

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

Meeting Type: EIBSS Focus Group

Meeting Date: 10 October 2023

Location: Crowne Plaza London - Kings Cross

## Attendees from EIBSS NHSBSA:

Amy Turner (AT) – Assessor

Hollie Edminson (HE) – Service Delivery Manager

James Hardy (JH) – Senior Service Delivery Manager

Sarah Patterson (SP) – Team Manager

<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>Introductions were made and 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>Beneficiaries were sent a breakdown of the number of beneficiaries on the scheme as of 1 October 2023 ahead of the meeting. We have also included them here for a written record.</p> <table border="1" data-bbox="319 1467 917 2051"> <thead> <tr> <th>Infection Status</th> <th>Active Beneficiary Count</th> </tr> </thead> <tbody> <tr> <td>Hep. C Stage 1</td> <td>1380</td> </tr> <tr> <td>Special Category Mechanism (SCM)</td> <td>546</td> </tr> <tr> <td>Hep. C Stage 2</td> <td>557</td> </tr> <tr> <td>HIV</td> <td>66</td> </tr> <tr> <td>Co-Infected (HIV &amp; Stage 1)</td> <td>80</td> </tr> <tr> <td>Co-Infected (HIV &amp; SCM)</td> <td>84</td> </tr> <tr> <td>Co-Infected (HIV &amp; Stage 2)</td> <td>55</td> </tr> <tr> <td>Carers / Dependants</td> <td>111</td> </tr> <tr> <td>Widow / Widower / Civil Partner</td> <td>751</td> </tr> <tr> <td><b>Total</b></td> <td><b>3630</b></td> </tr> </tbody> </table>	Infection Status	Active Beneficiary Count	Hep. C Stage 1	1380	Special Category Mechanism (SCM)	546	Hep. C Stage 2	557	HIV	66	Co-Infected (HIV & Stage 1)	80	Co-Infected (HIV & SCM)	84	Co-Infected (HIV & Stage 2)	55	Carers / Dependants	111	Widow / Widower / Civil Partner	751	<b>Total</b>	<b>3630</b>
Infection Status	Active Beneficiary Count																						
Hep. C Stage 1	1380																						
Special Category Mechanism (SCM)	546																						
Hep. C Stage 2	557																						
HIV	66																						
Co-Infected (HIV & Stage 1)	80																						
Co-Infected (HIV & SCM)	84																						
Co-Infected (HIV & Stage 2)	55																						
Carers / Dependants	111																						
Widow / Widower / Civil Partner	751																						
<b>Total</b>	<b>3630</b>																						

	<p>JH explained that there is no set agenda for the meeting.</p> <p>EIBSS beneficiaries were then invited to ask any questions.</p>
<b>3</b>	<b>Comments and Questions from EIBSS Beneficiaries</b>
	<p><b>1. Beneficiary Question</b> – <i>There is a lack of continuity within EIBSS that beneficiaries find demeaning and hurtful. Often different assessors handle or deal with the same piece of work which can often create confusion or result in misinformation being provided. Is it not possible to have one assessor deal with the same piece of work from start to finish?</i></p> <p><b>EIBSS Response</b> – Assessors are quality checked to ensure staff are giving the correct information to beneficiaries, and that they are being empathetic and supportive. Quality checking ensures that if there are any issues, they can be fed back to the relevant team members. Due to the work allocation system we use, annual leave, sickness, etc. it isn't possible to always have the same assessor handle one piece of work from start to finish. This shouldn't be necessary as all assessors should be providing the same information.</p> <p><b>2. Beneficiary Question</b> – <i>There are too many application forms and the forms are too difficult to fill in. There is nobody there to provide guidance on completing the forms, which is frustrating and puts people off making applications as the processes are too difficult. I once made a claim and EIBSS lost the form. I dread calling EIBSS sometimes because I feel like they can be so unhelpful. Why are there so many different forms?</i></p> <p><b>EIBSS Response</b> – We are really, sorry to hear that you feel that way about calling for help as that should not be the case. The team are there to support with the completion of any forms. We used to have one generic discretionary application form, but we received feedback that the form wasn't specific enough, which is why we now have a separate form for each discretionary payment. The team can fill forms in on behalf of a beneficiary, then send the form out to be checked and signed by the beneficiary which should make things easier for people who need the additional support. The DHSC require EIBSS to have financial controls in place with regards to public spend, which is why our processes are designed this way.</p> <p><b>3. Beneficiary Question</b> – <i>I think I'd find it quite difficult to locate the forms and navigate the website. How many forms are available?</i></p> <p><b>EIBSS Response</b> – There are currently 12 application forms for discretionary one-off payments. One of the recommendations that has been made off the back of the inquiry is for the discretionary application</p>

process to be removed and a one-off payment be made yearly for beneficiaries to use to help cover these costs instead.

