

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

Meeting Type: EIBSS Focus Group
Meeting Date: 13 February 2024
Location: Royal Station Hotel - Newcastle

Attendees from EIBSS NHSBSA:

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

1	Welcome																						
	<p>The EIBSS focus group is a meeting between the NHSBSA who administer the scheme on behalf of the Department of Health and Social Care (DHSC) and the beneficiaries who the scheme supports. All registered beneficiaries are welcome to attend, and those who do attend can provide feedback regarding the scheme.</p> <p>Introductions were made and everyone was welcomed to the focus group. A brief overview of the service was given.</p>																						
2	Updates from EIBSS																						
	<p>MR provided a breakdown of the number of beneficiaries on the scheme as of 31 January 2024.</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: center;">Infection Status</th> <th style="text-align: center;">Active Beneficiary Count</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">Hep. C Stage 1</td> <td style="text-align: center;">1392</td> </tr> <tr> <td style="text-align: center;">Special Category Mechanism (SCM)</td> <td style="text-align: center;">541</td> </tr> <tr> <td style="text-align: center;">Hep. C Stage 2</td> <td style="text-align: center;">555</td> </tr> <tr> <td style="text-align: center;">HIV</td> <td style="text-align: center;">67</td> </tr> <tr> <td style="text-align: center;">Co-Infected (HIV & Stage 1)</td> <td style="text-align: center;">79</td> </tr> <tr> <td style="text-align: center;">Co-Infected (HIV & SCM)</td> <td style="text-align: center;">84</td> </tr> <tr> <td style="text-align: center;">Co-Infected (HIV & Stage 2)</td> <td style="text-align: center;">55</td> </tr> <tr> <td style="text-align: center;">Carers / Dependants</td> <td style="text-align: center;">126</td> </tr> <tr> <td style="text-align: center;">Widow / Widower / Civil Partner</td> <td style="text-align: center;">771</td> </tr> <tr> <td style="text-align: center;">Total</td> <td style="text-align: center;">3670</td> </tr> </tbody> </table>	Infection Status	Active Beneficiary Count	Hep. C Stage 1	1392	Special Category Mechanism (SCM)	541	Hep. C Stage 2	555	HIV	67	Co-Infected (HIV & Stage 1)	79	Co-Infected (HIV & SCM)	84	Co-Infected (HIV & Stage 2)	55	Carers / Dependants	126	Widow / Widower / Civil Partner	771	Total	3670
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	<p>There was a press release on Thursday 9 November 2023, from the UK Health Security Agency (UKHSA) and the University of Bristol regarding an opt-out testing programme being done by NHS England (NHSE) to identify bloodborne viruses in patients attending 33 emergency departments in England since April 2022. Link here: https://www.gov.uk/government/publications/bloodborne-viruses-opt-out-testing-in-emergency-departments</p> <p>During the first year, the 33 emergency departments conducted 857,117 HIV tests, 473,723 HCV tests, and 366,722 HBV tests – (1,697,562 tests in total)</p> <p>Data from NHSE indicates that nearly 2,000 people were newly diagnosed with the following bloodborne viruses:</p> <ul style="list-style-type: none"> • 499 people with hepatitis C • 1,143 people with hepatitis B • 341 people with HIV <p>Various external stakeholders have passed comment on this link: https://www.gov.uk/government/news/thousands-diagnosed-with-hiv-hepatitis-b-and-c-following-programme</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>This question is related to the ongoing discrimination between infected beneficiaries and bereaved partners in terms of regular support received from the scheme. Within EIBSS, there are several categories of infected people and four categories of payments. We do not believe the payments are fair. Infected people are not being paid fairly and this needs to change. This issue has been raised before and needs to be addressed. When an infected beneficiary dies, their bereaved partner will receive 75% of the infected beneficiary’s payment. Some bereaved partners are being paid more than infected people. Why are bereaved partners treated differently?</i></p> <p>EIBSS Response – When going through parity, EIBSS tried to take the best from all of the devolved administrations in terms of payments. The rational was that a bereaved partner would be used to a certain standard of living based on the household income at the time the beneficiary was still alive, therefore the bereavement payments allow the standard of living to be maintained.</p>

