

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

Meeting type: EIBSS Focus Groups
 Meeting dates/time: 5 September 2024
 Location: Crowne Plaza, London

Attendees from EIBSS NHSBSA:

James Hardy (JRH) – Senior Service Delivery Manager
 Joseph Helliwell (JCH) – Service Delivery Manager
 Hollie Edminson (HE) – Operational Service Delivery Manager
 Sarah Patterson (SP) – Team Manager
 Jess Ballard (JB) – Assessor

1	Welcome																						
1	<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 beneficiaries are welcome to attend and those who do attend can provide feedback regarding the scheme.</p> <p>There were thirteen EIBSS Scheme beneficiaries who attended the EIBSS Focus Group.</p> <p>Introductions of EIBSS service were made.</p>																						
2	Updates from EIBSS																						
	<p>JCH provided a breakdown of the number of beneficiaries on the scheme as of 1st August 2024.</p> <table border="1" data-bbox="268 1496 1471 1962"> <thead> <tr> <th>Infection Status</th> <th>Active Beneficiary Count</th> </tr> </thead> <tbody> <tr> <td>Hepatitis C Stage 1</td> <td>1,407</td> </tr> <tr> <td>Special Category Mechanism (SCM)</td> <td>536</td> </tr> <tr> <td>Hepatitis C Stage 2</td> <td>547</td> </tr> <tr> <td>HIV</td> <td>67</td> </tr> <tr> <td>Co-Infected (HIV & Hepatitis C Stage 1)</td> <td>79</td> </tr> <tr> <td>Co-Infected (HIV & SCM)</td> <td>84</td> </tr> <tr> <td>Co-Infected (HIV & Hepatitis C Stage 2)</td> <td>54</td> </tr> <tr> <td>Carers / Dependants</td> <td>158</td> </tr> <tr> <td>Bereaved Partners</td> <td>786</td> </tr> <tr> <td>Total</td> <td>3,718</td> </tr> </tbody> </table>	Infection Status	Active Beneficiary Count	Hepatitis C Stage 1	1,407	Special Category Mechanism (SCM)	536	Hepatitis C Stage 2	547	HIV	67	Co-Infected (HIV & Hepatitis C Stage 1)	79	Co-Infected (HIV & SCM)	84	Co-Infected (HIV & Hepatitis C Stage 2)	54	Carers / Dependants	158	Bereaved Partners	786	Total	3,718
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JCH advises that in the interest of time, it may be best to go around the room and allow for each beneficiary to ask their EIBSS related queries, allowing all beneficiaries to have a chance to be heard. If time is left afterwards further discussions around IBCA related queries could be had.

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Comments and Questions from EIBSS Beneficiaries

1. **Beneficiary question:** Do you have the numbers of Beneficiaries who die by suicide?

EIBSS response: Cause of death is not recorded by EIBSS .

Beneficiary comment: Mental health and suicides of the community are not being taken into consideration.

EIBSS response: Cause of death is not something that is monitored by EIBSS but we do hold numbers on beneficiaries that have passed away.

Beneficiary comment: The death toll for HIV and HCV mono-infected persons, It was advised that there has been a large number of deaths for HCV infected persons since 2017. This information was gained from FOI requests from EIBSS and data from the Infected Blood Enquiry. This is in part due to the larger number of HCV infected people. This led to a discussion of the breakdown of the Infected Blood Compensation Authority's (IBCA) fourth stage for HCV infected persons and how there is still only one stage for HIV infected persons to apply under.

EIBSS response: EIBSS has no input into the setting of compensation rates or stages, we can note the concern raised and share this with IBCA and Cabinet Office on your behalf.

Beneficiary comment: It is important for EIBSS to know the concerns so that they understand why they may be receiving frustrated calls.

EIBSS response: Thank you for sharing your concerns, we appreciate the need for sharing this.

2. **Beneficiary question:** Will the discretionary payments and winter fuel payments continue to be paid once the compensation payments start being paid and IBCA takes over?

EIBSS response: We don't yet have details on what support payments will look like under the IBCA, we are aware that there have recently been announcements regarding compensation levels and that a further announcement confirmed payments for life ([Government Update on the Infected Blood Compensation Scheme: 16 August 2024 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/government-update-on-the-infected-blood-compensation-scheme-16-august-2024)). However we have not been given the details of this yet.

