

England Infected Blood Support Scheme (EIBSS)

Focus Group - Summary Minutes

Meeting type:

Meeting dates/time:

Location:

EIBSS Focus Groups

15 - 17 February 2023

Online – Microsoft Teams

Attendees from EIBSS NHSBSA:

Amy Turner (AT) – Assessor

Emma McCook (EM) – Assessor

Hollie Edminson (HE) – Service Delivery Manager

Mal Ross (MR) – Service Delivery Manager

Sarah Thornton (ST) – Team Manager

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 groups.</p>																						
2	Updates from EIBSS																						
	<p>MR gave an update on the EIBSS operational services.</p> <p>Current EIBSS scheme members:</p> <p>There are currently 3,471 EIBSS members as of 31st January 2023. This is a net growth of 271 from 1st April 2022. Below is the breakdown of the EIBSS scheme members:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr style="background-color: #0056b3; color: white;"> <th style="text-align: left;">Type</th> <th style="text-align: right;">Count</th> </tr> </thead> <tbody> <tr> <td>Hep. C Stage 1</td> <td style="text-align: right;">1308</td> </tr> <tr> <td>Hep. C Stage 2</td> <td style="text-align: right;">553</td> </tr> <tr> <td>Special Category Mechanism</td> <td style="text-align: right;">556</td> </tr> <tr> <td>HIV</td> <td style="text-align: right;">64</td> </tr> <tr> <td>Co-Infected (HIV and Stage 1)</td> <td style="text-align: right;">81</td> </tr> <tr> <td>Co-Infected (HIV and Stage 2)</td> <td style="text-align: right;">56</td> </tr> <tr> <td>Co-Infected (HIV and SCM)</td> <td style="text-align: right;">85</td> </tr> <tr> <td>Carers / Dependants</td> <td style="text-align: right;">82</td> </tr> <tr> <td>Widow widower civil partner</td> <td style="text-align: right;">686</td> </tr> <tr> <td>Totals</td> <td style="text-align: right;">3471</td> </tr> </tbody> </table>	Type	Count	Hep. C Stage 1	1308	Hep. C Stage 2	553	Special Category Mechanism	556	HIV	64	Co-Infected (HIV and Stage 1)	81	Co-Infected (HIV and Stage 2)	56	Co-Infected (HIV and SCM)	85	Carers / Dependants	82	Widow widower civil partner	686	Totals	3471
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Scheme Spend:

FY 2021/22 Total Spend

Non-Discretionary Payments - £73,201,232.90

Discretionary Payments - £4,086,071.01

Parity Payments - £98,421,808.09

Total - **£175,709,112**

FY 2022/23 Total Spend to Date

Non-Discretionary Payments - £76,657,270

Discretionary Payments - £1,112,209

Parity Payments - £14,058,710

Total - **£91,828,189**

Compensation Payments - £339,000,000

Overall Spend - **£430,828,189**

MR explained that there is no set agenda.

MR explained that there had been a lot of media interest around the Inquiry and Compensation payments, and as a result, the scheme has seen a substantial increase in the number of applications to join the scheme, both legitimate and illegitimate.

EIBSS beneficiaries were then invited to ask any questions.

3

Comments and Questions from EIBSS Beneficiaries

1. Beneficiary question: MR you have mentioned that you have received some illegitimate applications to the scheme. Can you confirm how many you've received?

EIBSS response: It is a small number, but we cannot give an exact figure. One of the recommendations made as part of the Compensation Report by Sir Robert Francis is to change the criteria for joining the scheme and to make it more relaxed, however this could see an increase in false applications therefore we need to ensure appropriate controls are in place.

2. Beneficiary question: Have any of those illegitimate applications been from people with Haemophilia?

EIBSS response: We are unable to provide an answer today but will check and provide a response as part of our minutes of the meeting.

Beneficiary comment: I would like to know how many declined applications have been from people with Haemophilia. You will get people trying to fraudulently apply and I agree that we need to be careful with these; however, the application process needs to be made as easy as possible for genuine applications.

EIBSS response: We do try to approve as many applications as possible and to raise awareness of the scheme, but there are a minority who will attempt to apply illegitimately. A concern for any scheme responsible for public funds, is the entitlement to those funds, so there has to be processes in place, but we are happy to improve processes where we can.

Answers provided as part of these minutes, but not available at the time of the meeting.

EIBSS update: Since 17th August 2023, the date of the Compensation announcement, we have received 235 new initial applications to join the scheme. 85 were declined due to no evidence of Hepatitis C / HIV infection or no contact with NHS blood / blood products. 13 (not part of the aforementioned 85) were declined from Haemophiliacs. In these cases, they were declined due to being unable to produce evidence of testing positive for chronic Hepatitis C / HIV.

Beneficiary comment: *There were people who gave evidence during the Inquiry who were disappointed that they could not gain access to the scheme due to their genotype. There were cases where people came from Africa or Afghanistan for example, who had prevalent genotypes in their country and could not prove that they had treatment in the UK therefore were unable to join the scheme. I believe that the infected blood community and EIBSS could lose public support if anybody and everybody could apply. There needs to be stringent methods put in place. I was disappointed to see some solicitors at the Inquiry working on behalf of infected people saying the peoples' words should be taken, which we don't agree with as people from wherever could just ask you to take their word for it.*

EIBSS response: We agree, and Compensation recommendation number 4 regarding changing the scheme entry criteria to accept a statement of fact would make it more difficult for us to ensure we are supporting the right people and protecting the funding for genuine beneficiaries.

3. Beneficiary question: I want to address the issue of natural clearers. People who have naturally cleared the virus are currently excluded from the scheme if they have not had the virus for six months or more. Are EIBSS keeping a record of people who have been declined because they naturally cleared the virus so if the scheme rules were to change, you can go back and approve applications where necessary?