Beneficiary Comment – *When the 75% model was introduced, we were not consulted in England. It was first brought about in Scotland. The only thing we had, which was arranged by the Infected Blood Inquiry (IBI), was a meeting with the Cabinet Office where they wanted groups of individuals to attend a meeting to discuss their needs. Something which was agreed was that no infected individual should receive less money than a bereaved partner. But they are paid more in some circumstances, and it is shameful. It needs to change. What about infected individuals who are used to a good wage and unable to work? The same applies if a bereaved spouse cannot work due to caring for infected partner. It is so frustrating. As much as the government try to justify it, we never asked for it.*

EIBSS Response – There was consultation held between the devolved administrations, and the decision was made to introduce the support to bereaved partners. Nobody was disadvantaged by this. We used to have income top-up payments for infected beneficiaries, then the annual payment rates increased to eliminate the need for income top-up payments. However, they still existed for bereaved partners. These were then replaced entirely by the equivalent beneficiary payment for one year, then 75% after that. The government then decided to mirror this across all schemes. Nothing is being considered in terms of changing this, but we are waiting for the announcement regarding the final report.

Beneficiary Comment – *We could end up with a situation where it continues, and it is oppressing.*

EIBSS Response – We can feed this back to the DHSC, but even if it does go out for consultation, it could end up where people are in a worse position.

Beneficiary Comment – *We are looking for an uplift in payments, not a reduction for everybody.*

2. Beneficiary Question – *Is there any update in terms of being able to guarantee that EIBSS payments will be for life?*

EIBSS Response – There has been no update since this was last raised in the February 23 Q&A. EIBSS still holds the belief that the scheme provides much needed support to many vulnerable beneficiaries, and we are aware that this is also the preference for a number of you as well. This has been raised to DHSC, but we will need to wait to see the government response to the final report when it is released.

3. Beneficiary Question – *Are you all worried about your jobs?*

EIBSS Response – From a duty of care perspective, we want the scheme to continue for you all. We have seen instances where people were paid the interim payment but did not know how to manage their money. People have asked for the support payments to continue, however others are looking for a final payment and would like to see the scheme closed so they do not have to be involved with it any more. We hope that people are given the choice, however it comes down to the government decision which will be led by the

final report. We believe some people would benefit longer term from regular support.

Beneficiary Comment – *For some beneficiaries in very poor health, having the scheme pay out a lump sum may be better.*

EIBSS Response – We believe this should be a choice for beneficiaries, but this is our personal opinion.

Beneficiary Comment – *The problem is that a chunk of our lives was taken away. If they do not continue with the regular support payments, that would be so wrong. There should be compensation as well as regular payments. They destroyed everyone's lives. If you take the compensation but do not have long to live, it might not be viable to even do anything with that money. There are too many different issues around this.*

EIBSS Response – We think that beneficiaries are best placed to decide what is right for them. It has been a constant concern raised with us that the infected were being drowned out by the affected community. We are here as your voice to ensure this does not happen, although we are here for both, affected people are not so bothered about the scheme continuation as it does not really affect them.

Beneficiary Comment – *We talk about infected and affected as though they are two different things, but infected people are also affected.*

EIBSS Response – This is just terminology which has been continually used, but we do not mean anything by this, nor do we mean that infected people are not also affected.

4. Beneficiary Question – *We come across people every day who find it so hard to prove that they were infected. The new testing scheme has brought about letters informing people of their Hepatitis C diagnosis, and straight away people will say that they are not drug users or sex workers for example. Infected people who are already on the scheme are also wondering if the burden of proof will be placed on them again in terms of eligibility. This is complicated when people struggle to obtain evidence of their eligibility. Can you help me to understand the appeals process?*

EIBSS Response – When an application is made to the scheme, it is sent for medical assessment. We currently have five medical assessors, and each application is reviewed by two assessors. If those two assessors are in agreement, an application is either approved or declined. If one assessor approves the application and other declines it, the application is then sent to a third assessor for review. The majority decision is then taken. If an application is declined, the applicant can then choose to appeal the decision. The appeals panel is made up of a legal chair, specialist in tropical diseases and practicing doctors. They are completely independent from the medical assessors and will review everything seen by the medical assessors as well

as any additional information which may have been supplied as part of the appeal.

