

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

Meeting Type:
Meeting Dates:
Location: Online:

EIBSS Focus Groups
21-22 June 2023
Microsoft Teams

Attendees from EIBSS NHSBSA:

Amy Turner (AT) – 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 3,570 EIBSS members as of 20th June 2023. This is a net growth of 370 from 1st April 2022. Below is the breakdown of the EIBSS scheme members:</p> <div style="text-align: center;"> <p>Active Beneficiary Count</p> <table border="1"> <thead> <tr> <th>Category</th> <th>Count</th> </tr> </thead> <tbody> <tr> <td>Hep C Stage 1</td> <td>1353</td> </tr> <tr> <td>Hep C Stage 2</td> <td>556</td> </tr> <tr> <td>SCM</td> <td>554</td> </tr> <tr> <td>HIV</td> <td>65</td> </tr> <tr> <td>Hep C Stage 1+HIV</td> <td>81</td> </tr> <tr> <td>Hep C Stage 2+HIV</td> <td>56</td> </tr> <tr> <td>SCM+HIV</td> <td>85</td> </tr> <tr> <td>Carers & Dependants</td> <td>93</td> </tr> <tr> <td>Bereaved - Not Infected</td> <td>727</td> </tr> </tbody> </table> </div>	Category	Count	Hep C Stage 1	1353	Hep C Stage 2	556	SCM	554	HIV	65	Hep C Stage 1+HIV	81	Hep C Stage 2+HIV	56	SCM+HIV	85	Carers & Dependants	93	Bereaved - Not Infected	727
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	<p>Scheme Spend:</p> <p>FY 2022/23 Total Spend</p> <p>Non-Discretionary Payments - £89,387,733.00 Discretionary Payments - £1,451,497.00 Parity Payments - £17,377,942.00</p> <p>Total - £108,217,171.00</p> <p>Compensation Payments - £346,000,000.00</p> <p>Overall Spend - £454,217,172.00</p> <p>FY 2023/24 Total Spend to Date</p> <p>Non-Discretionary Payments - £17,098,204.00 Discretionary Payments - £232,572.00 Parity Payments - £3,632,330.00</p> <p>Total - £20,963,106.00</p> <p>Compensation Payments - £4,500,000.00</p> <p>Overall Spend - £25,463,106.00</p> <p>MR explained that there is no set agenda for the meeting.</p> <p>EIBSS beneficiaries were then invited to ask any questions.</p>
3	Comments and Questions from EIBSS Beneficiaries
	<p>1. Beneficiary Question – <i>Would it be possible to be sent the figures and statistics ahead of the focus group meetings? I always find the numbers very interesting, however whilst I can sit and listen to them, I can't actually process them in the short time they are covered in the meeting. However, if I have them beforehand, I can read them and understand them.</i></p> <p>EIBSS Response – It is possible. We have had some feedback that people didn't want to hear the figures during focus groups, as they feel the media attention that's come with the Interim Payment has not always been positive.</p> <p>Beneficiary Comment – <i>I think it's useful to know how many beneficiaries you've got, the growth in size of the numbers and how this compares to the number of staff that you've got. It would be good to know if your team is growing comparative to the amount of people joining the scheme and whether you have enough resource to manage discretionary payments for the infected when all of the affected are going to be coming on board.</i></p> <p>EIBSS Response – Going forward, when we send out the invites, we can certainly make the numbers available, but they are always included in the minutes too.</p>

Beneficiary Comment – *You do publish your spend in your annual report anyway, so people will see the numbers, regardless of whether they want it covered in the meetings or not.*

2. Beneficiary Question – *I would be interested to know how many applications EIBSS have had from people with Haemophilia i.e. how many have been successful, how many are still pending and how many have been declined. Are these figures that you can provide?*

EIBSS Response – Unfortunately, we don't record Haemophilia status. We don't have a need to record the status of infected people, as all that we need to know is how you were infected then if successful, you would become a scheme member. We wouldn't have on your record that you are a Haemophiliac.

Beneficiary Comment – *That's really quite concerning because if somebody applies who has Haemophilia and Hepatitis C, then there is no way you can say that that person didn't get it from their treatment. So not knowing that somebody has Haemophilia seems crazy.*

EIBSS Response – That information might be used on the medical application form to assess your application, however in terms of us administering your payments we don't need to know if you're a Haemophiliac or not. We just need to know that you've had a successful application and been approved onto the scheme. There's nowhere in our system which would allow us to record the Haemophiliac status. We received an FOI request from the Haemophilia society and the only information we could give them was the volume which was given to us as part of the handover back in 2017. GDPR has a data minimisation principle, meaning we should only retain the information we need to be able to administer the scheme. We record infection type i.e. Hepatitis C or HIV to enable people to receive the correct payments, but we wouldn't record how they became infected.

3. Beneficiary Question – *So when my doctor completed my application form and put down about how many units of blood I received, the reason for the transfusion, etc. is this information not stored anywhere?*

EIBSS Response – That information is used when your application is medically assessed. We only keep information which is relevant to make the correct payments to people. Regardless of how you became infected, we don't record that we just record the infection type to make the correct payments.

4. Beneficiary Question – *So is there a difference in payments between Stage 1 and Stage 2 Hepatitis C?*

EIBSS Response – Yes, there are different payments for different infection types, so there's HIV, Hepatitis C Stage 1, Special Category Mechanism (SCM), Hepatitis C Stage 2, Co-infected (HIV and Hepatitis C Stage 1), Co-infected (HIV and SCM) and Co-infected (HIV and Hepatitis C Stage 2).