EIBSS response: We do keep a log of declined applications and the reasons why they were declined, so yes, we can go back through and check those, should the scheme rules change.

Beneficiary comment: *It's difficult for infected people before PCR testing. There are lots of self-clearers who are not eligible, although their bodies were still violated. I've spoken to another beneficiary about the balance of probabilities. There are quite a few people in support groups who were self-clearers and even though they have antibodies in their system, medical records are disappearing, so they don't know where they'd stand.*

Beneficiary comment: *I'm aware of public legal action taken against the Skipton Fund which failed, but this links in to people who fall foul of the September 1991 settlement. I'm also aware that the legal action stayed recently until the inquiry concluded. I don't believe Sir Brian won't comment on these issues.*

4. Beneficiary question: There's one or two natural clearers in support groups that have been declined a few times by EIBSS, but now their applications have been accepted. Is this because EIBSS have relaxed their rules?

EIBSS response: No criteria has changed or relaxed. This may be because they have sent us further information, or they have successfully appealed the decision of their application. It's good that support groups exist to give each other information regarding what EIBSS need to see. Our medical assessors are consistent. Every medical application is assessed twice independently. If both assessors agree, then the application is approved or declined. If they are not in agreement, the application will be looked at by a third assessor and the majority decision is agreed.

Beneficiary comment: *Some people in the support groups have said that the whole process of applying to EIBSS is stressful, being declined then accepted, it's a real headache for some people. Doctors are not the easiest people to get appointments with. I've been very lucky as my case was straight forward. Communication from EIBSS could improve as the terminology used in the outcome letters can be hard to understand. We need more reassurance and clarity.*

EIBSS response: We can review outcome letters to make it clearer for applicants. For example, we could put 'Approved' or 'Declined' very clearly at the top of the letter, then outline the reasons for approval or decline which should make understanding the letter easier for everybody. **Action for ST & HE to review.**

Beneficiary comment: *It can be very stressful making an application and not knowing whether it will be accepted or not. I hope that the discretionary payment system will be scrapped. I hope that Sir Robert Francis' recommendation of uplifting the support payments is accepted as having to make repeat applications for things you need, for example dental costs, should not be necessary. It wouldn't be needed if regular payments were higher to cover all things needed.*

Beneficiary comment: *I do not apply for things like respite breaks as it's such a faffy process. I must have liver scans twice per year and constantly live with the worry that it could be cancer. I'd love to go away and have a break but cannot be bothered with the hassle of having to go to the doctors, etc, to get the form completed.*

Beneficiary comment: *That was the case with the alliance house schemes. The Macfarlane Trust paid the Winter Fuel Payment and respite payment (may have been called something else), which was also introduced to Caxton, so it has been in place in the past. Personally, I would like to see discretionary payments removed which would make EIBSS job easier. Uplifting support payments would mean that we can decide what to spend the money on, whether it be a respite break or dental for example.*

EIBSS response: This is something we can feed back to the Department of Health and Social Care. Uplifting support payments would be easier from an administration perspective than handling discretionary payment applications. One of Sir Robert's suggestions (2.53) was "A lump sum supplement should be added to all annual payments of, say £10,000, to cover other items such as increased insurance costs, additional transport costs and so on"

Based on current scheme numbers, this would increase the scheme spend by another £34m instead of the current £1.2m for discretionary payments, so this may be a factor if it is not accepted by DHSC.

Beneficiary comment: *We shouldn't have been infected in the first place. When talking in terms of money, you're making life feel worthless.*

EIBSS response: We apologise if that's how it came across, that's certainly not what was meant.

5. Beneficiary question: **It has been mentioned in previous focus groups about having somebody who works in policy at the Department of Health and Social Care in attendance at this focus group. Where are they?**

EIBSS response: We did discuss the attendance of a policy person from the Department of Health and Social Care; however, their attendance isn't required as MR works closely with them. We administer the scheme on their behalf and we feedback to them but they would not attend focus group meetings.

Beneficiary comment: *If we can go back to the overall spend increase with regards to discretionary payments, there's an argument to say that the uplift in support payments (if implemented) should be going to infected individuals only as they are*

the ones at risk of dying. The death toll is horrific, and you can see where people are dying in the figures, and this is the infected people not the affected. If there is an issue of cost, the payment should just go to infected people not affected. When we have meetings, we talk about infected and affected people as if they are one, but they are not and that needs to be recognised. Affected people are being paid more than infected people in some cases.

Beneficiary comment: Sir Brian has muddied the waters as EIBSS is supposed to be about supporting people living with infection, but he added in widows and affected people. By putting widows into the support scheme, they are receiving more money than they infected people when they have never lived with the virus.

6. Beneficiary question: In terms of support payments, why are the government supporting non-infected people more than infected people? This just doesn't make sense. The inquiry set up a group to come up with a set of principles to approach the cabinet office with. One of the principles suggested was that no infected individual should get less than an affected individual. Then they introduced the 75% model. Nothing was put to discussion; it was just implemented.

Beneficiary comment: As the death toll within the community impacts the infected beneficiaries far more than the affected registered with EIBSS, there is a concern that the infected will be marginalised. In fact, this already appears to be happening as the majority of the infected receive far less financial support from EIBSS than many non-infected spouses/partners. It is requested that this concern is taken back to DHSC for urgent review.

EIBSS response: We have previously held focus groups where we have been asked by beneficiaries what would happen to their widows if they passed away when they are used to a certain level of income and standard of living. That's some of the basis that those decisions have been made on so that standard of living is not compromised for widows.

Beneficiary comment: That argument could be used for an individual who has lost their job or cannot work anymore. It's completely wrong for affected people to be paid more than infected. We have not had the chance to debate anything in England at all.

