

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

Meeting Type: EIBSS Focus Group
 Meeting Date: 16 May 2024
 Location: The Met Hotel Leeds

Attendees from EIBSS NHSBSA:

Hollie Edminson (HE) – Service Delivery Manager
 Joseph Helliwell (JH) – Service Delivery Manager
 Sarah Patterson (SP) – Team Manager
 Amy Gray (AG) – Assessor

1	Welcome																						
	<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>Introductions were made and everyone was welcomed to the focus group. A brief overview of the service was given.</p>																						
2	Updates from EIBSS																						
	<p>JH provided a breakdown of the number of beneficiaries on the scheme as of 1 May 2024.</p> <table border="1" data-bbox="308 1460 1350 1906"> <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;">1390</td> </tr> <tr> <td>Special Category Mechanism (SCM)</td> <td style="text-align: center;">538</td> </tr> <tr> <td>Hepatitis C Stage 2</td> <td style="text-align: center;">549</td> </tr> <tr> <td>HIV</td> <td style="text-align: center;">68</td> </tr> <tr> <td>Co-Infected (HIV & Hepatitis C Stage 1)</td> <td style="text-align: center;">79</td> </tr> <tr> <td>Co-Infected (HIV & SCM)</td> <td style="text-align: center;">84</td> </tr> <tr> <td>Co-Infected (HIV & Hepatitis C Stage 2)</td> <td style="text-align: center;">54</td> </tr> <tr> <td>Carers / Dependants</td> <td style="text-align: center;">142</td> </tr> <tr> <td>Bereaved Partners</td> <td style="text-align: center;">777</td> </tr> <tr> <td style="background-color: #003366; color: white;">Total</td> <td style="background-color: #003366; color: white; text-align: center;">3681</td> </tr> </tbody> </table> <p>JH explained that there is no set agenda for the meeting. EIBSS beneficiaries were then invited to ask any questions.</p>	Infection Status	Active Beneficiary Count	Hepatitis C Stage 1	1390	Special Category Mechanism (SCM)	538	Hepatitis C Stage 2	549	HIV	68	Co-Infected (HIV & Hepatitis C Stage 1)	79	Co-Infected (HIV & SCM)	84	Co-Infected (HIV & Hepatitis C Stage 2)	54	Carers / Dependants	142	Bereaved Partners	777	Total	3681
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1. Beneficiary Question – When we have applied for Special Category Mechanism (SCM) payments and been approved, do we need to continue to prove eligibility for the payments?

EIBSS Response – No. Once you have had an SCM application approved, you will continue to receive these payments without having to prove continued entitlement.

2. Beneficiary Question – What is the difference between Hepatitis C Stage 1, SCM and Stage 2?

EIBSS Response – When somebody makes an initial application to EIBSS if they were infected with chronic Hepatitis C as a result of treatment with NHS blood, blood products or tissue prior to September 1991, they will make a Stage 1 application.

You can apply for Hepatitis C Stage 2 payments if you have or have had:

- Cirrhosis.
- primary liver cancer.
- B-cell non-Hodgkin's lymphoma.
- a liver transplant or are on the waiting list to receive one.
- type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN).

You can apply for SCM payments if you have Hepatitis C Stage 1, and your condition has worsened but is not Stage 2. You may be eligible if:

- your infection, its treatment, or associated conditions, has a long-term negative impact on your ability to carry out daily activities.
- your condition has worsened but is not stage 2.

SCM recognises the impact of your infection and linked conditions and the effects of treatment. The scheme aims to respond to your changing health and needs.

3. Beneficiary Question – Are EIBSS expecting a huge influx of applications once the final report is published?

EIBSS Response – It depends on how it's communicated to the public. If it's not well explained, then yes, we would expect a large amount. If it's well explained, then we will probably receive less. At the moment, the scheme is in a good position as we are on top of applications. If another interim payment is announced, this will also initiate high application figures. When the last interim payment was announced in 2022, there were a higher number of declined applications than approved.

4. Beneficiary Question – Can you provide some information around the cut-off dates?

EIBSS Response – The current scheme eligibility criteria is that you can apply to join EIBSS if you were infected with chronic Hepatitis C prior to September 1991, or HIV prior to October 1985 as a result of treatment with NHS blood, blood products or tissue.