Beneficiary Comment – *When an application is declined based on the balance of probabilities, this is disappointing for people. There is still a big issue around self-clearers as people who no longer have Hepatitis C have still had it. There were multiple people infected by the same blood bank, but no records are available as the hospital no longer exists. There has been a lot of downsizing in terms of hospitals. People are concerned about applying when they have no records available to provide as evidence.*

EIBSS Response – People are not necessarily declined based on having no records, it is not quite as black and white as that. Our medical assessors will look at all of the evidence that is available in order to reach a decision and will use the balance of probability assessment when no clear records are available. They look at things such as witness statements, GP records of historic visits and evidence of treatment which led to the use of blood / blood products, for example. We do sometimes receive applications that are very vague where people do not want to or will not provide the necessary information and we also receive fraudulent applications. Often when an application is declined, the appeals process is pursued. We have to try and filter out legitimate applications.

5. Beneficiary Question – *Does this mean that people who have already been accepted onto the scheme would need to prove their eligibility again when it comes to compensation payments?*

EIBSS Response – There should be no reason beneficiaries would need to do this, other than if they were applying for Special Category Mechanism (SCM) or Stage 2 payments (in relation to Hepatitis C).

6. Beneficiary Question – *Will our reference number continue to exist and carry through with any compensation payments?*

EIBSS Response – Your reference number is linked to your EIBSS record, so in terms of our scheme that number connects to everything. However, if a separate arms-length body is set up to administer the compensation payments this may not necessarily connect to your EIBSS reference number.

7. Beneficiary Question – *There are other people on the scheme who are not so affected by their illness. Is it fair that people who have not suffered as much get the same amount as people who have been, or continue to be, severely affected?*

EIBSS Response – The way I (MR) understand it is that individual circumstances will be accounted for in terms of final compensation payment, for example how much harm has been done to that person. If we passed our data on based on the current payment categories we have in place (i.e. Hepatitis C Stage 1, SCM, Hepatitis C Stage 2, etc) it may be that each group would get so much, but that wouldn't take into account personal circumstances such as loss of income, amount of treatment required, etc.

There have been five different awards recommended based on individual circumstances. One of the recommendations was for an independent arms-length body to administer a compensation scheme, and there have been a couple of specialists appointed. We have advised the DHSC that we are equipped to do this, but the route the government are going down is for a separate arms-length body. It would require several panels, medical specialists, etc so there needs to be different ways in place to assess people quickly without causing much distress and considering people who are passing away. These are all crucial factors.

Beneficiary Comment – *Recent figures show that since the IBI started in 2017, 504 people in England, 131 in Scotland, 31 in Wales and 14 in Northern Ireland have passed away, that is 680 in total. Infected people are dying, not the affected. They should be prioritised, and people with a terminal diagnosis should also be prioritised.*

EIBSS Response – We have a range of age groups within the scheme. The majority of our beneficiaries are within their 40's, 50's and 60's (about 70%), but we do have some older and some younger beneficiaries. So if we are talking about guaranteeing payments for life, this would need to consider secondary infectees. The youngest person on the scheme is less than 10 years old and they were infected through birth. When looking at life expectancy, people are living longer so hopefully treatment is working. This gives the DHSC and Treasury something else to consider in terms of support.

Beneficiary Comment – *Hopefully, the treatment younger people receive will be better to give them a longer life expectancy.*

Beneficiary Comment – *Personally, I think that the EIBSS eligibility and application process are good. I would not want people to be able to join the scheme if they cannot prove anything. We have people trying to join our campaign group (CBC) who are trying to defraud the system and they ask how to do this. Within the Inquiry hearings, some people gave oral evidence from Africa and Afghanistan who said they applied to EIBSS and were rejected which they weren't happy about, however when they were questioned it came to light that they had no records of being infected in England, and their genotype was prevalent in their country of origin.*

EIBSS Response – All of this information, such as genotype and likelihood of place of infection are included in what our medical assessors must look at and consider when making an assessment.