EIBSS response: This was raised in the last focus group, and it was taken away and put to the DHSC. It was already an established principle in Scotland and Ireland, so based on the research done it was introduced to England as part of the Parity announcement, and once the 75% was reached those payments would continue for an indefinite period, but not stopped after 3 years as per previous Wales scheme rules.

7. Beneficiary question: Do they have Special Category Mechanism in Scotland, or does everybody with Hepatitis C get the same amount of money?

Beneficiary comment: They don't specifically have Special Category Mechanism, but they do take the word of the individual as to how ill they are.

Beneficiary comment: If everybody with Hepatitis C got the same amount of money, the issue with widows would be a non-issue as affected people wouldn't be paid more than infected people. I've applied for Special Category Mechanism, but because I live in Spain now speaking to the doctors and trying to get them to understand and sign the forms is difficult. We can resolve this issue without going back to the Department of Health and Social Care as it's not policy.

EIBSS response: This is policy. Special Category Mechanism was introduced in 2018 following the establishment of EIBSS. You are suggesting a change to policy. Scotland has a severity rating, which may be where Sir Brian's and Sir Robert's recommendation came from regarding changing the entrance criteria.

8. Beneficiary question: I've seen an exchange of emails between EIBSS and a HIV beneficiary who was looking to access the funeral prepayment plan grant. They were told they were not eligible. Why can Hepatitis C Stage 2 beneficiaries claim the funeral prepayment plan, but not HIV beneficiaries? The NHSBSA recognise HIV as a manageable condition, but Stage 2 as a terminal condition.

EIBSS response: The funeral prepayment plan is for Hepatitis C Stage 2 beneficiaries, as well as any beneficiary who has been given a terminal diagnosis, regarding of infection type.

Beneficiary comment: *The people dying in the largest numbers are the Stage 2 infected people. However, they are being paid less than a co-infected widow. This is a nonsense and needs to be addressed. Please take this back to the Department of Health and Social Care. Beneficiaries think it's disgusting and needs to change moving forward.*

EIBSS response: Department of Health and Social Care's position remains unchanged regarding any changes to the scheme whilst they await the final recommendations from the Inquiry.

Beneficiary comment: *We would like to see the scheme continue and for payments to be guaranteed for life.*

EIBSS response: We would like to see the scheme continue too. We know that we have a lot of vulnerable people on the scheme, and we want to protect those people and help them with ongoing support, including financial.

Beneficiary comment: *There are a lot of vulnerable people who have been taken advantage of. Imagine giving somebody thousands of pounds, people will be taken advantage of and stripped of that money. The advantage of regular payments is that they are paid overtime, which provides more security.*

Beneficiary Question: With regards to vulnerable people, can we go back to discretionary payments. I don't have a problem with discretionary payments, I apply for anything I'm eligible for and don't have a problem doing so, but I can see why people do. We accept that there are vulnerable people on the scheme and people who struggle with managing money. EIBSS don't offer support with completing discretionary applications. Could EIBSS provide a service whereby better support is provided for people completing applications?

EIBSS response: The team are always more than willing and happy to help beneficiaries with completing any application. They can go through the forms step by step with people, explain how to complete them and what they need to do next.

Beneficiary comment: *It's frustrating asking for a respite break as you must get your GP to complete a section. Not everybody has a helpful GP, then you must go through everything all over again. Every other discretionary application just needs quotes. I can't understand why it's needed for Stage 2 beneficiaries to get a break. Some doctors won't complete the form at all, and it can take three weeks just to see a doctor.*

Beneficiary comment: *Time is precious for people with terminal conditions spending time and effort going through these processes, which is why I'd like to see the discretionary payments system scrapped. I do have more questions but may not have time to ask them.*

EIBSS response: Please email us with any questions and we can include them in the minutes.

9. Beneficiary question: Are the focus group minutes published on the website?

EIBSS response: Yes. The minutes from the last two focus groups are also available on the website.

Beneficiary comment: *There was an issue with how long it took to receive the minutes from the focus group pre-covid.*

EIBSS response: We do apologise for this; we did have previous staffing issues. We will aim to publish the minutes from this meeting by the end of February, depending on workload.

Beneficiary comment: *With regards to the minutes, we should have gone through the minutes from the previous meeting and reviewed what has been followed up in terms of accountability.*

10. Beneficiary question: People are finding it's taking longer to have discretionary applications assessed. It used to be a relatively straight forward process with a decision made usually within one week. Why are they being pushed to the 30-working day limit now?

EIBSS response: This is due to the high volume of applications we are receiving. As we touched on earlier, when the interim payment announcement was made, we were put into a backlog. The standard service level agreement is 30 working days, but we do try to process them as quickly as possible. We have previously asked beneficiaries which discretionary applications they would like to see prioritised (if any), however it was decided to leave this alone and continue with processing in date order after receiving further feedback. We are currently working on emails received the same day and around two days on post.

11. Beneficiary question: How many staff are currently working for EIBSS?

EIBSS response: Within our Beneficiary facing team, there are eight assessors, one Team Manager, one Service Delivery Manager, and one Senior Service Delivery Manager.

12. Beneficiary question: Do the assessors make the final decision on applications?

EIBSS response: The assessors are responsible for assessing discretionary applications based on criteria that must be met. Medical applications are not assessed by EIBSS assessors, they are independently assessed by medical professionals.

13. Beneficiary question: How many staff specifically work on discretionary applications?

EIBSS response: The team are all multi-skilled and therefore work on a variety of things, such as post, emails and processing.

14. Beneficiary question: Do the staff work on anything other than EIBSS?

EIBSS response: No, they don't work on anything other than EIBSS.