5. Beneficiary Question – *What is Special Category Mechanism (SCM)?*

EIBSS Response – It is in between Stage 1 and Stage 2. So if you are Stage 1 and your condition has worsened because of your Hepatitis C, but it's not quite at Stage 2 yet meaning you have not been given a terminal diagnosis, you could apply for SCM payments.

6. Beneficiary Question – *Do you know what the ratio is between infected and affected?*

EIBSS Response – Are you referring to people registered on the scheme?

Beneficiary Comment – *Yes, I would imagine there's a lot less infected than affected.*

EIBSS Response – On our scheme, we have 3,570 beneficiaries in total. Within that total, 754 are bereaved partners so affected people. I would say roughly it's around 80:20 infected to affected. When we are talking about affected people, we are referring only to people who had a partner registered on the scheme who has passed away.

Beneficiary Comment – *The community were very anxious whilst awaiting the announcement regarding the payment rate increase. People were calling EIBSS every day for information, but you didn't know anything, and we were just told that you were waiting to hear from Department of Health and Social Care (DHSC). I think EIBSS need to push the DHSC to say this can't happen again when people need to know where they stand financially when they rely on the money to pay bills.*

EIBSS Response – Apologies on behalf of us for the anxiety caused. We use the September CPI rate from the year before, so as soon as October is finished and the rate is declared, I (MR) go through the regular payment values and send our recommendations to DHSC to be signed off. This went to DHSC on 5 November 2022. The biggest challenge within the DHSC this year, is that they had to ensure the devolved administrations (Scotland, Ireland, and Wales) were all going to sign up to the 10.1% increase and that they had the budgets in place for this, before they could get back to us. We chased this up every month as we should be writing out to everybody in February, however we weren't able to write out until 5 March 2023. I'm pleased to say that there have now been some changes within the DHSC and there are new policies in place to make this process much smoother, assuming regular payments continue. There was a backup plan in place, if we hadn't received approval from DHSC, people would have continued to get their regular payments at the 2022/23 rate, then once the 2023/24 rate was confirmed, we could pay everybody the new rate plus any monies owed.

7. Beneficiary Question – *It wasn't fair that Scotland and Wales knew about the payment increase before we did. Everybody should find out at the same time, and this caused great anxiety. Would it be possible for the devolved nations to work together to put that information out on the same day? This will save EIBSS at lot of calls and emails. Or simply update the news page on your website. It's not really used for anything, and it would be good if it was used to improve communication and transparency. I didn't know this meeting was taking place, I only found out yesterday. At the last meeting in February, I specifically requested to come to this meeting, yet I wasn't sent an invite. This is why I believe there is a breakdown in communication and transparency. Although it wasn't a problem for me to join on, and thank you ST for your prompt response, I think if it was on the news page to make people aware this would be better so that people don't have to go searching for information. I also think it's particularly difficult to locate the minutes from the focus group meetings, but I do think it's brilliant that they are published now because it makes it easier to share them with various support groups.*

EIBSS Response – In terms of the communication around the payment increase, all of the devolved administrations did agree to share the information at the same time, however due to the amount of members we have and the fact that people are notified in different formats (postal, electronically, etc.) it can result in people receiving the information at different times but the agreement is, that it's a coordinated response, where the message should be relayed to everybody at the same time. But you are right in saying that we can update the website with the relevant information, when we do have it, to provide some more clarity. With regards to the focus group invite, if you registered your interest, you should have received an invitation, so we do apologise that you didn't receive that. For anybody else who would be interested in attending future focus groups, if you would like to share amongst your community that you can go onto the EIBSS website on the 'Contact EIBSS' page, there is a 'Sign up for the EIBSS Focus Group' link. You can then register your interest using your EIBSS reference number. This information then goes onto a spreadsheet which ST's team can then access and use to send out the invitations for future focus groups.

8. Beneficiary Question – *We're all aware that the payments we receive are exempt from income tax and benefits calculations, and that we don't need to notify anybody about those payments. Over the past 18 months, a lot of us have had significant payments from EIBSS and the monthly payments amounts have gone up significantly, and a lot of us are now starting to save, put money away in investments, etc. Those accounts are now starting to show a return and my question is around tax implications? I've got a letter somewhere from The Macfarlane Trust where it states that any money you receive, or any profit made from investments you received off those payments are exempt. On the EIBSS website, it doesn't mention anything about profit made off investments, so I think there needs to be some clarity around that so that people aren't faced with a tax bill, or a fine / prosecution for tax implications that they weren't aware of.*

EIBSS Response – Any payments received from EIBSS should be declared. If you are in receipt of any benefits, you should also make the Department for Work and Pensions (DWP) aware, but they will not take these payments into consideration when calculating benefit entitlement. EIBSS payments are not subject to tax, as you know. In terms of income made from EIBSS payments from investments and so on, it's our understanding as a scheme that these payments are taxable. We do have some beneficiaries who have invested money in property for example, then went on to sell these properties to make a profit meaning that the profit made would have tax implications. So, any tax return that you do, or declaration to HM Revenue and Customs (HMRC) or DWP, you should always declare your EIBSS income, but then any additional income made off the back of EIBSS money will attract tax implications, unfortunately.

DHSC Response: This is correct, please declare EIBSS payments, including the Interim compensation payments, to DWP and HMRC. This includes any earnings.

