question – Is it still the case that only people with Hepatitis C Stage 2 can apply for a pre-paid funeral plan?**

**EIBSS Response** – Yes, this is still the case. There has been no change made to the criteria.

**Beneficiary Comment** – The medical experts used by EIBSS confirmed that when people are diagnosed with liver cirrhosis, this is a terminal condition whereas HIV is a manageable condition. Another huge disparity between the mono Hepatitis C and mono HIV community in terms of how the conditions are viewed so differently between departments.

**21. Beneficiary Question – Should we be informing EIBSS of any health updates?**

**EIBSS Response** – Only if it's condition-related, so a deterioration to your Hepatitis for example. Anything not specific to the condition but that may be relevant as part of your assessment by IBCA can either be sent to EIBSS to put in your file or provided directly to IBCA when you are contacted by them.

**22. Beneficiary Question – Is there any way of accessing the minutes from every EIBSS focus group?**

**EIBSS Response** – The minutes on the website are all that is held by EIBSS.

We only started capturing and publishing the minutes from the full focus group meetings in 2021.

**23. Beneficiary Question – I am currently applying for talking therapy support. Can you confirm what the letter from the therapist needs to say? Also, how would bank details be provided if not already held by EIBSS?**

**EIBSS Response** – The letter needs to confirm the approved register that the counsellor / therapist is on as well as their membership / registration number, the recommended number of the sessions and the cost per session. You can also claim the cost of an assessment carried out to determine potentially how many sessions are required, and the cost of this assessment should also be detailed in the letter. If the application is approved, payment is made directly to the applicant rather than the therapist. For any children applying under the age of 18, payment can be made to a parent / guardian. As well as an application form and letter from a counsellor / therapist, a 'Contact preferences and personal details form' should also be sent to obtain bank details if not already held by EIBSS. AG offered to send beneficiary an email confirming all of the information provided.

**24. Beneficiary Question – If an application is subsequently approved at the appeal stage, are payments backdated to when the application was first received?**

**EIBSS Response** – Yes, payments would be backdated to the date the application was received by EIBSS.

**25. Beneficiary Question – With IBCA due to last for a period of 7 years, what will happen to people who choose to receive ongoing support payments for life and who will oversee it?**

<p><b>EIBSS Response</b> – We have been advised by IBCA that a smaller team will remain in place to oversee beneficiaries who choose to receive payments for life.</p>
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