

England Infected Blood Support Scheme (EIBSS) Focus Group

Minutes

Meeting type: EIBSS Focus Group Minutes
Meeting date/time: 30/11/2021 to 03/12/2021
Location: Via Teams

Attendees from EIBSS NHSBSA:

James Byers (JB) - Teams Manager
Hollie Edminson (HE) – Service Delivery Manager
Mal Ross (MR) – Service Delivery Manager
June Omadoye (JO) - Admin support

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 beneficiaries who the scheme supports. All beneficiaries are welcome to attend and those who volunteer can provide feedback regarding the scheme. Feedback can also be submitted anytime directly to EIBSS.</p> <p>There were Fourteen EIBSS Scheme beneficiaries in total who attended the EIBSS Focus Groups across the three dates. Introductions were made and everyone was welcomed to the focus groups.</p>
2	Updates from EIBSS
	<p>Mal Ross, Service Delivery Manager gave an update on the EIBSS service and the primary focus of the team;</p> <p>Current EIBSS scheme members: There are currently 3,166 members of the EIBSS scheme as of the 1st of November 2021, detailed as follows:</p> <p>Hep C Stage 1 = 1189 Hep C Stage 2 = 562 SCM = 564 HIV = 63 Hep C stage 1 + HIV = 85 Hep C stage 2 + HIV = 57 SCM + HIV = 87 Carers & Dependants = 45 Bereaved not infected = 514</p> <p>Parity Payments: The Cabinet Office announced changes to the scheme on the 25th of March 2021 to bring broader parity across all of the devolved schemes, and EIBSS received confirmation of the changes on the same day. The team have subsequently been focussed on understanding the changes, creating digital payment solutions where required and ensuring correct payments could be made to affected beneficiaries within the calendar year where</p>

possible. The majority of the payments were made to beneficiaries in July 2021 and September 2021.

***Updated** – By **31/12/2021**, the total breakdown of parity payments paid as a result of the announcement is 3,449 payments made, totalling an additional £94,007,628.

The full payment breakdown is listed below per condition:

- HIV - £10,650,500
- Hep C/ SCM - £56,740,000
- Bereavement Lump Sum - £60,000
- Bereaved partner payments - £26,557,128

There are 24 beneficiaries where further information is awaited from DHSC, to review and calculate if any additional payments are required to be made as a result of the announced changes, these cases will be resolved as quickly as possible once the information is received.

Income Top-Up (ITU): Income Top-Up payments will be replaced by bereaved partners payments from 01/12/2021. A re-assessment is ongoing to review historic ITU payments for FY 18/19, FY19/20, and FY 20/21 due to a change in the assessment criteria to exclude any disability related elements from the means tested assessment.

EIBSS are working with DWP to identify if they can provide the additional data required to enable the recalculation, otherwise EIBSS will be writing out to beneficiaries to request any additional information to enable a re-assessment where required. If there are any recalculated payments to be made, these will be paid directly to the beneficiary, with 8% interest added. This work will continue across 2022.

Neil Bateman - benefit advisor: Neil Bateman has now retired and there are temporary benefit advisors in place to ensure a continuation of the service. The benefit advisors are Amy Swinnerton & Jayne Knights, and they will continue providing benefit advice for beneficiaries until a procurement exercise has been completed for permanent longer-term advisors. Beneficiaries are advised to use Amy and Jayne's services where required. The support they provide has received positive feedback from beneficiaries and support groups.

Compensation Framework / Public Inquiry: MR informed the beneficiaries that Sir Robert Francis has extended the deadline for written submissions to Sunday 19 December 2021. Beneficiaries are advised to submit any information to the compensation framework that they wish to be considered by this date. Sir Robert's report to the Government will now be submitted no later than Monday 14 March 2022.

Future communications exercises and Support Groups: EIBSS are also looking at how to raise awareness about the EIBSS scheme across networks of trusts, GP's and also through social media channels. This awareness is to encourage people to get tested and come forward for EIBSS Scheme support where appropriate.

EIBSS are in contact with The Haemophilia Society, Hep C Trust & Terence Higgins Trust to assist in raising the awareness of the EIBSS scheme within their communities, and to encourage people to get tested UK wide and to come forward if there is any possibility of them having received infected blood or blood products from the NHS in England.

There is also a DHSC press release planned for December to encourage bereaved partners to come forward to receive the newly created bereaved partner payments. Backdated payments can be claimed until 1 April 2022. Bereaved Partners can still come forward and join the scheme after the 1 April 2022 date, but their payments would start from date of application, and not backdated to 1 April 2019.