Tax exemption only extends to the periodical payments or annuities in respect of the damages. Any return from investing those sums is not exempted. Once any money received from interim compensation and the support payments is invested any interest received on that investment will be taxable in the normal way and should be declared in tax returns and self-assessments. Independent financial advice should be sought as previously advised.

9. Beneficiary Question – *I don't think it states that anywhere on the website, so can we make that an explicit part of the criteria?*

EIBSS Response – It's something that we have raised with the DHSC because we want a few things to be legislated. One of them is around the compensation payments, because although compensation payments to EIBSS beneficiaries are not subject to income tax, inheritance tax and so on, if you give any money away to family members, they will become liable to pay tax and the money will affect their benefits, if they receive any. That's why there has been a delay in deceased estates payments to family members, who were due to receive a compensation payment, if we paid the £100,000.00 straight away to the estates, they could be liable for up to 40% tax immediately and it could stop them from being eligible to continue to receive DWP benefits. So, there's a lot of work going on across government organisations (DHSC, DWP, HMRC) to agree this legislation. But I'll certainly take this away, to try and get clarity for you all, and get the website updated to confirm if tax would be applicable on income derived from EIBSS payments.

DHSC Response: As above. We are working with NHSBSA to update the website with the correct information shortly.

To note, when introducing the interim compensation, the UK government agreed that in the small number of cases where an infected beneficiary, or bereaved partner beneficiary of a UK IBSS dies after 29 July 2022 but before payment is made, and has no partner who satisfies the eligibility criteria to register as a bereaved partner with the relevant UK IBSS, one payment of £100,000 can be claimed by the executor or authorised representative of the estate.

The UK Government identified a potential gap in the existing means-tested benefits capital disregard rules. Left alone, this would mean that children of a deceased infected person or their partners could receive an interim infected blood compensation payment (via the estate of the deceased) which could in turn affect their claims to means-tested benefit.

We have taken cross government action to remedy this by changing existing regulation to ensure the children's benefit entitlement is not adversely impacted. The interim compensation payment to the remaining eligible estates are now being paid.

10. Beneficiary Question – *So just to be clear, the monthly payments I receive from EIBSS should be declared to HMRC, but they won't act on it?*

EIBSS Response – That's correct. Our understanding is that DWP, HMRC, etc. all speak to each other in terms of having triggers on bank accounts for example, so ultimately if somebody has just had an £80,000.00 payment go into their bank account, they could question where it's come from. But if you're transparent and inform them where that payment has come from or what it is, there's an audit trail of where it came from and that there's nothing to hide. It'll also save any conversation under caution or anything like that, which sometimes occurs.

DHSC Response: This mirrors our understanding; however we are seeking confirmation cross government and will revert.

Beneficiary Comment – *It can be a bit of a touchy subject for some people as in the past, people have had interviews under caution and repeated alleged violations from HMRC about large amounts of money being received. And I think it can often depend on who you speak with in HMRC, as when speaking to higher-ups they were generally more cooperative, and the problem was generally within the local office.*

EIBSS Response – It is often just a lack of awareness and understanding of the EIBSS scheme. We have been doing a lot of work with other government organisations to get points of contact to ensure that they are filtering down to the frontline that EIBSS beneficiaries should not be getting their privacy invaded or being dragged in under caution. Everybody should be aware of what these payments relate to, and you all should not have to jump through hoops every year when you're completing a tax return or re-assessment. So, this is a working process, unfortunately it is a bit slower than we would like.

DHSC Response: Thank you for highlighting this issue. We will raise this with HMRC.

Beneficiary Comment – *Going back to the question about income made from EIBSS payments, I believe I have seen a document which was talking about income made from EIBSS payments not being taxable. I know about inheritance tax, but there was a document which talked about capital gains tax and that it would not be payable. When you get something like a periodic payment, the law is expecting you to invest that money to make a return and that's part of your compensation package, therefore it would seem inequitable to charge you tax on that when they are expecting you to invest it. I do believe I have a copy of a document which states that capital gains tax is not applicable on that principal investment sum. So there really does need to be transparency around this as it can create huge problems for individuals if they are not declaring those amounts and they have some income from investments. They need to make sure everything is done legitimately and that the relevant authorities are notified appropriately.*

Beneficiary Comment – *For a lot of us, this is the first time we will have had this amount of money and be subject to any kind of tax implications, and we need to know about inheritance tax, capital gains tax, etc. when we have never had to think about this before. This is why it needs to be very simple for us to understand and simply laid out, so we know what to do. I know that a lot of people I speak to just put the money in an account and do not tell anybody about it, and my fear is that they could end up in court liable for something which they should or shouldn't be. There absolutely is a document from The Macfarlane Trust, but I think there is a large assumption that the rules from The Macfarlane Trust were rolled into the EIBSS rules.*

Beneficiary Comment – *I was investigated by a compliance officer from the DWP with regards to the Interim Payment, but Jayne Knights (Benefits Brighton) really helped me with this. She has a contact within the DWP, and she got a document from them to send out to various local authorities to explain everything.*

EIBSS Response – I (HE) believe there were five schemes which were merged to create the EIBSS scheme as it is now, and each of those schemes were slightly different which is why one central scheme was created, so everybody got the same. Then we went through parity to make sure all the devolved nations

payment values were aligned. It does not sound like something we have inherited as part of our scheme, but it would be useful if we could have a copy of that document, so that we can send it to DHSC. Our beneficiaries who were part of a previous scheme and transferred over to EIBSS may still think that the rules from their previous scheme apply, therefore this could result in significant consequences for something they are not aware of. Thank you for highlighting this to us, and we will endeavour to get this clarity for you.