15. Beneficiary question: And do they work from home or in the office?

EIBSS response: We operate a hybrid model so they can work from home or in the office, but the team mostly work from home.

16. Beneficiary question: Do you find they encounter any problems working from home?

EIBSS response: No, we actually find that the team are more productive when working from home as there are fewer distractions.

17. Beneficiary question: In a previous focus group meeting, EIBSS talked about how workloads were likely to increase, and MR agreed that staffing levels should increase. Have they increased?

EIBSS response: Yes. We used to have six assessors, but we now have eight. We have gained two full-time equivalents who work 37.5 hours per week each.

18. Beneficiary question: Will you be looking for more staff?

EIBSS response: When we know what the future looks like following the final Inquiry and Compensation recommendations, we will be able to review staffing levels.

19. Beneficiary question: Do EIBSS publish their running costs?

EIBSS response: We don't publish running costs for EIBSS specifically. Overheads are looked at by the NHSBSA as a whole, but nothing EIBSS specific.

Beneficiary comment: *The cost of managing the running of the scheme would be interesting to know. It would be interesting to see if this would exceed the cost of the support payments uplift.*

20. Beneficiary question: It has been mentioned that other family members may be allowed to join the scheme, such as parents, siblings, etc. Personally, I can't see that happening but have EIBSS had any discussions with the Department of Health and Social Care around this?

EIBSS response: It is something we have raised in previous meetings as we have also been watching the inquiry. We believe the scope of the scheme will change. We are currently waiting for the final recommendations to be published before we can look at how the scheme will be structured. One of the recommendations is that there should be an independent Arm's Length Body administering the compensation payments.

Beneficiary comment: *We have an issue with this as we had that with alliance house, but whenever we raised an issue with alliance house they passed it back to the government, but government then passed it back to alliance house, so it was back and forth.*

EIBSS response: When we made the interim compensation payments, we did our best to make it the best process possible, and payments to be made as quickly as possible. There will be a lot to consider in setting up an independent Arm's Length Body.

Beneficiary comment: *If the scheme does change and there is potential for other affected individuals to join the scheme, although I can't see it, one concern we have is that the voice of the infected people could be seriously impacted by the affected people. It's a huge worry because we are so different, and you can't compare the two. There have been calls for having separate organisations for the infected and affected. The death toll is horrific and as time goes on, the number of infected people will decrease, and it could mean that the voice of the infected people would be drowned out by the affected people in meetings like this.*

Beneficiary comment: *This has already happened to me on a tainted blood Facebook page. I used to regularly interact on this, however since the interim payment announcement affected people are beginning to silence the voice of the Haemophilia society. So, this has already happened.*

EIBSS response: We have seen an impact in increased correspondence and contact. Some families have been advised to contact EIBSS and try to register on the scheme just in case they can get compensation in the future. The EIBSS team are having to triage what is relevant to the infected community vs people just trying to register who are currently

outside of the scheme criteria.

Beneficiary comment: *I would like to see separation of the infected and affected people. I don't like saying it because we're talking about division, but if other family members were to be included our voices would be lost.*

Beneficiary comment: *There is the potential to have at least four or five affected people to one infected person and we would definitely be drowned out by the numbers.*

Beneficiary comment: *Infected people suffer with things like brain fog and fatigue, therefore are not going to have the capacity to fight their corner over time as opposed to the affected people who would have the motivation to fight their corner.*

EIBSS response: We do understand where you're coming from, but we do welcome everybody. We could possibly talk about how we could manage the division internally.

Beneficiary comment: *It could be managed by 2 separate schemes. If the support scheme supported infected people only, then a compensation scheme could be set up for infected and affected people. I still cannot understand why regular support payments were introduced for affected people.*

EIBSS response: This was the voice of the community requesting payments to be introduced for affected partners.

Beneficiary comment: *If widows are going to be paid, I don't necessarily disagree with that. But if I die, there's potential for my widow to be paid less favourably than other widows. Something needs to change regarding this. It's regularly discussed in support groups.*

21. Beneficiary question: *If I die my partner will get some of my pension, but it's 50% not 75% - So why should widows get 75%?*

Beneficiary comment: *It's not a pension, nor is it looked at as a pension. Most widows would get a pension anyways. You could argue that they are getting 2 pensions essentially.*

22. Beneficiary question: *We know that EIBSS payments are not affected by income tax, but if the money from EIBSS is put into a separate account and interest is made off the money, is the interest taxable?*

EIBSS response: It would depend on where the money is invested, but we are not financial advisors therefore not best suited to offer advice around this. We believe any income earned from investing EIBSS money would be taxable, but not the payment from EIBSS itself. We understand that people will want the money to work the best for them, but it's always best to seek advice on money being invested. There is information on our website regarding legislations on tax disregards and EIBSS payments. However, we will also refer this question to Department of Health & Social Care for confirmation with cross Government bodies.

Beneficiary comment: *We need financial advisors to help us with stuff like this.*

Beneficiary comment: *My financial advisor told me that it's tax free at source, but whatever you do with the money would be taxable.*

EIBSS response: There is information on our website about financial advisors, however we can't specifically recommend financial advisors.

Beneficiary comment: *Financial advisors can cost a lot of money, whereas EIBSS currently pay for benefits advisors. It's something we have asked for in the final*

submission.

23. Beneficiary question: Will our regular monthly payment increase in April?

EIBSS response: We are unable to confirm at this stage. Previously, payments have increased in April based on the previous September's CPI rate. In November, we forwarded the proposed CPI increases to the DHSC for consideration.

We are simply awaiting confirmation so we can send payment schedules out ahead of the new financial year.

Beneficiary comment: *My financial advisor has nobody to talk to about EIBSS money as he doesn't know any other financial advisors dealing with somebody whose income is increasing.*

24. EIBSS question: Is your financial advisor a family member or are they a professional financial advisor?

Beneficiary response: They are a professional financial advisor.