Beneficiary Comment – *If the scheme were relaxed too much, it would mean that anybody could apply and be accepted which would ruin the credibility of the scheme.*

Beneficiary Comment – *Personally, I think that the EIBSS eligibility and application process are good. I would not want people to be able to join the scheme if they cannot prove anything. We have people trying to join our campaign group (CBC) who are trying to defraud the system and they ask how to do this. Within the Inquiry hearings, some people gave oral evidence*

from Africa and Afghanistan who said they applied to EIBSS and were rejected which they weren't happy about, however when they were questioned it came to light that they had no records of being infected in England, and their genotype was prevalent in their country of origin.

Beneficiary Comment – *There is still such a lack of awareness regarding Hepatitis C in GP practices, hospitals, dental practices, etc.*

EIBSS Response – We have been working to try and ensure that there is more awareness across the various NHS trusts in regard to this issue.

8. Beneficiary Question – *With regards to the significant increase in fraudulent applications you mentioned, what do EIBSS do to try and weed out fraudulent applications and ensure they do not take up too much valuable time?*

EIBSS Response – We can never accuse anybody of not making a genuine application, therefore any application would still go through the standard process and be sent for assessment. Our medical assessors are best placed to know, based on the information received, what is genuine i.e. symptoms, treatment received, etc. Anybody applying has to meet the relevant criteria to be approved onto the scheme. Sometimes declined applications can later be approved on appeal if further information is provided.

9. Beneficiary Question – *On the EIBSS website, it mentions about improving the service based on feedback. In the minutes from previous focus groups, tax implications have been spoken about, but I am unable to find this information on the website.*

EIBSS Response – This information should have been published on the EIBSS website week commencing 8 January 2024, as well as the other devolved administrations websites. AG will send link to where to find this information on the EIBSS website to all focus group attendees (sent on 28 February 2024).

10. Beneficiary Question – *How long do the NHS keep hold of medical records?*

EIBSS Response – There is no centralised system that holds all medical records. Records are held by individual trusts. The Inquiry has made a recommendation that the onus should be on the scheme to source additional records if necessary. The Vaccine Damage Payment Scheme (VDPS), which is another service administered by the NHSBSA, can approach GP practices and hospitals for records, however there is often costs attached that we have to pay, and the records can take 6-8 months to obtain. This was a legal requirement of the VDPS. If beneficiaries wanted the compensation scheme to source records, they would need to be prepared for a delay, but if beneficiaries already have their records or wish to source them themselves it would be quicker.

11. Beneficiary Question – *I am registered with a haemophilia bank which hold records going back to when this started, but I wonder how obtaining records affects other people?*

EIBSS Response – The National Haemophilia Database only holds records for Haemophiliacs, but not for all who have received a blood transfusion. These applicants must try and source records from the hospital they received treatment at, their GP practice or via Primary Care Support England for example. Historically, the alliance house organisations tracked how many haemophiliacs they had within the service. At the moment, this is not something EIBSS do or need to hold for people on our scheme. For data minimalization, we only hold information relevant to beneficiaries. We have in the past received queries around these statistics.

12. Beneficiary Question – *When Skipton was dealing with Hepatitis C Stage 2 applications, they took into account certain tests and scans. What do EIBSS consider when assessing a Stage 2 application.*

EIBSS Response – The eligibility criteria are listed on the website. It is quite a robust form and our medical assessors do consider fibro scans as well as all of the information provided on the form by the medical practitioner who has completed it, such as liver histology and simple indices predictive of cirrhosis.

13. Beneficiary Question – *Has any further consideration been given to changing the cut-off dates?*

EIBSS Response – This is part of the recommendations and is subject to judicial review. There is consideration being given to extending or removing the cut-off dates, but we are waiting for the final report. We have not been directed to change the scope of the scheme. Another recommendation was to open the scheme up to people infected with Hepatitis B.