DHSC Response: Since 1988, successive governments have set up various schemes to provide financial support to individuals infected with Hepatitis C, HIV or both through NHS treatment with contaminated blood products. The longstanding position has been that such ex gratia payments should be exempt from tax.

Following the introduction of new schemes, legislation was introduced in 2017 to ensure that periodical payments to beneficiaries from those schemes were exempt from income tax, in the same way as periodical payments from existing schemes.

The exemption only extends to the periodical payments or annuities in respect of the damages. Any return from investing those sums is not exempted. Once any money received from interim compensation/support payments is invested any interest received on that investment will be taxable in the normal way and should be declared in tax returns and self-assessments.

Independent financial advice should be sought as previously advised.

Beneficiary Comment – *I have found the document in question regarding income made from EIBSS payments.*

EIBSS Response – That document is referring to EIBSS payments being made to you, not income derived from these payments. The document refers to compensation payments but does not refer to income made from EIBSS payment. Our website does include information about seeking financial advice regarding any income received.

11. Beneficiary Question – *The Discretionary and Child Payments were not raised like the regular payments, and people do not understand why. Everything that people are purchasing has increased, for example if they go to repair / replace something in their home, so people are saying why haven't these payments been uplifted to reflect these increases? If there's a rationale as to why they aren't uplifting the payments, that is fine, but they need to be clear as to why they aren't doing it. I've spoken to members of the EIBSS team to ask this question and they were brilliant but did not know why they hadn't been uplifted either. Additionally, for people who were with The Macfarlane Trust the Child Payments were not means tested and I'm aware that other devolved nations do not involve means testing when it comes to child payments. Why is this still applicable in England? It's seen as a major flaw in the system.*

EIBSS Response – Discretionary Payments are not linked to CPI increases, and that was a decision made as part of the alliance house organisations transferring over to EIBSS. Regular payments are reviewed annually and increased with CPI, whereas Discretionary Payments are not, therefore the amounts for Discretionary Payments will remain as they are. This was the direction given to us by DHSC

when we inherited the scheme. The idea behind Discretionary Payments is to provide beneficiaries with short term support.

DHSC Response: EIBSS understanding is correct. The discretionary payments are to help to provide immediate support in the short term.

12. Beneficiary Question – *But doesn't the government recognise that intrinsically things are more expensive now and that there is now a short fall? If prices had remained the same for those elements, then I could understand that, but they have not.*

EIBSS Response – That's why regular payments increase. Originally when EIBSS was introduced, regular payments were a lot lower than they are now. This was reviewed in 2018 and the amounts were increased significantly to consider the cost-of-living increases. The amount we pay out in Discretionary Payments is very small. But to confirm, those amounts will remain the same as they are not linked to CPI. One of the suggestions made by Sir Robert Francis was to remove Discretionary Payments all together and provide everything with a one-off lump sum, and I believe this is currently under consideration. DHSC will not consider making any changes to the scheme until all the recommendations made have been reviewed. With regards to Child Payments, England was initially the only scheme offering child payments and the reason means testing was part of this is because it was linked to income top-up. Income top-up payments were made to bereaved partners up until December 2021 when Bereaved Partner Payments were introduced in England instead. Scotland and Wales already had Bereaved Partner Payments for 3 years. When the parity payments were brought in, England removed income top-up payments and Scotland and Wales extended Bereaved Partner Payments to an indefinite period, meaning all the devolved nations were consistent from that perspective. Wales then approached us to ask us how we administer Child Payments because they were considering introducing them to their scheme, so we shared all our processes and documentation with them, which they took to the Welsh government. The Welsh government then said they were going to introduce Child Payments, but that they were not going to be means tested because of the low numbers of applicants they have. The English scheme has not changed at all. The means tested element has remained consistent from the beginning. We have spoken to DHSC regarding this as it does create a disparity, and it is something they've taken away to discuss with Wales.

DHSC Response: We appreciate these concerns. The Infected Blood Inquiry is considering the nature and the adequacy of the treatment, care and support (including financial assistance) provided to people who were infected and affected (including the bereaved).

We will await its final report and consider its recommendations in full before considering making any changes to the UK wide infected blood support schemes.

Beneficiary Comment – *I completely understand that, but all Wales have done by introducing it without means testing is destroying the parity that was achieved across all schemes.*

EIBSS Response – We were disappointed that after supporting Wales and helping them to understand our process that they chose not to include means

testing, but we have fed this back to DHSC to see if we can make that change as well. So far there has been no change agreed to the scheme.

DHSC response: We will take this back to our Welsh colleagues. As above, no changes to the schemes will be made until after the final report's recommendations have been considered.

13. Beneficiary Question – *Although you have provided details about how the Child Payments in Wales came about, it does leave a lump in people's throats. You could be on one side of the border or the other, and depending on which home nation you are in would determine your situation. I feel like the wrong people are in the room here, we need DHSC in the room. We understand that your hands are tied and that you will need to take this away to DHSC, but they should be here and part of this discussion. You mentioned about how the CPI increase had to be agreed and signed off by all the devolved nations, so how do WIBSS get to introduce Child Payments without means testing without this needing to go through the same process? It is not about money, it's about equality. It was said that parity would be achieved for all, but it is still not there and we're seeing a gap opening.*

EIBSS Response – We completely appreciate what you are saying. Nobody in England is disadvantaged in terms of the scheme as nothing has changed. Child Payments have been in place for several years, so EIBSS beneficiaries have had the opportunity to receive these payments since 2017. Welsh beneficiaries have not had this. Welsh regular payments were also less than the English payments, prior to parity.