**Beneficiary Comment** – *What is frustrating is the complexity of the forms and the processes. I understand you are set a mandate, and this is out of your control, however when people are unwell and struggling the last thing they want to do is fill in a complex form. People’s individual stories end up getting lost.*

**EIBSS Response** – When any Inquiry recommendations are approved, EIBSS aim to implement them as quickly as possible. A one-off payment would also be simpler to administer.

**4. Beneficiary Question** – *With regards to Child Payments, why can we not put in an appeal for payments to be backdated? I was not told about the available funding when I’ve spoken about this to the EIBSS team previously.*

**EIBSS Response** – There is a complaints process in place for non-medical based applications, child payments can be contested by this route, if a person disagrees with the initial outcome. The Appeals process is for medical-based applications, as these require medical experts to assess them. However, the rules regarding backdating are written into the DHSC Scheme Specification, so EIBSS are unable to overrule these timings.

**5. Beneficiary Question** – *Why is there a time limit to apply for the Bereavement Lump Sum? Is there any flexibility around this? People are dealing with trauma and the loss of a loved one, and the last thing on people’s mind is to be making applications for stuff. By the time they realise, it’s too late to apply.*

**EIBSS Response** – We understand that this is a difficult time for the family of beneficiaries, however the 6-month time limit is in place to encourage timely receipt of applications We can put this point to DHSC to see if there is a possibility to extend or remove this time limit.

**Beneficiary Comment** – *The forms are so difficult to complete, therefore it’s not easy to apply. Additionally, the website is not easy to navigate at all.*

**EIBSS Response** – The website is designed in our corporate style. Every service within the NHS Business Services Authority (NHSBSA) all use the same format, which we appreciate isn’t completely user friendly. It’s standardised so that if you use multiple services within the NHSBSA it’s the same layout. In terms of flow, what suits some people doesn’t naturally suit others. But that’s where the EIBSS team come in and they can help with navigating the website, locating forms, or completing forms on behalf of people.

**6. Beneficiary Question** – *What happens if a beneficiary passes away? What support is available from the scheme for their family?*

**EIBSS Response** – This is entirely dependent on people's circumstances. There is a funeral grant available for the person who paid for the beneficiary's funeral, there is a bereavement lump sum available for the executor of the beneficiary's estate, or the beneficiary's bereaved partner, if they have one. We also offer regular bereaved partner payments if the beneficiary had a co-habiting spouse, civil partner, or long-term partner. Additionally, the scheme offers counselling for family members.

**7. Beneficiary Question** – *What are the cut off dates for applying for the scheme?*

**EIBSS Response** – For people infected with Hepatitis C, the cut-off date is September 1991. For people infected with HIV the cut-off date is October 1985. All NHS blood in England was being screened for HIV from October 1985 onwards so it is very unlikely, although not impossible, you would have received HIV through infected NHS blood after October 1985.

**8. Beneficiary Question** – *Nearly all EIBSS applications have some kind of time frame and sometimes that is an obstacle for people. Have you considered getting in any experts or volunteers who have a better understanding of the difficulties beneficiaries face?*

**Beneficiary Comment** – *I think it would be really beneficial if you had victims working as volunteers or part-time staff who are core participants within this situation we find ourselves in.*

**9. Beneficiary Question** – *Do you have anybody within the EIBSS team who are in our position?*

**EIBSS Response** – There was a girl previously on the team who had a relative with Hepatitis C and she had some experience with this. None of the current team members are directly or indirectly affected. They are well informed, and a lot has changed over the past year, so we have been somewhat in a transitional period. If somebody was to apply for a job on the scheme, it's not a question we would ask or would be required. We have had calls previously with the Hepatitis C Trust and the Haemophilia Society where we've addressed questions from people trying to join the scheme and how they can be supported. I think you have raised an interesting point, regarding beneficiaries directly in some way, we will consider how this could be included in the future.