	<p>Satisfaction Survey: EIBSS intend on sending out a satisfaction survey to beneficiaries in the new year to gather feedback on the EIBSS service as a whole. EIBSS drafted a survey to send out to all scheme members earlier in 2021, but due to the prioritisation of the Parity Payments, the survey was put on hold whilst everyone focussed on delivering these. The survey will be revisited and updated in 2022 and will be sent out once all of the parity changes are concluded.</p>
3	Comments and Questions from EIBSS Beneficiaries
	<p>MR informed the focus group attendees that all queries received from the focus group meeting will be compiled and shared with Department of Health and Social Care (DHSC), with responses to all questions to be uploaded on the EIBSS website for all beneficiaries.</p> <p>1. Is there any help available for parents who had lost their child through infected blood?</p> <p>EIBSS Response: NHSBSA administers the EIBSS scheme in accordance with a scheme specification (a set of rules) provided to NHSBSA by DHSC. Financial support for parents who have lost children due to NHS infected blood or blood products is not currently part of the scheme specification.</p> <p>The Department of Health and Social Care (DHSC) are awaiting the findings of the Infected Blood Inquiry (IBI) and any recommendations it makes regarding possible changes to the criteria relating to Parents and/or children.</p> <p>The EIBSS Scheme has evolved over the years to offer counselling for parents and family members, and most recently to include Bereaved Partner payments. The scheme will continue to evolve, where it is agreed with DHSC that changes should be made and the rules EIBSS works to are updated.</p> <p>2. Beneficiaries would like bereavement counsellors for parents who lost their children through infected blood, as they feel their children have been forgotten as they've had no support as bereaved parents.</p> <p>EIBSS Response: EIBSS explained that counselling is available to parents who have lost their children through infected blood if they were registered with either EIBSS or an AHO previously, and can choose any preferred counsellors, including bereavement counsellors. EIBSS will pay up to £900 per year towards this.</p> <p>To apply for the counselling discretionary payment, the applicant must be either:</p> <ul style="list-style-type: none"> an infected beneficiary registered with the England Infected Blood Support Scheme (EIBSS) a bereaved beneficiary registered with EIBSS family members of an infected beneficiary registered with EIBSS or previous schemes <p>Please see the https://www.nhsbsa.nhs.uk/counselling-support section of our website for further details.</p> <p>3. Are there any plans to widen the scope of the scheme? For example;</p> <p><i>Help for parents who are bereaved and bereaved children who have lost their parent/s to be considered for the EIBSS Scheme. Beneficiaries requested the inclusion of parents who had lost their child to be part of the EIBSS scheme.</i></p>

EIBSS Response: Changes to the scheme do take place, as per the recent Cabinet Office announcement, there is now support for bereaved partners, with regular ongoing payments starting in December 2021.

However, DHSC are awaiting the findings of the Infected Blood Inquiry (IBI) and any recommendations it makes regarding possible changes to the criteria relating to widening the scope of the scheme. Until the recommendations are completed and received by DHSC, EIBSS are not able to change the criteria of the current scheme.

4. What will happen with the Inquiry recommendations, in terms of who would administer all the payments to beneficiaries?

EIBSS Response: EIBSS confirmed that the NHSBSA would continue to make existing payments and will work with DHSC regarding any Inquiry recommendations.

5. Some beneficiaries want a one-off compensation payment, some want ongoing support, or compensation payment with ongoing regular support.

EIBSS Response: EIBSS explained that any recommendations made by the IBI to DHSC would be reviewed.

EIBSS are unable to plan or resource in advance of the IBI recommendations, however, staff and the resourcing required to implement any agreed IBI recommendations would be prioritised once requirements are known. The IBI may make recommendations for any of the above support scenarios requested.

It was requested by an attending beneficiary that there should be a lived experience beneficiary support steering group which should contribute towards the Inquiry recommendations. Beneficiaries are advised that they should contribute their views and/or experiences directly to the IBI to ensure these are considered.

EIBSS confirmed that as a scheme, we cannot be part of beneficiary steering group, but beneficiaries are able to share their experiences with support groups and/or core participation groups involved within the IBI.

Beneficiaries are advised that Sir Robert Francis and Sir Brian Langstaff do host physical meetings that beneficiaries can attend, and their input is important. Beneficiaries are also informed that the Inquiry also holds focus groups periodically for beneficiaries to attend so that everyone is involved in the Inquiry

EIBSS confirmed that some beneficiaries would prefer a one-off lump sum compensation payment, some would prefer continued ongoing support, while some would prefer a lump sum compensation with ongoing support.

6. Will EIBSS be handling the results from the Public Inquiry and Compensation payments, or will it be outsourced to someone else?