EIBSS response: Your financial advisor should consider getting in touch with the Infected Blood Inquiry directly as they may be able to put them in touch with other financial advisors dealing with a similar matter. The inquiry should still have an administrator even though they have concluded.

Beneficiary comment: *We as a community don't get to see the pressures faced by EIBSS in terms of trying to get answer from the Department of Health and Social Care and the issues faced by staff, so I just want to say that I appreciate everything you do for us. Your hard work does not go unnoticed. Please pass this feedback to the rest of the team.*

25. Beneficiary question: When will the next focus group be held?

EIBSS response: We are looking at holding a focus group in May, with the possibility of this being face to face. We will try and work out the logistics to see if it's possible to arrange a face-to-face meeting and reach out to beneficiaries to see what would work for people.

Beneficiary comment: *It would be good to have two per year, potentially one in London and one in Newcastle which would spread it out.*

EIBSS response: The feedback received from beneficiaries is that it was easier to commute on the one train line which covers Newcastle and London. We can have a look at the logistics of this.

26. Beneficiary question: Is the interest generated from the regular EIBSS payments, including all lump sum payments, taken into account for Income Tax purposes and does all this have to be declared if someone fills out a self-assessment tax return.

EIBSS response: As per Q22, we will also refer this question to DHSC for confirmation with cross Government bodies.

27. Beneficiary question: The income thresholds for child payments haven't moved since inception. With inflation running at 10% can this matter be referred back to DHSC with a request for an uplift in threshold income levels, possible with EIBSS being brought in line with WIBSS.

EIBSS response: This was referred to DHSC, and they confirmed their position remains unchanged regarding any changes to Child Payments whilst they await the final recommendations from the Inquiry.

28. Beneficiary question: Have you had any discussions/communications with/from DHSC regarding the eligibility criteria including the Hepatitis C cut off dates, Hepatitis B, bereaved/non-bereaved but affected parents/children etc.

EIBSS response: No specific discussions, however, we are aware of ongoing legal cases regarding the cut off dates. Regarding any other changes to the scheme, DHSC confirmed their position remains unchanged regarding any possible changes to the scheme criteria whilst they await the final recommendations from the Inquiry.

29. Beneficiary question: Do EIBSS realise the stress caused to beneficiaries when applying for grants and change of condition uplifts, including applying for SCM or stage 2? Each application effectively re-traumatizes the beneficiary as they often waiting many weeks/months for an outcome. These applications seem to be taking longer. If EIBSS were able to apply the recommendation of Sir Robert Francis KC that support payments should be increased by 10k per annum, with the removal of begging bowl grant system, this would have the positive effects of stopping beneficiaries being re-traumatized by having to make grant applications and it would cut down the workload of EIBSS staff, leaving more time to concentrate on important issues.

EIBSS Response: This was raised in our last focus group. 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. At present, DHSC will be making no changes to the scheme until all recommendations from the Infected Blood Inquiry have been considered.

30. Beneficiary question: Currently payments are made from the date of an approved application. (*minutes Aug 2022, item 17*). This is consistent with other devolved Administration infected blood schemes.

If the infection date is irrefutable, regardless of what current guidelines are, it is morally the right approach to pay compensation from the date of infection. Consistency with other administrations does not make the current guidelines unquestionably right.

EIBSS response: As confirmed in the minutes quoted, this question was previously referred to DHSC, and the 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 of an application. This decision is also consistent with the other Devolved Administration infected blood support schemes which were established to pay ex-gratia payments from date of application being approved. DHSC have confirmed their position remains unchanged and are awaiting the final recommendations by the Infected Blood Inquiry before considering any changes to the scheme.

Beneficiary response: It is morally wrong to not pay with effect from an irrefutable infection date. The date of application very much depends on the point in time when the infected person is advised of the scheme's existence (possibly by a medical professional) and that they may wish to consider applying. That is grossly unfair to the infected person as it could be multiple years lost before the awareness of scheme is apparent.

EIBSS response: This is something that has been raised in a previous focus group and has already been raised to DHSC, they have advised that they will not make any changes to the scheme whilst awaiting the final recommendations by the Infected Blood Inquiry.

31. Beneficiary question: Are lump sum or regular payments from the scheme subject to tax. I have invested a lump sum from the 100k interim payment for future financial security and (surprisingly) expect the interest received to exceed the annual Personal Savings Allowance currently being basic rate tax for £1,000 or over. All infected beneficiaries should be given tax-free status for savings.

EIBSS response: EIBSS payments are discounted for tax and state benefit purposes. The relevant regulations are the:

- Infected Blood Schemes (Application of Sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005) Order 2017
- Social Security (Infected Blood and Thalidomide) Regulations 2017
- The Care and Support (Charging and Assessment of Resources) Regulations 2014 make provisions for payments to be disregarded under the Income Support (General) Regulations 1987
- The Social Security (Infected Blood and Thalidomide) Regulations 2017 amended the Income Support Regulations to include an 'approved blood scheme'. This means "a scheme established or approved by the Secretary of State, or trust established with funds provided by the Secretary of State, for the purpose of providing compensation in respect of a person having been infected from contaminated blood products", this includes EIBSS.

EIBSS payments should also be disregarded by local authorities in making assessments for social care. However, any income received as a result of investment may be subject to Tax and should be discussed with a financial advisor, this should also be declared on any Tax returns.

32. Beneficiary question: The narrative to be made clearer please. It states it is a one-off winter fuel payment without reference to it reoccurring annually. Please make it clear the payment is made annually when included within the scheduled payments.