**Beneficiary Comment** – *If you look at most statutory services, they all have 'the voice of' within their service. So for EIBSS, that would be the voice of the infected.*

**EIBSS Response** – It could be a middle ground, but we would have to come up with a way of integrating the view into our organisation. It may not be as easy as having volunteer workers, but we could explore

beneficiaries informing our staff as part of their core training, which could help enhance their knowledge.

**10. Beneficiary Question** – *Are the staff (including assessors) given a profound and meaningful insight into the past and ongoing suffering of the beneficiaries as part of the new employee inductions, and if not, why not?*

**EIBSS Response** – The first part of training covers the background of the contaminated blood scandal. We make sure new assessors know what they are being trained in. With regards to the medical assessors, who assess the medical applications, they were practicing medicine at the time of the scandal. Three out of five of the assessors are still practicing now, so they are up to date with current practice. However, because they were practicing at the time of the scandal, they have learned knowledge. Clearly, a vast amount of personal stories are available on the Infected Blood Inquiry website, and we include some of these stories within our EIBSS training.

**11. Beneficiary Question** – *Why haven't discretionary payment amounts been uplifted? Regular payments are uplifted every year in line with CPI, but discretionary and Child Payments are not. Previously we have been told that the government haven't instructed EIBSS to increase them, but the community want to put pressure on this because they want to know why, based on the cost of living, that they wouldn't be representative. Since the beginning of the scheme, have any of them changed?*

**EIBSS Response** – Any uplift in discretionary rates is solely a DHSC matter, we would of course increase any payment rates, if instructed by DHSC to do so.

**Beneficiary Comment** – *There's no longer parity across the nations with regards to Child Payments in terms of income thresholds.*

**EIBSS Response** – This will be looked at as part of the outcome of the inquiry report. Unfortunately, Wales implemented child payments which are not means tested. The matter is consistently being fed back to DHSC.

**12. Beneficiary Question** – *The Caxton Fund didn't pay Child Payments. People who missed out and had children who had just achieved adult status and therefore didn't meet the EIBSS qualifying criteria were not offered any back pay. People who were registered with The Macfarlane Trust, for example, did receive Child Payments. Why were people who didn't receive them not offered backdated payments to bring it in line with other charities?*

**EIBSS Response** – EIBSS commenced on the 1 November 2017, all payments became our responsibility from this date. We will pass on your question to DHSC for consideration.

**Beneficiary Comment** – *When all of the information about EIBSS came out, a lot of people were going through treatment and therefore couldn't deal with it. I'm unsure as to why it wasn't addressed more thoroughly and why more clarity wasn't given at the time.*

**EIBSS Response** – That would be a very unique circumstances that would need to be put to the DHSC. Unfortunately, we are unable to comment on the decision making of DHSC and/or the Alliance House Organisations (AHOs)

**Beneficiary Comment** – *The community, especially the blood transfusion community, is feeling increasingly marginalised as there appears to be much louder voices coming from people who are not infected but affected.*

**EIBSS Response** – In previous focus groups, we have talked about the belief that the infected community are being drowned out by the affected community because there's less infected people. This has meant that infected people are worried that affected people will receive more money or special treatment in comparison to somebody who has suffered the most. One person's set of circumstances cannot be compared to another's. This point has been provided to DHSC previously, and we'll ensure it is passed on again.

**13. Beneficiary Question** – *I'm part of a Patient Participation Group which is a group of volunteer patients, carers and GP practice staff who meet regularly to discuss and support the running of their GP practice. PPGs look at the services the practices offers, patient experience and how improvements can be made for the benefit of patients and the practice. The NHS now offers free testing for Hepatitis C. Can we try and make more people aware of this?*

**EIBSS Response** – There are currently lots of issues that the government is trying to tackle, so you will see different things advertised more at different times of the year. Also, advertising is better in some areas than others. We can certainly put it to the DHSC to see if advertising for Hepatitis C can be increased.

**14. Beneficiary Question** – *Getting two quotes for car repairs is an absolute pain! We're all very tired and this can be exhausting. Why do we need to get two quotes?*

**EIBSS Response** – This question has been asked previously. Because we're responsible for spending taxpayers' money, we have to ensure that we are spending it in the most efficient and economical way possible and we do this by obtaining more than one quote for most discretionary applications. We understand that sometimes certain circumstances may not allow for that, and discretion can sometimes be applied depending on the circumstances, but for example if your car tyres needed replacing you would have time to look around and get a couple of quotes to compare

prices. If it's an emergency repair by the roadside for example, this is where we could look at using discretion.