Beneficiary comment: EIBSS makes the discretionary payments and there has been a mention of support payments, you would think it falls under the same umbrella but they are two different payment types. We don't want people to get confused thinking these are the same thing if they are not.

Beneficiary comment: Hepatitis C Trust has had a 50% increase in calls over this year with queries around discretionary payments and not knowing what is going to happen with them. Up to August 2024 they have received six and a half thousand calls to their volunteer line. There needs to be guidance around this from IBCA. The charity is having to recruit due to increased contact and they have had people referred to them from IBCA for advice and support. The charity does not have the facility to adequately support the community at this rate. Communications from IBCA have been confusing for many, most people are not able to understand the jargon used. Clearer communication is needed and basic tools such as a

calculator should be released so people can have a clear understanding. Trying to work out potential compensation from the different tables is almost impossible.

EIBSS response: Thank you for sharing this, If you have points and they are shared views around the table, we can provide the feedback, that this is a view echoed between all of you, rather than just one voice in the room.

Also if you have any metrics you'd like to share, we can include them alongside what we already have. This would greatly enhance what we share with the Cabinet Office and IBCA.

EIBSS response: We are also relying on the IBCA/Cabinet Office announcements, so we must wait for their updates and provide guidance based on that information. Unfortunately, we cannot answer any questions regarding what will happen after 31 March 2025, because we simply don't know yet. The main goal for today is to hear your thoughts on EIBSS, and any EIBSS specific questions and/or feedback beneficiaries have. Also, if there are questions about the future of EIBSS beyond 1 April 2025, we can hear these too.

- 3. Beneficiary question:** A beneficiary was eligible under the MacFarlane Trust for child support payments; he is now not eligible under EIBSS due to the 'cap' in terms of earnings. There is no cap in other devolved nations, where has the parity gone? Why is he not receiving these payments, and will he continue not to receive these payments in the future? Will this be part of the compensatory payment, or will it continue with the support payments? Will it be included as an extra on top of payments, we need clarification.

EIBSS response: Child payments are means-tested and subject to an earnings cap, which varies based on individual circumstances and is determined by the previous tax year. These criteria were established by the Department of Health and Social Care (DHSC) when EIBSS replaced the devolved administrations' schemes. We are unable to comment on the criteria used in previous schemes.

Child payments eligibility criteria (1 April 2024)

Infection Status	Earnings Cap
Hepatitis C (all stages) and HIV	Household income less than £37,900
Bereaved Partner	Household income less than £28,401
Primary Care Provider (for child of an EIBSS Beneficiary)	Household income less than £28,401

Who can apply

To be eligible to apply for a payment for children, the applicant needs to be registered with EIBSS. Everyone registered with EIBSS holds a unique reference number and will be in one of the following groups:

- Someone historically infected with HIV and/or Hepatitis C from NHS blood or blood products.
- A bereaved spouse, civil or long-term partner who lived with an infected beneficiary.
- Primary care providers of an infected beneficiary's biological child or children.

- 4. Beneficiary question:** Will there be any changes made to EIBSS between now and 1 April 2025?

EIBSS response: EIBSS don't expect any changes this financial year, however if DHSC instruct EIBSS to make any changes we would communicate these appropriately. EIBSS has a responsibility to communicate payment amounts by the end of March each year.

5. Beneficiary question: Is there going to be a telephone line to talk to for IBCA? I am not good with technology and struggle with brain fog. Will we be able to talk to a human being?

EIBSS response: We don't have a definitive answer at this time. However, we've been assured that it will be an accessible service, which means they will need to comply with legal requirements, including offering a telephone option. As for how many lines will be available, we don't know yet.

6. Beneficiary question: It would be very important to pass on to IBCA that they set up focus groups, especially coming up to the end of the year or the running up to March, so that they can answer the questions that you guys can't.

This could maybe even be a joint focus group, but should definitely be with the community because, ever since they have been in operation they have produced communications that have been confusing and elaborate.

They asked us to register with them and help to set up the scheme however I have never and not known anyone to ever receive a response from them. They have forgotten the most important narrative, which is the beneficiaries and the community. They need to realise we are not numbers in a spreadsheet.

EIBSS response: EIBSS understand the importance of focus groups and hearing from beneficiaries directly, we can pass the importance of this forum onto them.

Beneficiary comment: I have a lot of anxiety and fear around losing EIBSS as they are a safe space for me when I call. You have empathy and a kindness that I don't believe IBCA will have.