All NHS blood in England was being screened for HIV from October 1985 onwards and Hepatitis C from September 1991 onwards, so it is very unlikely, although not impossible, you would have received HIV through infected NHS blood after October 1985 or Hepatitis C through infected NHS blood after September 1991.

These dates are soft cut-off dates. If people are able to evidence being infected beyond these dates, we will always consider all circumstances and discretion can be applied if necessary.

As part of the Infected Blood Inquiry (IBI) recommendations, there is consideration being given to extending or removing the cut-off dates, but we are waiting for the final report. We have not been directed to change the scope of the scheme. Another recommendation was to open the scheme up to people infected with Hepatitis B and widen the scheme to anybody who has received infected blood.

5. Beneficiary Question – Will we receive a letter confirming the announcement when the final report is published?

EIBSS Response – We will hear the report at the same time as everybody else on Monday (20 May 2024) when it is live streamed on YouTube through the IBI channel. We will not get early access to it. We then expect the government to provide a response on Tuesday (21 May 2024). We will then receive instruction and update our website at the earliest opportunity. We will communicate any necessary information with our beneficiaries.

6. Beneficiary Question – Will regular EIBSS support payments be guaranteed for life?

EIBSS Response – This is part of the IBI recommendations, so we hope that the support scheme will continue. One of the main reasons that we can't operate the compensation scheme suggested by the IBI is because it's not in our charter that we can run a national scheme. One of the key recommendations by the IBI is that a new, completely independent arms-length body is set up to administer the compensation scheme. We did deliver the interim payments announced in 2022 which did make up a part of compensation, but we also deliver regular support whereas the other arms-length body will deliver compensation only.

7. Beneficiary Question – Is it better to get a solicitor to help with handling final compensation claims?

EIBSS Response – We cannot provide advice on whether beneficiaries should obtain a solicitor.

8. Beneficiary Question – What is the criteria and the process for making an application for accommodation repairs?

EIBSS Response – A discretionary payment of up to £2,500.00 per rolling 12-month period is available towards repairs to the home that are required to prevent serious risk to the health and safety of an infected beneficiary.

To apply, we require the following:

- A completed accommodation repairs discretionary one-off payment application form.
- Confirmation from your insurance company that support you're applying for is not covered or only partly covered.
- Two quotes for the work on letter headed paper.
- If you live in rented accommodation, we also require confirmation from the homeowner that the repair is not their responsibility.

9. Beneficiary Question – Why do people have different payment dates each month for regular support payments?

EIBSS Response – The payment date depends on the type of support you receive. They are as follows:

- Bereaved Partners & Discretionary Support – 1st, 15th, 20th or 27th depending on when an application is approved.
- Co-Infected & HIV – 15th of each month.
- Hepatitis C Stage 1 – 20th of each month.
- Hepatitis C Stage 2 & Special Category Mechanism – 27th of each month.

Psychological Support Information

NHS England are currently working with campaign groups as well as mental health experts to create a bespoke psychological support service for EIBSS beneficiaries and their families. It has been announced that services should start to come online this year.

We would encourage those who do need support to continue to access the EIBSS provisions until this time.

EIBSS is able to provide funding towards counselling and talking therapy costs for private treatments. This support is available to:

- an infected person who is registered with the EIBSS
- a bereaved person who is registered with the EIBSS
- family members of an infected person registered with the EIBSS or previous schemes

Funding is available for:

- the cost of an assessment with a registered therapist
- the cost of talking therapy sessions

There are two types of funding available:

- Initial Funding - Up to £900.00 per year to fund the cost of your talking therapy sessions with your counsellor / therapist. This will be paid directly to you.
- Further Funding - If you and your counsellor / therapist agree that a further treatment plan is required once you have exhausted the initial £900.00, EIBSS can fund this directly with your counsellor / therapist.

This support will continue whilst the new service is stood up.

There are also a number of other support options available. The Red Cross will be in attendance on the day of the final inquiry report being published, and urgent care can be sought with <https://www.nhs.uk/nhs-services/mental-health-services/where-to-get-urgent-help-for-mental-health/>.

For anyone needing talking therapies, these can also be accessed here: <https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/>