**Beneficiary Comment** – *I just wanted to explain that sometimes we don't have the capacity to get more than one quote due to tiredness, etc.*

**EIBSS Response** – We do appreciate and understand where you're coming from, please do contact us prior to making any payment and we can see if there is any discretion that can be applied based upon your individual circumstance

**15. Beneficiary Question** – *With regards to accommodation repairs applications, why do you require our home insurance policy?*

**EIBSS Response** – In our scheme specification, it explains that the discretionary support is to be used where no other support is available. We require the home insurance policy to ensure that the issue cannot be addressed through the insurance and to confirm that we are not double funding.

**16. Beneficiary Question** – *Why do we have to wait until a discretionary application is approved before paying out any money?*

**EIBSS Response** – Generally speaking, anything paid for in advance of approval cannot be reimbursed. This is in the scheme rules. Like anything, people sometimes have unique circumstances, and this can be considered of course. We understand that sometimes it is not possible to submit an application in advance, such as an emergency situation, in which case we would encourage a beneficiary to contact us and discuss this.

**17. Beneficiary Question** – *When will the Winter Fuel Payment be paid and how much is it this year?*

**EIBSS Response** – It will be paid in December 2023, and this year the payment will be £618.00.

**18. Beneficiary Question** – *Are EIBSS payments affected in any way by benefits?*

**EIBSS Response** – No, payments from EIBSS are not affected by benefits. Additionally, benefits are not affected by EIBSS payments. It may be worth speaking to Benefits Brighton who can offer benefits advice.

**19. Beneficiary Question** – *Do EIBSS offer any help with making wills or applying for Lasting Power of Attorney for example? Going to a solicitor can be difficult as it is mind number to try and think of what needs to be covered.*

**Beneficiary Comment** – *There's nobody to call and help us with queries about tax either. We know that money made from EIBSS payments is taxable, but this can be confusing to understand.*

**EIBSS Response** – EIBSS provide information on our website regarding where monetary advice is available. We will also add any information to this section regarding tax rules for EIBSS payments.

<https://www.nhsbsa.nhs.uk/financial-and-support-services>

**20. Beneficiary Question** – *Is benefit support available for children of beneficiaries?*

**EIBSS Response** – We will take this away to the DHSC and find out.

**21. Beneficiary Question** – *With regards to employment training, would EIBSS update or provide technology? If no, why is that? I only have a phone, and reading on there is sometimes quite tricky as it's very small. Also, with Zoom meetings becoming more prevalent it's something to consider. I've never bought a laptop as I thought it would be an unnecessary expense, but if people are going to move into education to get back into work, they will need more advanced technology.*

**Beneficiary Comment** – *Since COVID-19, a lot of places require people to work from home but not all employers offer the equipment required to do so. I also don't have any technical knowledge, so I struggle with stuff like that.*

**EIBSS Response** – We would have to put that to the DHSC with regards to the scope of employment training. It's predominantly to cover re-training for people who have had their career path altered due to illness. But we will definitely take this away to the DHSC.

**22. Beneficiary Question** – *Going back to the website, would it be possible to have a frequently asked questions (FAQ's) page broken down into segments i.e. discretionary payments, medical applications, etc? This would be so beneficial.*

**EIBSS Response** – We don't specifically have an FAQ's section on the website due to the corporate layout, but in the discretionary payments section there's information specific to each application which explains what you can and can't apply for. Going back to what was said earlier, what might suit some beneficiaries wouldn't necessarily suit others.

**23. Beneficiary Question** – *Do you know if EIBSS payments are going to be guaranteed for life?*



**EIBSS Response** – This is included within the Infected Blood Inquiry recommendations, that the payments will be guaranteed for life, and it will be up to the Government to decide if this is accepted.

**Beneficiary Comment** – *Life insurance for people with a Hepatitis C diagnosis carries a much higher premium. This seems so unfair as it's something that was done to me, I didn't do this to myself. It would be good if the government would consider a supported scheme in related to life insurance.*

**EIBSS Response** – We will absolutely feed this back to the DHSC.

**Beneficiary Comment** – *There is also still such a stigma in medical settings i.e. doctors, dentists, hospitals with regards to people affected by contaminated blood. This was fed back to the IBI but it's so frustrating that it still carries such a stigma.*

**EIBSS Response** – This is helpful for us to be able to take first hand experiences of beneficiaries to DHSC, as we did not realise there was still a stigma surrounding this within medical settings.