7. Beneficiary question: I am going to ask these questions, which you will likely not be able to answer but if they can be raised with IBCA that will be appreciated. With regards to support payments, if they are taken as periodic payments, will they rise with CPI each year as they currently do with EIBSS. We have questions coming to the Hep C Trust asking about what will happen if they take the lump sum? Will they get that additional uplift, or will they lose that? The communication around this is not clear.

EIBSS response: The latest cabinet office statement has attempted to provide additional information, which may help answer some of your questions. We will provide the link to this within the minutes of this meeting.

Beneficiary comment: Do you know what is happening with the payments?

EIBSS response: We only know what has been shared on the government website.

Link: [Infected Blood Compensation Scheme overview: Living infected persons](#)
[Infected Blood Compensation Scheme overview: Estates of a deceased infected person](#)

Beneficiary comments: The Government has created a situation where the community are confused due to the over complicated documents and statements that have been put out to the public. There are very educated and highly trained professionals with PhD's, in the community who are struggling to understand the information provided, how are we expected to look at it and know what is happening, never mind explain it to others?

There is a 'cap' in the IBCA payments that has been mentioned and not explained. They have thought of it for a reason but not given that reason. It will make a difference to people's daily lives and benefits, this needs to be elaborated on and cleared up. Transparency is needed within the community.

EIBSS response: Our correspondence is written in line with the national reading age which used to be 11 and is now 9 years. We always try to make the letters and emails we send meet this reading level.

Beneficiary comment: I have raised the issue of the cap via email a number of times with IBCA and have either had no response or been told that this is an issue for the Cabinet Office policy team, are we able to talk to them and who are they?

EIBSS response: We will pass this on to the IBCA and Cabinet Office on your behalf.

8. Beneficiary question: The guarantee letter is not viable as a guarantee letter, but since the payments are going to be guaranteed can you provide a letter that can be used by those who would like to apply for a mortgage? There is a letter available in Scotland but not in England. We would love to see a revised letter.

EIBSS response: We can take this away and look to see what amendments can be made to the letter. There are some limitations to what we can advise in this letter as we cannot advise that EIBSS payments are guaranteed for life as at this point, we do not know if the payments will be classed as from EIBSS or support payments from IBCA.

9. Beneficiary question: Discretionary payments invoices, I was advised that an invoice is not seen as proof of payment. I have asked for the contractor to stamp paid onto the invoice; will this be acceptable?

EIBSS response: Yes, this will be accepted, if you provide us with an invoice it needs to be a paid invoice to show the work has been completed and payment has been made.

10. Beneficiary question: How do you make a funeral prepayment plan?

EIBSS response: A discretionary one-off payment of up to £4,500 is available towards a prepayment funeral plan for an infected beneficiary that has received the Hepatitis C Stage 2 payment.

You will be required to send:

- A completed [funeral costs discretionary one-off payment application form](#);
- A quote for the pre-payment funeral plan.

11. Beneficiary question: Is there anything you can tell us that we do not already know? That is, I walked in here confused and it looks like I will be leaving confused. I was asked by my children to find out about the affected and what will be happening with them, as I was infected and I receive my payments, but my children have had to deal with this for a long time. So, is there anything else you can tell us? When can they apply?

EIBSS response: We can only share what the government have already announced. They've confirmed that those infected will be the first to join the scheme, with the affected being addressed over the course of the next calendar year. That is all the information they've provided so far.

12. Beneficiary question: I can't apply for the funeral prepayment plan because I am chronic Hepatitis C stage 1 and not stage 2, can I? I am going to die one day though, so can my family apply on my behalf?

EIBSS response: Yes, the funeral grant is something your family can apply for, it is something we usually take the invoice for retrospectively and make the payment after arrangements have been made.

A discretionary payment of up to £4,500 is available for the person arranging the funeral, when an infected beneficiary has passed away.

To apply for a funeral cost payment, the applicant must send:

- A completed [funeral costs discretionary one-off payment application form](#)
- A copy of the death certificate
- A copy of the funeral invoice and/or receipt

13. Beneficiary question: There have been a lot of people on benefits, who are on the Facebook group pages, that have been told that their benefits are going to be stopped. I have been telling them to ring you (EIBSS) to get a letter, but why are the benefits systems doing this?