14. Beneficiary Question – *Is there a cut-off date for HIV, and if so, what is it?*

EIBSS Response – October 1985 is the HIV cut-off date, but it is not a hard cut-off. All NHS blood in England was being screened for HIV from October 1985 onwards so it is very unlikely, although not impossible, you would have received HIV through infected NHS blood after October 1985. People have been able to provide evidence of infected blood beyond this date where it has been borderline.

15. Beneficiary Question – *Why is there a hard cut-off date for Hepatitis C, but a soft cut-off for HIV?*

EIBSS Response – All NHS blood in England was being screened for Hepatitis C from September 1991 onwards, so similar to HIV it is very unlikely, although not impossible, you would have received Hepatitis C through infected NHS blood after September 1991. However, if people are

able to evidence being infected beyond this date, we will always consider all circumstances and discretion can be applied if necessary.

16. Beneficiary Question – *So we know that benefits advice has now been brought in-house after previously being provided by Neil Bateman, then Amy and Jayne at Benefits Brighton. How many benefits advisors do EIBSS have?*

EIBSS Response – We have recruited two external candidates as Amy and Jayne are retiring. The two recruited have become part of the EIBSS team but are dedicated benefits advisors. HE and Amy (Benefits Brighton) did the shortlisting and interviewing, and Amy used her expertise regarding benefits advice to help pick the best people for the role. We will be sending out letters to all beneficiaries with the 2024/25 payment rates shortly and this letter will include an overview of the new advisors. The new benefits advisors also have a better understanding of beneficiaries as they have received EIBSS background training.

17. Beneficiary Question – *Do they only work on anything else within EIBSS, or are they just there specifically for benefits advice?*

EIBSS Response – They are just there for benefits advice, but this is not to say they may not point people towards support that EIBSS can offer, such as discretionary support. They are both reporting to Sarah, therefore they are able to sign post more of the service. Not all beneficiaries took us up on the offering of the Benefits Brighton service.

18. Beneficiary Question – *What background / experience do they have?*

EIBSS Response – Emma has nearly 10 years of welfare benefits experience and has worked for user led charities and disabled people's organisations across England, specialising in disability benefits for adults and children. Sam also has nearly 10 years of welfare benefits experience and has worked for Student Union advice services, the Royal British Legion and Macmillan Cancer Support. Her most recent role was as a Welfare Benefits Specialist at London Citizens Advice Bureau.

19. Beneficiary Question – *Some beneficiaries are concerned about the NHSBSA holding highly personal information in regard to benefits. Would EIBSS fund separate benefits advisors who are not in-house?*

EIBSS Response – If a beneficiary chose not to accept the support available from the scheme and chose to seek private support, EIBSS would have to consult with the DHSC, but it may be unlikely as it is something the scheme can provide already.

20. Beneficiary Question – *Can anybody access / see the benefits information?*

EIBSS Response – No. Only Emma and Sam have access to the information regarding benefits, the rest of the EIBSS team cannot access this information. It is in confidential files and access is restricted.

21. Beneficiary Question – *As we move forward through to compensation and based on sums of monies already received from EIBSS, it is important that our money is protected. As beneficiaries, we do not have experience on how to manage finances and pensions. Would EIBSS pay for independent financial advice / pensions advice?*

EIBSS Response – Not at present, although this has been fed back to the Cabinet Office and the Treasury. We have benefits advisors as they were part of the original alliance house organisations. There will be no changes to the scheme as things stand until the Inquiry reports. We have said that we believe this support should be available, but at present our liability stops with making payments. We can signpost people to financial advisors, but we cannot provide advice as we would be liable if incorrect financial advice was provided.

22. Beneficiary Question – *Currently, EIBSS offer £500.00 per rolling 12-month period for Motability deposits and car repairs. Could this amount not be raised to £2,500.00 similar to accommodation adaptations, accommodation repairs and mobility aids?*

EIBSS Response – Discretionary applications are supposed to be short-term support for people who need immediate support. Regular payments from the scheme increase each year, therefore they should cover what is needed. Part of the recommendations is to get rid of discretionary applications and introduce a lump sum payment each year.