14. Beneficiary Question – *Are Child Payments in Wales allocated based on salary?*

EIBSS Response – No, they are not.

Beneficiary Comment – *In England, if you apply for Child Payments, it will be based on your income. I get the point you are making, but what I'm saying is that today, a person in Wales does not have to go through the same process as a person in England and be told they are not eligible because they are above the threshold.*

EIBSS Response – That is correct, however Wales have not been making these payments since 2017 like we have. From day one, if you were in Wales, you could not apply for Child Payments but if you were in England, you could. Now, England feels slightly worse off as we have means testing in there, however the English regular payments were higher than the Welsh regular payments making England slightly better off. This is why parity was introduced to bring everybody up to the same level. To my knowledge, there are only 15 people receiving Child Payments in Wales. In England, we have approximately 180 families receiving Child Payments. We completely understand your frustrations, as we did not expect this to happen either.

DHSC Response: As above – No changes will be made to the UK wide infected blood support schemes, until the government has carefully considered the Inquiry's final report and its recommendations in full.

15. Beneficiary Question – *Is there any work that EIBSS are doing around the report published by Sir Brian Langstaff?*

EIBSS Response – Are you referring to the second interim report, or the main report?

Beneficiary Comment – *Take your pick, there's gap / void and we do not seem to know anything. Anything you call tell us would be appreciated.*

EIBSS Response – We share your frustration regarding the lack of communication from DHSC. We are conscious that the compensation framework report was published in February 2022 and there is yet to be a formal response to date. The only action that has been taken so far, is the Interim Payments made to beneficiaries which we were able to deliver within 10 weeks. There have been very limited conversations between DHSC and ourselves around the second interim report, which came out in April 2023, recommending Interim Payments for bereaved children, parents and siblings. Sir Brian and Sir Robert both recommended an independent arm's length body to administer compensation payments.

If this is the decision that is made, it could take several months, if not years, to establish this new arm's length body. It would be extremely challenging to create a new organisation, this calendar year. to make payments.

We have looked at our capacity to see what we can do if we get asked to administer the compensation payments. We were able to administer the Interim Payments so quickly as we already had information for the infected and bereaved partner beneficiaries. If we were asked to administer the interim payments to children, parents, or siblings there's preparation the government must do, such as legislation, eligibility criteria, data protection. EIBSS support the approach that people are paid as quickly as possible.

Beneficiary Comment – *I don't think anybody within the community would have an issue with for example EIBSS starting off and then maybe an arm's length body coming in at a later date to take over. It's all about instilling confidence in our community and better communication. Too much is better than too little, because now we know nothing and EIBSS are doing their best with what information they have, but if there was more open and honest communication about how this is going to work that would be great in helping to build the confidence in our community.*

EIBSS Response – We have been having conversations with DHSC around this. We have explained to DHSC that we delivered the Interim Payments seamlessly and everybody who should have got paid, did get paid, on time as promised, and communicated to.

Therefore, we have demonstrated that we would be capable of making future payments, but once again, DHSC need to do all of the preparation work first. However, all the recommendations must be considered and one of those was for the independent arm's length body to deliver compensation payments.

There is a debate in the House of Commons on Thursday (22 July 2023), so I hope we'll hear an update from the Minister, as to where they are up to with the recommendations.

16. Beneficiary Question – *A lot of people within the community who are very unwell with severe cirrhosis or liver cancer for example will likely not be here when the compensation payments are made, whether that be in six-month*

time or longer. Some of the recommendations that Sir Robert Francis made brought them some hope that they would get an uplift in the payments to match the median salary across the UK, or that they would have the Discretionary Payment lump sum paid to at least give them some control over their finances before something happens to them. Is there no way that you can put pressure on DHSC to make payment to these people who potentially won't be around to see the compensation?

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 is suffering the most.

As a result of this, consideration is being given to how payments could be prioritised and who should be paid first. And then when looking at who should be paid and how much they should receive, there's such a wide scope when looking at parents, children, etc.

We appreciate that this money does not bring lives back. There is a lot of work involved, but ultimately somebody will have to decide who will be paid first. EIBSS are very conscious that people are passing away and we very sadly see this every day, and we understand that people don't have time on their hands. We completely empathise and we do our best to turn things around quickly, where they are within our control. However, in terms of compensation payments, they are very much out of our control.

17. Beneficiary Question – *It has been mentioned before in previous focus group meetings about having one of your senior people attend one of these meetings. It's very difficult for you guys (HE, MR & ST) who sit there and take the brunt of what we have to say, but ultimately, I would like to see the person above you (MR) or whoever you go to, to attend one of these sessions. And if they don't want to or can't, I'd like them to write to me personally to explain why because it's not fair on your guys. With these focus group meetings, it isn't like you read the minutes from the last meeting, then it's agreed and seconded, then there's an agenda we work from before coming to any other business. It's a bit of a free for all open forum to talk about anything, but I would like to see a bit more structure to it although I do think you all do a fantastic job. If EIBSS are saying they communicate and are transparent, there's no reason why that senior person can't be here.*

EIBSS Response – When you are referring to a higher up person, are you referring to mine (HE) and MR's senior?

Beneficiary Comment – Yes, that is who I'm referring to.