EIBSS response: If a scheme member contacts us to say that this is happening to them, our in-house benefits advisors, Sam and Emma, can contact DWP directly and ask them to amend their system to ensure the meeting is cancelled and no further letters are sent.

Beneficiary comments: This is still extremely distressing and upsetting.

EIBSS response: We fully appreciate this is upsetting, we will continue to pass any comments regarding the upset DWP contact has on the community to DHSC. Please do spread the word about our benefits advisor service, as they will always try and help.

In the letters sent out with the interim payments, we've clearly outlined the benefits advice available through Sam and Emma. We've also stated the importance of declaring these payments to the DWP, as failure to do so may lead to them questioning the source of the funds.

14. Beneficiary question: Will PPC's continue to be automatically be renewed?

EIBSS response: The continuation of PPC's will need to be confirmed to us by DHSC, we will put the question to them.

15. Beneficiary question: Is the compensation tax exempt? Are the support payments tax exempt?

Beneficiary comments: Everything is exempt but the interest. Another point to raise from the Hepatitis C Trust, on the back of this question, is that a lot of people are afraid that they are now going to have to complete tax returns because of the interest earned on the back of compensation payments. This is a complexity they have no idea how to deal with. Fear around the possibility of getting tax returns wrong, tax implications and missed payments.

There is also the fact that if some people take periodic payments and others take lump sums, the periodic payments will not pay any tax and receive the automatic CPI uplifts; whereas the lump sums will need to be wisely invested and pay tax on the interest.

EIBSS response: There appears to be a broader need for support, including additional roles such as financial advice, which will need to be addressed by IBCA. We will share your concerns on this point with IBCA.

16. Beneficiary comment: If you are dependant on your benefits, however much you receive, if you put away a large sum of money and you want to draw on it, if you draw more than £6,000 your benefits will stop. This is because it is considered to be savings.

Beneficiary comment: I think its exempt, is it not?

Beneficiary comment: No, the compensation is exempt, but the interest/earnings are considered savings, and this will be what stops your benefits.

EIBSS Response: It seems this will need to be considered within the broader context of financial guidance, as well as medical, psychological, legal, and benefits advice. We can raise these concerns and emphasise that the compensation scheme should not only provide payments but also offer support, guidance or signposting to beneficiaries for how to manage them effectively.

17. Beneficiary question: I have concerns about IBCA not knowing anything and not understanding us, but my main concern is that they mention that legal aid will be covered. I believe it needs to be our solicitors, if we have one, because they know our cases and they can make the applications on our behalf. We should be able to make use of them and have their costs covered, especially if we do not fit the mould of the applications and supplementary application design. We should not have to have a legal person that they have chosen and defined, as they will not know us. It should be an option for applications but not necessary.

EIBSS response: Is your point, firstly that everyone should be able to make use of their own private solicitors to represent their claims through to IBCA? And two, if IBCA have legal advice attached to the scheme, the only people who used should be those that provided legal input and advice into the report and Inquiry, therefore they have the necessary background knowledge?

Beneficiary comments: Yes, I don't want their solicitors, I want my solicitor to deal with my case.

EIBSS response: We will pass this on to IBCA and Cabinet Office for their consideration.

18. Beneficiary question: They have stated that punitive damages do not sit within the compensation payments. Where do they sit? If this is the worst medical disaster in the NHS history, punitive damages, or exemplary damages as they are also known. Even if they are £1, I want to have them. This means they accept that what they did to us was bad and the treatment that we have received over the years was poor.

Beneficiary comments: Yes, and that's why they won't include it. Because it "smacks of blame". All they are doing is paying us for financial losses, and this really upsets me. These payments are being made on moral grounds not legal grounds. If they introduced punitive damage that would immediately suggest that they have done wrong and they don't want to admit that. They are not morally paying this; they are criminally paying this.

EIBSS response: Unfortunately only IBCA and Cabinet Office can provide an answer to this point, we will of course share this feedback with them.

Beneficiary question: Can you feedback to IBCA that they need to make sure any information they provide is appropriate and accessible, as what has been provided to date is far too technical. It is also across multiple documents which makes it so hard to understand what the latest information is.

EIBSS response: We will pass your feedback to IBCA and Cabinet Office.

Beneficiary comment: I have had a positive experience with the benefits advisors through EIBSS, that helped me with PIP application. They were extremely helpful and spent a lot of time with me on the phone. I would encourage anyone to take the opportunity to talk to them.