EIBSS response: A payment schedule is sent out annually ahead of the new financial year, confirming the years payment rates, and also states the Winter Fuel Payment separately. This is already confirmed on an annual basis.

Beneficiary response: Please read the site information, it is not clear for a new visitor, the wording needs improving please, that is all. Extract below. "A one-off winter fuel payment" would be better read as "A one-off annual winter fuel payment"

EIBSS response: We will amend wording to make it clear it is an annual payment.

33. Beneficiary question: I personally paid £140 per 45-minute session for bereavement counselling. My local (East Midlands) investigations showed that to be an average rate. The £900 per rolling 12 month is based on £70 per session, can these EIBSS values be revisited please?

EIBSS response: EIBSS does have some discretion regarding the on-going need for counselling payments however, EIBSS would require confirmation from the Counsellor that the proposed treatment is appropriate, and the number of sessions required to determine if this can be authorised.

This request was also referred to DHSC following a previous Focus Group and DHSC confirmed "We are working with the EIBSS team and NHS England and Improvement to consider how the current psychological support offer could be improved."

In the meantime, beneficiaries with greater need should contact EIBSS to apply for discretion to be applied in their case." Therefore, EIBSS can apply discretion if additional sessions are required.

Beneficiary response: Good to see there is some flexibility.

34. Beneficiary question: EIBSS (Dec 2021 minutes item 12) "Hepatitis C has been known to cause oral health issues and thus was included within the scheme

specification, as the scheme provides discretionary support to cover costs that have been brought about as a result of infection or its treatment and are otherwise unable to be met. These issues are most likely to be linked to cirrhosis, so should be considered as part of monitoring.”

If HCV is linked to oral issues, all dental fees of HCV infected claimants should be reclaimable (or considered as ‘exempt’) as long as reasonable evidence is provided (excluding purely cosmetic), but aesthetics should be allowed (e.g. if a visible tooth removal within the smile requires a bridge or implant).

EIBSS response: The answer quoted above, was in response to a question previously raised “Is there a specific reason beneficiaries receive support for dental treatment? Are we at increased risk of dental problems, and does this need to be monitored?”

A discretionary payment of up to a band three NHS dental treatment charge is available per annum for an infected beneficiary where the dental treatment is deemed necessary following a check-up.

A discretionary payment is not available for the cost of an NHS dental check-up or for a private dental check-up, as this is a standard treatment for every member of the public. A beneficiary can attend a private dental clinic for treatment, however only up to the maximum NHS band three dental charge can be claimed. A full breakdown of what is included in each NHS band of treatment is included here : <https://www.nhs.uk/nhs-services/dentists/dental-costs/what-is-included-in-each-nhs-dental-band-charge/>

As not all oral issues are directly caused by HCV, the NHS Band 3 treatment covers all clinical requirements as stipulated.

Cosmetic treatments are not covered however, a bridge for example would be covered under NHS band three treatment as shown in the link above.

Unfortunately, DHSC will not make any changes to the scheme whilst awaiting the final recommendations by the Infected Blood Inquiry.

35. Beneficiary question: It is now recognised other fatal organ failures or causes of death are a direct result of HCV, and has been stated as such on death certificates citing cause of death was as a result of being infected with Hep C. Therefore, it may not be a stage 2 diagnosis that is the resulting final scenario for infected recipients who die. The funeral plan payment should be open to all infected recipients as a one off, along with the ability to claim reimbursement by providing an official receipt or certificate if one has already been purchased.

EIBSS response: A discretionary funeral grant payment of up to £4,500 is available to the person arranging a funeral, when a registered infected beneficiary has passed away, and is available to all registered infected beneficiaries regardless of infection type. A discretionary pre-payment funeral plan of up to £4,500 is available to those infected beneficiaries who have been confirmed with a stage 2 diagnosis, however, EIBSS can apply discretion to other registered infected beneficiaries who have received a terminal diagnosis.

All infected beneficiaries can receive the funeral grant payment of up to £4,500 regardless of infection type or cause of death. If an infected beneficiary receives a terminal diagnosis (not necessarily HCV related), a pre-payment funeral plan can be considered by EIBSS. I will be updating the website to clarify that our funeral pre-payment plan is not exclusively for HCV stage 2 beneficiaries.

36. Beneficiary question: Regarding respite breaks, these should be extended to cover the primary carer to take a separate break in their own right. Primary carers may be in desperate need of respite.

EIBSS response: The respite break is for an infected beneficiary registered with EIBSS,

following a period of ill-health as a direct result of the HIV and/or hepatitis C infection or its treatment and must be recommended by a medical professional. A discretionary payment of £750 is available towards the cost of a respite break on a rolling 12-month basis for the infected beneficiary and also their carer, if required.

Beneficiary response: Ok, thank you.

37. Beneficiary question: If an applicant didn't get receive treatment blood products prior to September 1991, how can they put in a claim?

EIBSS response: They will likely be declined if they apply as a primary beneficiary where there is no evidence received to show they had received blood, blood products or tissue prior to September 1991. The reason is due to the screening, I believe heat treatment was also fully introduced by September 1991 which is why the cut-off date has been set by the DHSC. Please note that an applicant could apply to NHS Resolutions, if they believe they were infected after September 1991.

38. Beneficiary question: How many people on this call are registered EIBSS beneficiaries?

EIBSS response: There are three. On the call we also have myself (MR) and I am a Service Delivery Manager. HE, also a Service Delivery Manager, ST, the EIBSS team manager, and EM, an EIBSS assessor who is taking notes.

39. Beneficiary comment: I am unsure if this is the appropriate forum for this, however, I have an interest in meeting and supporting others whose lives have been impacted by hepatitis C, in particular the impact of treatment for the infection.