EIBSS Response – We had a face-to-face focus group in 2019 which was attended by the previous EIBSS manager and mine (HE) and MR's senior, James Hardy. It's a conversation that MR and I (HE) can pick up with James to see if he would be able to attend another session. He may not be available to attend all focus group sessions within a week, but he may be able to attend some of them.

18. Beneficiary Question – *What are the chances of getting somebody who you liaise with at DHSC to attend one of these sessions? We appreciate that you follow direction from DHSC and that if you don't have the answers to certain*

queries you have to take it away to them, but it would be helpful for somebody to be here who could potentially answer these questions.

EIBSS Response – It is very unlikely that this would happen. This has been asked several times previously and the response that's given is that's why EIBSS are in place to deliver the service on behalf of DHSC. Even if somebody from DHSC was to attend, ultimately, they wouldn't be the decision maker either and would need to take queries away.

DHSC Response: NHSBSA and the EIBSS administer the scheme on our behalf and work very closely with the Department. We understand that these focus groups offer beneficiaries the opportunity to raise issues related to the schemes and it is felt that having DHSC attendance may detract from these discussions. NHS BSA feed back all the issues raised from these meetings, and this vital feedback helps to gather evidence that will inform any future policy decisions.

19. Beneficiary Question – *It was said at the last focus group meeting that this session would be face to face. Can I ask why it's not?*

EIBSS Response – When beneficiaries registered their interest to attend focus group meetings via the form on our website, the majority of people said they would prefer a meeting via Microsoft Teams rather than face to face. We decided to go with the majority vote to ensure we could speak to as many beneficiaries as possible this week.

Beneficiary Comment – *But nobody knew that the focus group meetings were taking place this week, unless I was just the exception who didn't receive an invite which is what I touched on at the beginning of the meeting.*

EIBSS Response – I (HE) will pick this up with ST and the team to see what happened with those invites, but we apologise for that.

Beneficiary Comment – *Thank you and I appreciate that. But something that could have been put on your news page is that going forward focus group meetings will be held via Microsoft Teams.*

EIBSS Response – People's preferences can change, and we will continue to ask you all whether you would prefer an in-person meeting or a meeting via Microsoft Teams. It may be the case that we could have one face-to-face meeting and one meeting via Teams the next time to cover both options. The next meeting will be around September time.

Beneficiary Comment – *I would avoid September as that's when Sir Brian's report is due to come out.*

EIBSS Response – Possibly October time. We also have to consider that people who may want a face-to-face meeting may be in several locations across the country and finding a central meeting point is not always easy, but we will certainly take this into consideration for the next one.

Beneficiary Comment – *Something to also consider is that the Infected Blood Inquiry still hold regular meetings, one of which was supposed to be today, but this has been rescheduled due to the debate in the House of Commons. But these things can clash, therefore communication is important to try and avoid this.*

EIBSS Response – We offer a couple of focus group slots across the week so that if people are unable to attend one session, there's another for them to choose from as we're conscious of your availability. Also, if any of you do have any questions that we have not had time to cover please email them over to us and we can include them in the minutes when they're published. Additionally, you don't have to wait for a focus group session if you ever do have a list of questions that you would like answered you can send them over by email and we can get them answered for you whenever.

Beneficiary Comment – *That's really helpful, thank you very much.*

EIBSS Response – We are in the process of writing out to everybody within the next week or two because our email address will be changing from the beginning of July. We're moving away from an nhs.net email address to an nhsbsa.nhs.uk email address. We will have a 30-day migration period where one mailbox switches off and the other switches on. You will all receive correspondence regarding this, but if you're happy to share this within your groups that would be great. All of our other contact details will remain the same.

Beneficiary Comment – *On a separate note, using figures when talking about stuff is very sensitive and it's maybe something to move away from when we get down to the compensation. That £100,000 figure has been thrown around so many times.*

EIBSS Response – We appreciate that it's a sensitive matter. We opened up the meeting by going over figures, such as how many scheme members we have, and this information has been requested by people who have attended previous focus group meetings. People are also interested in knowing how much money has been spent by the scheme, so that is why these figures are shared. The compensation element was quite a difficult subject during our last focus group, and we know that some people have been sharing on some of the support groups, social media about some of the expensive things they have bought with their compensation money, then on the other hand you've got people who were asked for money from family members who knew their lifestyle could be changing. We can try and protect the information as much as possible, however the media always want to share as much as possible.

Beneficiary Comment – *It's not common in my area to talk about your salary or money, so I don't understand why the figures need to be made so public when it should be a confidential matter. And this was raised with the inquiry team too.*

EIBSS Response – We understand where you're coming from, and that's why we ensure that these focus group remains a safe and secure environment for our beneficiaries, and why we don't believe at the minute that the invitation should be expanded out to family members. Further down the line, if payments are made to other affected people (children, parents, siblings etc.) and individual awards may be paid based upon individual circumstance, the values may be different. The recommendation made regarding the Interim Payment was that everybody was to receive the same amount, however we don't know if that will be the same for children, parents, siblings etc. or how the amount will be decided.

Beneficiary Comment – *I just believe that leaving figures out of it makes it very subtle, and that's what the community were getting at when they flagged this. There will be individuals who will do what they want to do, however from a*

confidentiality perspective it would be great if there's no reference to monetary value.

Beneficiary Comment – *It would also be nice if the media didn't know before us.*

EIBSS Response – The media know even before we do sometimes, but more often than not this is because we may have received the information by email outside of our normal working hours, but the media operate 24/7 and put the information out to the world before we've had a chance to react to the information we've received.