EIBSS response: One of the benefits we have seen from having an in-house benefits advice team, is that they have a better understanding of the community. Their background

is solely benefits-based which we believe can be seen in their empathy and readiness to help.

Beneficiary comment: There should be a duty of care for the community whereby we should have access to benefits without application. Just because we attend these meetings and look healthy does not mean that there are not serious illnesses and cases here. Yet we are expected to put ourselves through the processes and strain of the benefits applications and potentially get declined, which is not helpful to our situation.

19. Beneficiary question: The NHS website has changed the date of infection with infected blood to reflect up to 1996, there have been applications made that go past EIBSS criteria date of 1991, why is that the NHS website has changed the cut-off date, but EIBSS has not? Similarly, when will Hepatitis B be introduced, to apply for through EIBSS? The Government have agreed that it is 1996, why have EIBSS not?

EIBSS response: We except that the Inquiry made recommendations regarding the amendment of cut-of dates and the inclusion of Hepatitis B. EIBSS operates to the policy set by DHSC, if DHSC change their policy, EIBSS would be able to accept applications. EIBSS will pass your feedback to DHSC.

20. Beneficiary question: Do you know what the rational was to add in cut off dates for the other infections, when they had not had them previously? There was not one for HIV.

EIBSS response: **EIBSS criteria for the HIV cut-off date has been included here for clarity.**

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.

21. Beneficiary question: How do you go about having the cause of death changed on a death certificate?

EIBSS response: This is not something that we can do for you, but suggest contacting the coroner who completed the death certificate, in the first instance. They can help you look further into death certificates and updating them on the government website.

[Correct a death registration – gov.uk](#)
[The Coroners' Society of England and Wales](#)

Beneficiary comment: We would like to ask that IBCA also take into account the co-morbidities that have come to light with regards to treatment and infection with Hepatitis C. The categories put forward have only taken into account HIV and co-infection when there are so many more things that go far beyond the liver.

EIBSS response: Thank you for sharing that, we will pass the information to IBCA and Cabinet Office.

22. Beneficiary question: Can I give a gift of inheritance while I am alive, without tax implications? Is the person I give the gift to going to be taxed once I die.

EIBSS response: We have the tax regulations on our website. We will provide the link to the tax regulations in the minutes.

[EIBSS website – Finance and support services](#)

Beneficiary comment: The issues around inheritance tax (IHT) are complex, it is the people left behind when we die that have to sort the estate out. Therefore, it would be sensible for those people to have a 'certificate' or statement of all monies received from EIBSS/IBCA that are excluded from being IHT relevant. This would provide irrefutable

information and evidence at the relevant time when winding up an estate. Can this be provided please for payments to date, then updated and issued each time it happens going forward.

23. Beneficiary comment: People who are on SCM, it does not look like they will be recognised in the new compensation scheme. It is creating a lot of unease and anxiety.

Beneficiary comment: It looks to have been covered in the Supplementary Route. Look for the Annex C: Health impacts Eligible For Supplementary Route awards under [Additional awards available through the Supplementary Route](#).

24. Beneficiary question: When applying for acceptance onto the scheme, do you have to start at stage 1 to then move to SCM and stage 2?

EIBSS response: Yes, we require stage 1 acceptance and then we supply the information with the acceptance letter for the next steps to other stages.

25. Beneficiary Question: I am on the working group for the bespoke psychological service from NHS England and have found that there will be 40 counsellors for the whole of the country. Like any new service, it is not going to be available to everyone when it begins. I have asked them, and am raising it with you as well, if I get the EIBSS funding for a counsellor, will I have to stop seeing my current counsellor and move over to the new service?

EIBSS response: We have raised this with them ourselves. We have discussed that if anyone has been approved through EIBSS for payments for counselling that they will be allowed to continue with that counsellor until the sessions cease from our payments.

The service will provide both in person and online sessions. This is specifically for the infected and affected. Information about this service will be publicised by NHS England and EIBSS, at the appropriate time.

Beneficiary comment: Looking at the input and response NHS England have been asking for from those infected, to help set up the service, what I found concerning was that there was only one person who was infected through transfusion. There is not enough equality in representation.

EIBSS response: NHS England have stated that the service is also based upon the findings of the IBI, which includes the views of all infected/affected.