Beneficiary Comment – *What we are hoping for as a community is that they get rid of discretionary applications and implement the one-off payment each year to cover the support as per the recommendations. It will make it easier for people who are physically / psychologically unwell and put off from applying.*

EIBSS Response – EIBSS currently pay out £1,500,000 each year in discretionary support, which could potentially increase to around £36,000,000 if this change did take place. EIBSS is a demand led service, the money is there for people and there is not a pot which could run out as was the case with the alliance house organisations. But ultimately, any changes in how discretionary funds are distributed in the future will be informed by the response to the final report.

23. Beneficiary Question – *Are Child Payments going to increase?*

EIBSS Response – We are aware that Wales have increased their payments recently, however there are no changes planned to our scheme at present. We have seen less demand for this particular payment now due to people's children growing up.

24. Beneficiary Question – *Are funeral prepayment plan applications only available to Stage 2 beneficiaries?*

EIBSS Response – Yes, but if somebody who is not a Stage 2 beneficiary has received a terminal diagnosis, we can look to apply discretion. We have done this in the past for people who do not want other people to be aware of their condition. Each case is looked at on its own merit. We have recently received a Freedom of Information request specifically around this recently on which I (MR) am currently working.

25. Beneficiary Question – *Is the reason these applications are only available for Stage 2 beneficiaries because they have received a terminal diagnosis? Are they not available for people with a HIV diagnosis?*

EIBSS Response – That is correct, but as we have said we can look to apply discretion if / when needed.

Beneficiary Comment – *There is a lack of knowledge regarding discretionary support available from EIBSS. Some people have never made an application for discretionary support but could certainly benefit from it. On the EIBSS website, it is not immediately obvious what support is offered by the scheme.*

EIBSS Response – A satisfaction survey we conducted which received a 54% response rate identified three primary areas which require updating; the EIBSS website, application forms and the discretionary payment guidance document. The guide has recently been revamped and more detail has been added as to what can be applied for and what each application will cover. This revamped guide will go out with the new payment schedules this year and the document will be uploaded to the website.

26. Beneficiary Question – *Discretionary support can be quite difficult to comprehend. Do EIBSS offer any kind of payment for carers?*

EIBSS Response – We do not specifically offer a payment for carers, but if you think this could be something beneficiaries would benefit from, we could take this to the DHSC and make a recommendation. If you apply for a respite break, we will pay for a carer, if one was required to accompany you on the break.

27. Beneficiary Question – *The sort of problems I have experienced in the past have been around dates, deadlines and rolling periods. I have previously received conflicting information when querying these things. Would it not be good to have an allocated person to go through and tell people what period they can and cannot claim for? I feel like I am set up for failure when it comes to these applications.*

EIBSS Response – What we could do, is when a beneficiary makes an application for a discretionary one-off payment, we could confirm what the remaining allowance is for that particular support element and when the

rolling period refresh date is. This may then make it easier for beneficiaries to keep track of their allowances. Some beneficiaries use discretionary support all of the time and therefore generally are aware of what they have remaining, however some rarely use the support, only if they require it in an emergency. People don't always want us to proactively contact them, but like we say it's information we could provide when an application is made.

28. Beneficiary Question – *With regards to the introduction of psychological support, will EIBSS still provide funding for talking therapy?*

EIBSS Response – The current support scheme will remain in place while the new dedicated psychological support service is set in place. This new scheme is set to be in place by Summer 2024 and will be a bespoke service for those infected and affected. This is following the advice set out in the interim report and will be led by NHS England.

29. Beneficiary Question – *It is so hard to find a reliable therapist who knows anything about infected blood victims. Often, we have to explain everything about contaminated blood, which is retraumatising, before even getting into other issues. WIBSS have introduced specialists. Is this something EIBSS can do?*

EIBSS Response – What NHS England want to do is set up dedicated psychological support similar to this. At the moment, beneficiaries have to find their own therapist and send the details to us. EIBSS are currently helping to prepare a document to act as a background read for counsellors and psychologists to give them greater understanding of the situation. There has been some pushback regarding the wording, but this is being re-drafted and should mean people are better informed before treating you. This is being funded by the Treasury.