Additionally, some campaigners are journalists as well and may be involved with press releases, so they have visibility ahead of us.

Just going back to the Interim Payment, what we had to do when we were asked to administer these payments was to keep everything separate to your regular payments, so that it can fall under the banner of 'Infected Blood Compensation'.

As you'll know your regular payments are made with a reference of 'Hosted 6', however the Interim Payment had to be made under a different reference to separate the payments.

The reason for this is because if we are not asked to administer future compensation payments, we need to be able to differentiate what your payments have been for, so that we can transfer the information to the future administrator of the scheme.

20. Beneficiary Question – *Has there been any movement yet with regards to the cut-off dates (September 1991 for Hepatitis C and October 1985 for HIV)?*

EIBSS Response – That was one of the recommendations made in the April 2023 report. It's been recommended that people infected with chronic Hepatitis B should now be included as part of the scheme, as well as the removal of the cut-off dates. These recommendations are still being considered by DHSC. These changes, if accepted, would have the ability to affect both the future compensation scheme and EIBSS criteria.

Beneficiary Comment – *When talking about infected and affected people, I feel like infected people should be prioritised. By dealing with all three groups, it is holding everything up. And I mean no disrespect to bereaved or affected people by saying this as they are just as entitled to compensation as everybody else, however because people are dying at the rate they still are they might not have time to spend the money.*

EIBSS Response – You have made some valid points. One of the things we have talked about in past focus group meetings is that the infected community potentially being drowned out by the affected community.

Beneficiary Comment – *We just need to know how we are going to be paid. There's been talk of a one-off compensation payment and regular payments being stopped, and it's hard to plan the time we have left without knowing. The regular payments only equate to a salary that we can't earn anymore due to our health, therefore we rely on them to help with the cost of living.*

EIBSS Response – The infected community were prioritised when it came to the Interim Payments, so we ensure that everybody registered with the scheme were paid first. It's only the EIBSS community who have received compensation because we haven't been given any instruction to pay anybody else at the moment. Please be assured that infected have so far been a priority.

21. Beneficiary Question – *Is it the House of Commons that you put your recommendations forward to, and are we allowed to know what these recommendations are?*

EIBSS Response – The recommendations were made by Sir Brian Langstaff and Sir Robert Francis in the initial compensation framework report. Sir Brian then published a second report in April 2023 with further recommendations. All of the recommendations are currently being considered by the Cabinet Office and the DHSC. We've been advised that all options are currently being considered, in response to the recommendations.

22. Beneficiary Question – *How does the feedback from these focus groups then feed into that discussion? In the last focus group we had, we talked about the fact that some widows receive higher monthly payments than infected people even though they are not infected themselves.*

Beneficiary Comment – *The amount of money I receive monthly from the scheme is less than I was earning in employment. If everybody who was infected individually sued the NHS, we would be looking at millions in compensation.*

EIBSS Response – The final compensation package hasn't been determined for anybody yet. In terms of Bereaved Partner Payments, these were introduced in 2021 as a result of the parity announcement.

Beneficiary Comment – *A widow of somebody who was infected with both HIV and Hepatitis C will get 75% of what their partners payments would have been, which is more money than an infected person receiving Stage 1 or Stage 2 Hepatitis C payments. It's wrong and unfair.*

EIBSS Response – Both the Scottish and Welsh schemes prior to the parity announcement already included payments for bereaved partners for a period of 3 years, so when the parity announcement was made, they were introduced to our scheme. The aim was to ensure the loss of household income from the infected person passing away continued for at least 12 months at the same level, then reduced to 75% after that. We do acknowledge that some widows are receiving higher payments than some infected people. We did feed this back after the last focus group and were advised that no changes would be made to the payment rates, while the inquiry is ongoing.

23. Beneficiary Question – *Who makes the decision on what monthly payments people receive?*

EIBSS Response – They are reviewed annually based on the CPI rate of the previous September and generally increase year on year, your condition and how severe your infection type is, will determine the agreed rate.

24. Beneficiary Question – *In terms of when the compensation package is decided, are we going to have a lot of forms to complete?*

EIBSS Response – We don't know yet. The main recommendation was for a judge to set up a framework for compensation and to oversee it all. Also, for individual assessments to be done, I believe, so each individual would need to be assessed in some way. However, we don't know what this is going to look like yet, as we have not been involved in any of these conversations.

25. Beneficiary Question – *And what still have to wait until September / October when potentially more people have passed away?*

EIBSS Response – That is when the inquiry is due to report,

26. Beneficiary Question – *I feel like since the inquiry ended, everything seems to be taking way longer in terms of discretionary payments. I don't know if it's coincidental, but every application I've put through since then seems to be taking a long time to be processed. Before the inquiry, everything was so easy. I would just like to know why? Is it due to being short staffed, or is it due to a higher number of applications since the inquiry ended?*

EIBSS Response – In terms of medical applications and people applying to join the scheme, you are right in thinking we have had a huge increase in applications off the back of the inquiry. We typically used to get around 3-4 applications per month from new people applying to join the scheme, which has now risen to approximately 120 per month. As a result, the resource has been directed towards trying to get the new medical applications processed.

Beneficiary Comment – *It does seem like the DHSC haven't given you more staff to be able to cope with that.*

EIBSS Response – All discretionary payments are responded to within 30 working days, and I don't believe we've gone over that Service Level Agreement (SLA) in regard to response rates. We have digital tracking system for all applications to ensure they are processed timely and efficiently. This also enables us to ensure we have sufficient staff to meet demand. If anybody has sent an application in and hasn't received any response at all within 30 working days of us receiving it, please get in touch with the team, who will be able to check and give you an individual update.