Beneficiary comment: I would be happy with that; however, we need to ensure that there is equal representation as people infected differently have different thought processes.

I would also like to find out if there is anything for children, my grandson could use some help with losing his mother, but various options have changed and closed due to COVID-19 and other situations.

EIBSS response: Are you specifically asking for counselling for children? We do not have an age restriction on who can apply for the talking therapies. If you find a therapist you are happy with for him, you can apply for funding for that.

26. Beneficiary question: Are the people who are going to be a part of this new bespoke service going to have the background knowledge? We could spend hours telling them information, but this is also extremely traumatic and energy consuming.

EIBSS response: This was one of the reasons for setting up the service, so that people will not have to relive their trauma, over and over again going to therapists who do not know or

understand what they have experienced. NHS England have stated that the training materials for supporting staff will be based on learning from the IBI directly.

Beneficiary comment: I have never known a level of confusion and fear created by the sheer amount of incoherent information produced by IBCA. The anxiety and fear the communication and announcements has created is beyond comprehension. Who can understand all this? We have highly trained professionals like engineers and doctors in our groups and they do not understand it.

EIBSS response: We fully appreciate the need for clear communications on this matter. We will pass on your concerns to IBCA and Cabinet Office. To help in passing this information on, what do you think could help you understand or make IBCA and other compensation related communication with you better?

Beneficiary response:

- **Online calculator** – answer a series of questions that provide you with an estimated answer in the end.
- **Write in plain English** – use simple language. There is no reason to use the language they use. It should be made easy enough for a child to read. There are some people that have serious cognitive issues as well.
- **Webinar or focus group** – The IBCA reps could then come onto the platform and take the feedback directly, rather than leaving it to you and the charities to take on the brunt of the work. They can clarify the information there and then.

27. Beneficiary question: Please can you feed this back to IBCA. Why have they created a fourth stage for HCV, this makes no sense and seems like they are trying to make it harder for those who are suffering to receive payment. Why did they move away from the three-tier system? HIV only has one stage.

There needs to be transparency and engagement with the community. They have not made apparent what conversations have been had between the expert group and Cabinet Office.

EIBSS response: We will pass the points you've raised to IBCA and Cabinet Office.

Beneficiary comment: There is a section in the report released by Sir Robert where he talks about transparency and where there is an obligation for them to release the information on how they reached their outcomes. Hopefully this is going to be done soon.

Beneficiary comment: reference to Page 23 in the report – 'had there been a longer period of engagement' – the outcomes and IBCA have been rushed.

28. Beneficiary question: Will there be another focus group?

EIBSS response: We are not sure at the moment. However, we were considering a virtual focus group like the ones held during COVID-19, we had multiple groups that allowed us to hold more sessions with more people. This is something we are considering for January 2025; it is something we will still need to discuss though.

Beneficiary comment: I was going to suggest someone senior from IBCA to attend.

EIBSS response: We will need to align our focus group with what is happening with IBCA and payments at that time. The plan is sometime around January 2025. Once we know more about it, we will certainly let you know.

Beneficiary comment: It also should be people from the policy team so that they can actually answer questions. We need them to engage with us and see who we are and hear our stories.

30. Beneficiary Question: Under Data Protection, will it be EIBSS who send a letter to all recipients for agreement to move their data to IBCA? How can the recipient see all that data to verify it is correct pre-migration?

EIBSS response: At present, we do not have a great amount of information about this however, as EIBSS hold all beneficiary data, we would imagine it will be likely that we will help facilitate this. As IBCA are still in the early stages, the 'how' has not yet been decided.

Beneficiary comment: HIV treatment is now much more effective than early treatments, this is mirrored by HCV treatment which is also now more effective. With that parallel being the case, it is difficult to understand why IBCA treats HIV and HCV so differently not only with the severity bands for HCV where none exists for HIV, but also in the chasm between HIV/HCV compensations. This is a form of discrimination and should be addressed.

Beneficiary comment: The generalisation of the long-term treatment of Hepatitis C, has not been addressed. Anyone who had treatment with known drugs with terrible side effects (such as interferon), clearly will have suffered more than those who did not, including how long they had that treatment for. It should therefore be recognised that a one-size fits all approach within the 'Injury Impact' award for 'Chronic Hepatitis C' is not right and should be changed.

All focus group questions and answers will be collated and shared with DHSC and beneficiaries.