30. Beneficiary Question – *A while ago, I applied for a discretionary one-off payment for accommodation adaptations and got signposted to the council. The council have only provided half the funding needed for a new bathroom. I ended up getting frustrated and just paid for it myself. I thought we could come to EIBSS for these grants and the funds were available?*

EIBSS Response – It is a requirement when applying for discretionary support that if there is funding available elsewhere, this must be exhausted first before EIBSS would fund anything. If funding is not available elsewhere, or only partial funding is available, this is when EIBSS may be able to help. A lot of people come to us to let us know what they need, but do not tell us whether or not this is necessary or how this would benefit them. This is often why we must signpost first, then we can help afterwards.

31. Beneficiary Question – *With regards to dental costs, EIBSS only allow a certain amount of funding (up to an NHS band 3 charge). This*

doesn't come close to the funding which is actually needed. Why is that?

EIBSS Response – We can only cover what would be the highest cost incurred when receiving NHS dental treatment, although we do cover private treatment up to that amount. Some people live abroad and therefore do not have access to the NHS. Because of the direction of the Treasury, we have to cap this.

Beneficiary Comment – *Sometimes we find ourselves in a situation where emergency treatment is required, but we have to apply in advance which is not always possible.*

EIBSS Response – If any beneficiary finds themselves in a situation where they are unable to submit an application (for discretionary support) ahead of needing any treatment, we encourage them to contact us to discuss this and see what we can do to help.

32. Beneficiary Question – *How can somebody in our situation, suffering from illness, etc, queue for hours outside of an NHS practice in order to get an appointment?*

EIBSS Response – We would not expect you to. We understand the need for dental treatment linked to illness. One of the recommendations regarding dental treatment was for people to be able to have a dental plan in place in order to make payment for private treatment easier.

Beneficiary Comment – *There is still an issue around obtaining life insurance, travel insurance, etc at a reasonable price. These carry a much higher premium for people with a Hepatitis C diagnosis, which seems so unfair when this is not something we did to ourselves.*

33. Beneficiary Question – *Can you provide examples of what type of employment training beneficiaries have applied for?*

EIBSS Response – We have received applications for things such as a course to work on the oil rigs, a sewing course, and a course to learn how to use Adobe programmes to give a few examples. The purpose of employment training funding is to try to improve employment opportunities for beneficiaries. This may also be available to bereaved beneficiaries to support them to gain employment following the caring duties of the infected beneficiary. This application can be made once per year for up to £5,000.00. Anything costing over that amount needs to be reviewed by the DHSC. The training should really be appropriate to previous career patterns or have a purpose. Funding is not available towards higher education or child education-related costs.

34. Beneficiary Question – *Do you think a change of government will change the way EIBSS operate?*

EIBSS Response – We could not say. The challenge any government has is that there is no new money, so they have to find the money from somewhere. And with other ongoing issues (Horizon, Windrush, etc) this is difficult. It is an ex-gratia payment scheme, therefore the government are not required to make the payments. Neil Bateman promoted changing the scheme to a pension scheme, but as far as I (MR) know this hasn't been progressed and it will remain an ex-gratia scheme.

35. Beneficiary Question – *Do you know yet what the 2024/25 payment rates will be?*

EIBSS Response – I (MR) have recommended a 6.7% increase to coincide with the CPI rate. They have taken it away and it is currently sitting with the UK Minister who is in recess. I asked for a decision before the recess but have not received a response as yet. There is no reason they should disagree as they have used September's CPI rate every year previously. Ideally, we aim to have the letters out by mid-March.

36. Beneficiary Question – *I received a letter from EIBSS a few years ago to see if I was entitled to an uplift in payments. What was this regarding?*

EIBSS Response – EIBSS carried out a look-back exercise about 3 years ago due to an issue raised by a beneficiary. The issue was that means-tested EIBSS payment were taking into account disability elements. The Cabinet Office agreed that we could disregard any disability elements and move people up a bracket, and this meant that people were also back paid.

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.