27. Beneficiary Question – *Is it that discretionary applications are processed and paid within 30 working days, or is it that we get confirmation you have received an application within 30 working days? It took 5 days for one of the applications I have in at the moment to be acknowledged, and I was starting to wonder if it had gone missing. It would be good if we could get an automated email confirming receipt.*

EIBSS Response – We have got an automated email response setup on our inbox. It confirms that we've received your email / application and also gives a little bit of information regarding next steps depending on the contents of your email. This has been in place since around mid-April 2023.

Beneficiary Comment – *I don't recall ever seeing an automated response and I've had multiple applications in recently, so it might be worth looking into this. I also recall there being an issue with the phone lines recently when calling up.*

EIBSS Response – We certainly will have a look into the automated response email. With regards to the phone lines, all of the telephony lines for the entire

NHSBSA recently went down. We use Voice over Internet technology, meaning if the I.T. connection fails somewhere within our business it will affect all services. Where this happens, we will aim to fix it very quickly.

Beneficiary Comment – *How long did it go on for?*

EIBSS Response – On one instance it lasted for an afternoon, and on another instance it lasted for one day whilst everything was reset.

Beneficiary Comment – *I thought it was a lot longer than that and that your phone lines had been down for a couple of weeks.*

EIBSS Response – No, the longest it's ever been, is one day.

28. Beneficiary Question – *I wanted to raise something around counselling. The problem with counselling is that people locally don't understand this story or don't know about it, so you literally have to run through the whole thing and educate them about it before they can give you counselling. There should be professionals dotted around the country who are familiar with this where they can just get straight into helping you.*

29. Beneficiary Question – *We've previously talked about counselling in terms of somebody contacting you because they've just come out of an appointment with a doctor and had some very bad news. Having to wait a month for EIBSS to approve an application for counselling and then having to go and find a counsellor does not meet the very immediate need. We talked about the possibility of EIBSS offering some kind of immediate access counselling service for people who find themselves in that situation. Did you get any further with that?*

EIBSS Response – This is work in progress. One of the Inquiry recommendations was for England to introduce a bespoke psychological support service, similar to that found in the other devolved administrations. The DHSC are working with NHS England to setup this bespoke service, as quickly as possible.

DHSC Response: We are fully committed to developing options for a bespoke psychological service in England and are working closely with NHS England.

As beneficiaries may be aware, we commissioned research to look in the psychological needs of the infected and affected. This research was published on 10 August 2023, and the findings are being used to inform and shape the service design.

The published findings can be found here:

<https://piru.ac.uk/projects/current-projects/psychological-support-for-individuals-historically-infected-with-hiv-and/or-hepatitis-c-as-a-result-of-nhs-supplied-blood-transfusions-and-blood-products-and-affected-families.html>

30. Beneficiary Question – *With regards to car repairs, why are EIBSS still insistent on needing two quotes when it's often small amounts of money involved? Expecting people to obtain two quotes often just doesn't make sense, and I think the same applies to accommodation repairs. If the work I need doing is small, I don't see why it's worth getting two people out to look at it. I think the insistence on two quotes puts people off applying for small*

amounts of money. I know the argument in the past has been that you have to satisfy the auditors, but the service isn't actually meeting the requirements of the people who are using it.

EIBSS Response – 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.

Beneficiary Comment – *People wouldn't get two quotes to replace their tyres. They might have a quick look online and see where has the best deal. I've got a couple of loose tiles on the roof, but I'm not going to get two builders round to give me two quotes.*

31. Beneficiary Question – *Will you be publishing anything on the website following the debate in the House of Commons?*

EIBSS Response – We won't publish anything regarding the debate, as government communications are their own responsibility. Obviously, the debate will be streamed live and a public record made available shortly after.

32. Beneficiary Question – *What is the difference between EIBSS and the Infected Blood Inquiry?*

EIBSS Response – The Infected Blood Inquiry is an independent public statutory Inquiry established to examine the circumstances in which men, women and children treated by national Health Services in the United Kingdom were given infected blood and infected blood products, in particular since 1970. Further information can be found on the Inquiry website:
<https://www.infectedbloodinquiry.org.uk/>

Beneficiary Comment – *But they don't seem to inform you of anything as I have been forwarding information to you which I've received from them.*

EIBSS Response – All Inquiry recommendations are publicly available, so EIBSS are made aware of them at the time of publishing, and not before.

Beneficiary Comment – *So are they above you?*

EIBSS Response – They're a completely independent organisation, please refer to the Infected Blood Inquiry website for further information:
<https://www.infectedbloodinquiry.org.uk/>

Beneficiary Comment – *Where did they come from and who are they?*

EIBSS Response – EIBSS administer the payments to beneficiaries on behalf of the DHSC. We are an independent arm's length body making payments and managing the scheme, as instructed by DHSC.

Please refer to the Infected Blood Inquiry website for further information:
<https://www.infectedbloodinquiry.org.uk/>

33. Beneficiary Question – *So when are we looking to actually get some more compensation from this?*

EIBSS Response – We can't give a timescale unfortunately; the government will be responsible for any future compensation announcements.

MR thanked everybody for attending and confirmed that once the minutes were finalised, they would be sent out to everybody who attended, and published on our website.