There is a general discussion amongst the attending beneficiaries surrounding difficulty with diagnosis, the treatment options previously offered, those currently available and the impact these treatments have on mental health, physical health, employment, and personal relationships. No questions were directed to EIBSS during this time.

Beneficiary comment: There has been a lack of awareness and signposting of EIBSS/the Skipton fund from medical professionals.

Beneficiary comment: My GP was absolutely clueless. It wasn't until donating that it was discovered. A consultant advised that there was a hepatitis C infection with a prognosis of 10 years max. But the 'good news' was to contact the Skipton Fund.

Beneficiary comment: Yes. You are relying on the people who are aware of the schemes to sign post to the support available.

Beneficiary comment: Contaminated Whole Blood UK is a support group for those affected. You may be interested in joining such a group.

EIBSS response: Many good points raised, and we will try to address them all. Media response to the ongoing inquiry and recent government interim announcement has raised awareness of the scheme. Various Facebook support groups and campaigns exist and are external to EIBSS. However, we cannot be involved in any of the Facebook groups and must remain impartial.

Previously focus groups were done based on locality and took place in London, but since Covid it was decided to continue them digitally. HE and ST are looking to increase the frequency to possibly quarterly focus groups – 3 digitally, and 1 in person meeting across the year, and options are being considered.

We are also discussing with an internal team who work with a network of different trusts

across the country to see if there are any gaps or spots where communities may not have heard of EIBSS, and we'll be encouraging those to go for blood tests and then to apply where it's appropriate.

We want to avoid flooding the call centre with those who are simply nervous about treatment with NHS blood products, however an increase in applications is welcome, where appropriate, and we need to ensure we can provide support to those who are entitled to it.

40. Beneficiary Question: Is there any work being done in the background at the moment to prepare and work towards these possible recommendations in the Sir Robert Francis report, specifically in terms of compensation payments?

EIBSS Response: There has been no direction received from DHSC to do so. There are internal conversations that are happening around the report and how this could impact EIBSS in the future. This includes conversations surrounding the workload and people resources that would be necessary to administrate any future announcements on compensation.

41. Beneficiary Question: I helped London School of Economics and Political Science to do a report on the psychological services provided by EIBSS. Aside from that research, are there any conversations surrounding that?

EIBSS response: Was this following the EIBSS survey that was sent out in December 2022?

Beneficiary response: No, through the haemophilia society.

EIBSS response: We have done something similar with the Policy Innovation and Evaluation Research Unit (PIRU) team based at the London School of Hygiene and Tropical Medicine (LSHTM) and the London School of Economics and Political Science. They are undertaking research regarding the need for psychological support services for people who have received infected blood or infected blood products (or for their family members).

Beneficiary comment: *As a therapeutic counsellor I'd love to do something now to help others – particularly those going through treatment and for me it has many implications including lack of fertility in women.*

EIBSS response: It sounds like it would be good for you to join one of the support groups to share your experiences.

42. Beneficiary question: We are wondering when the payment schedule for this year will come out. What percentage will the uplift be?

EIBSS response: Great question. Usually, we send the payment schedule letter out in February. As of today, we have not had the rates confirmed by DHSC yet.

Previously, rates have increased based on the previous September CPI rate, and therefore 10.1% uplift is planned to be applied, however nothing has been confirmed by DHSC.

The slight delay this year is due to DHSC having to agree the rate with all Devolved Administrations, to maintain parity of payments.

We are optimistic that the new rates and payment schedules will be sent out before April.

Child payment recipients will also be receiving a letter about submitting a new application at this time of year to avoid any gap in receiving their payments.

43. Beneficiary Question: Welsh people have had a lot less than us year on year. Will the Welsh be treated equal in respect of these increases?

EIBSS response: We wouldn't be able to comment on the Welsh scheme unfortunately.

44. Beneficiary Question: I wonder what made them change, for the cirrhotic people to receive an uplift.

EIBSS response: Scotland made lump sum payments the other way round to EIBSS where they gave more money upfront for hepatitis C stage 1 to help in advance of any deterioration. A very small percentage of people do advance to stage 2 and when they then receive the £20,000 lump sum payment and an increase to monthly payments.

45. Beneficiary question: I understand from following the infected blood inquiry that there will be a base level of compensation and depending on circumstances, some people may receive an uplift. Will the Sir Brian Langstaff report this coming easter suggest a top-up of the £100,000 interim compensation payment to a 'foundation level' of what everyone might receive?

EIBSS response: Sir Robert Francis made 19 recommendations in total, with many different layers to the compensation. Sir Brian Longstaff has confirmed another interim report before Easter, which may change the scope to include parents who lost children and children who have lost their parents. Until he makes the next announcement, we will not know what is being proposed.

Beneficiary comment: *I felt guilty at the thought of receiving the £100,000. Many of us didn't want to disclose it with family and friends, I feel sort of embarrassed about it all.*

Beneficiary comment: *That is not something we should have to worry about. People have lost careers, friendships, their whole families, parents have lost their children. I don't feel one bit guilty about receiving it.*

EIBSS response: I am a mother, and yeah, I could never put a price on the life of a child. It's unimaginable. How can we compensate for such a thing? It's a hard one for a lot of people involved, including the government, to work out.

Beneficiary comment: *With a government organisation the only way we can get reparations is through financial means. I have also been in a situation where I told a friend about support, I receive through EIBSS and they brought up how I must have had the £100,000 announced in the news. I haven't heard from her since.*

Beneficiary comment: *It is quite embarrassing. Suddenly people were asking me. I wasn't comfortable being asked about that, and what I was going to do with it. It's already bad enough with the stigma attached and it feels all very distasteful. It is not something easy to share with someone. It's very discomforting.*

EIBSS response: It is understandable. A lot of people can also be vulnerable, and we have a duty of care to protect them especially with regards to their financial support received through EIBSS. We signpost where we can to the financial support services available through EIBSS and other services that may help an individual's situation – the hepatitis C trust, Citizen's advice, and Shelter amongst others.

Beneficiary comment: *It feels like blood money.*

EIBSS response: We hear many different stories of how beneficiaries will be spending their interim compensations payments - families setting it aside and saving it for later years or generations. I just hope that most people do get the opportunity to use it themselves.

Beneficiary comment: *I belong to several support groups for tainted blood. One person has been using these forums as a place to send begging letters. Just to make*

you aware of this happening.

EIBSS Response: It has been mentioned in other focus groups that have been some comments made in online support groups that were vulgar in terms of spending the money, this is insensitive towards other people's situations.

46. Beneficiary question: What happened to Jamie? (Referring to James Byers, previous EIBSS manager).

EIBSS response: He has a different role in a different department, but still working within the NHSBSA. We will pass on your well wishes.

47. Beneficiary question: Has anyone else here (EIBSS Staff) ever been personally impacted by contaminated blood?

EIBSS response: No, not to our knowledge.

EIBSS comment: Not personally no. However, people's stories and experiences do stay with you, including those shared in focus groups. You have to keep on your professional hat, but head and heart do play quite a role in it.

Beneficiary comment: *The infected blood inquiry recently invited those impacted people to attend and there was not a dry eye. I don't know how you can come away from that without taking on a little bit of that trauma.*

EIBSS response: It's the human side of it. We can provide a human voice to policy makers through these groups. We don't dilute feedback and we do pass it on. It is emotional and heart breaking. This scheme is the only one who holds regular focus groups within the NHSBSA with its users. We want to reach and speak with you all to make sure everything is alright. We launched a newsletter a little while back, in September 2020, but unfortunately it had a mixed response with negative comments from beneficiaries not wishing to receive it. But these groups are brilliant to meet everyone, and to hear about what you would like to see from the scheme.

Beneficiary comment: *It is great to meet others. I have never met another infected or affected person until now.*

Beneficiary comment: *I recall feeling so isolated. It was only when the infected blood inquiry started, and then I joined Facebook support groups. The government before was divide and conquer.*

48. Beneficiary question: Are there any burning issues, or questions you have for us?

EIBSS response: Not really. The first thing we reviewed was scheme information and we spent a lot of time understanding people's journeys and the reason for EIBSS, and the reason why we are here. We meet many lovely, varied personalities in the focus groups. One of the reasons we did the satisfaction surveys in December last year was to try and reach everyone to get a balanced perspective - including those who cannot attend the focus groups.

Beneficiary comment: *I don't recall having one?*

EIBSS response: We sent it to all of our scheme members by their contact preference choice, and there was a 56% response rate. 92% of which said they were 7/8/9/10 out of 10 satisfied or completely satisfied. 8% scored between 1 - 6, so we will be reviewing all of the comments and responses.

49. EIBSS question: Is there anything we don't do that you'd like us to do?

Beneficiary response: ST answered most questions already sent in early by email. But the more I learn the more questions I do have. It's like treading water waiting for inquiry coming

out. I've written to the government before about policies. Same replies saying no changes while the infected blood inquiry ongoing. The same issues were sent to the Infected blood inquiry direct.

EIBSS response: Unfortunately, we are in limbo waiting for Sir Brian's recommendations to come out. The community itself are mixed with the outcomes they want too. Some want a one-off final payment and then to be done. Other beneficiaries want the regular support to continue from EIBSS. Sir Brian may recommend ending the support schemes - we just do not know at this stage and have had no indications either way.

50. Beneficiary question: It very much depends on the individual and their financial situation. Others have wondered if a financial advisor will be provided. I do understand it is hard to say what someone should do with their finances.

EIBSS response: On the website we do signpost to financial support, but we cannot recommend and do not employ anyone. It would be the individual's choice. We do have two benefits advisers and EIBSS does currently fund their consultancy. Beneficiary applications such as PIP or ESA applications could be supported with, but we cannot provide support for the likes of mortgage applications or investment advice.

51. Beneficiary question: A letter confirming that the payments are for life could be introduced?

EIBSS response: EIBSS cannot confirm that payments will continue for life. Matt Hancock, before he left his role as Secretary of State of Health and Social Care, has previously provided reassurance that the Government is committed to continue the support to the infected blood community for as long as is required.

52. Beneficiary question: Are you saying no one should take for granted those payments?

EIBSS response: We cannot formally confirm in writing that they are for life. EIBSS is currently an ex-gratia scheme, Sir Brian might recommend a regular payment and compensation payment scheme with formal legislation in place. You cannot promise something that a future government may choose not to honour.

53. Beneficiary question: How could it be considered parity if Scotland sent out letter saying payments for life?

EIBSS response: We are unable to comment on the Scottish Government and their Scheme funding.

Beneficiary comment: This tory government might decide to cancel it all.

EIBSS response: I can't imagine this or a future Government cancelling the scheme.

Beneficiary comment: My gut feeling is that you are right but having it in writing would be so reassuring.

EIBSS response: Payments should be for as long as they are required. We want to support people, but we can only administer the scheme as directed.

Beneficiary comment: I understand. You are given a set of rules and are tasked with administrating it. It's the policy makers I need to target.

54. Beneficiary Question: Will the next focus groups be face to face?

EIBSS response: Possibly for a face to face - We would like to make it as accessible for as many people who want to attend as possible.

Beneficiary comment: It would be a lot easier if they hadn't scrapped the HS2.

No further questions or comments were raised for EIBSS, so everyone was thanked for attending, and the attendees said their goodbyes.

All focus group questions and answers will be collated and shared with DHSC, Beneficiaries and added to the EIBSS website.

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