EIBSS Response: When the results of both the IBI and Compensation framework are known, NHSBSA could be approached by DHSC to administer the resulting payment changes.

7. Communications to EIBSS beneficiaries:

Feedback was received on communications sent to beneficiaries regarding parity payments, advising the letters were difficult and confusing to read, and hard to understand for some beneficiaries. It was asked that EIBSS communicate using language that could be easier to understand when future communications are sent to beneficiaries.

Letters received from EIBSS can be very scary and worrying when received and the information included is not always clear and possibly intimidating.

EIBSS Response: MR apologised, advising EIBSS always try to send out easy read communications for beneficiaries, but unfortunately the Parity changes were very complex with different scenarios, which has been challenging to communicate.

The EIBSS team tried to communicate the Parity payments clearly and simply, including the relevant information, however, will take onboard the feedback to make communication improvements where possible.

8. How do I apply for a respite break?

EIBSS Response: The information is on the EIBSS website however, JB will send an application to the beneficiary who asked the question, the beneficiaries GP can assist them in completing the respite break form.

9. Why is a procurement exercise required for Benefits Advisors?

EIBSS Response: Jayne and Amy are working well with beneficiaries and have earned the beneficiaries trust through providing helpful assistance. However, Jayne and Amy were only put in place temporarily whilst a permanent supplier can be procured. NHSBSA is a public organisation and has to follow transparent procurement practices to appoint a longer term supplier.

EIBSS will shortly begin tendering for the future supplier to provide the benefit advisor support. The future scope of the future supplier has been informed directly by the assistance Jayne and Amy have provided to-date. There may be the opportunity for beneficiaries and support groups (Hep C Trust, Haemophilic Society, Terence Higgins Trust) to provide further input into the future contract and have been approached to speak with their communities. Any further suggestions are welcomed from beneficiaries but there is very limited time to do so.

It was asked if there are ways for EIBSS to pro-actively ask the community for assistance to contribute to the benefit advisor procurement – through Facebook groups for example, instead of suggesting that beneficiaries should approach EIBSS directly. MR explained that communities, support groups and campaign groups have been approached previously and invited to submit requirements for consideration.

10. Will you confirm EIBSS payments are for life and confirm in a letter as Matt Hancock promised the Inquiry?

Updated EIBSS Response (23.03.2022): During the Infected Blood Inquiry hearing in May 2021, the previous Secretary of State of Health and Social Care, Matt Hancock, was asked about the Government's future intention regarding the support provided to those infected and affected.

Mr Hancock provided a few related responses within his statement, details of where these can be found are included below. The most relevant response from Matt Hancock's statement is shown below for clarity.

"Yes, I would absolutely give a commitment to anybody receiving a payment, any of the beneficiaries infected or affected, that I would expect that to continue for their lifetime, absolutely. That's my expectation. I would say it goes without saying but sometimes these things need to be said".

The related points to this question can also be found on the [Infected Blood Inquiry website](#), evidence section within Transcript- London- Friday 21 May 2021.

Page 133 section 22- 25 & page 134 section 1- 3

Page 194 section 21- 25 & page 195 section 1- 4

DHSC are awaiting the findings of the Infected Blood Inquiry (IBI) and any recommendations they make, and as a result, are unable to confirm 'payments are for life' as the IBI may recommend different options, however, a letter can be provided to confirm EIBSS payments are currently being provided and are expected to continue for as long as they are needed.

11. Why is there a specific list of medical conditions on the EIBSS website relating to moving to Special Category Mechanism stage? Who developed the list, what consultation took place – and do I need to be monitored for these specifically?

EIBSS Response: MR confirmed he would investigate the Special Category Mechanism list further and also check on the query regarding specific monitoring as EIBSS staff are not medically trained.

UPDATE: NHSBSA cannot say for certain why these conditions are listed specifically, as we administer the EIBSS scheme based on the scheme specification which was provided to us by DHSC.

However, the majority of the medical conditions have been in place for many years, when the scheme was administered by the Alliance House Organisations (AHOs), prior to EIBSS becoming the administrators on 1 November 2017.

There was a detailed consultation on Special Category Mechanism (SCM) in early 2017, which resulted in changes to the conditions, details of this consultation can be found at:

<https://www.gov.uk/government/consultations/infected-blood-support-special-category-mechanism>

EIBSS can offer an opinion on how the original list was developed, which is that it was likely to have been based on the medical literature available at the time looking at the 'odds ratios' of these conditions - if they were statistically more common in patients with hepatitis C than matched controls (i.e., patients of the same age and sex without hepatitis C).

Generally, the only patients who do need monitoring, even after they have become PCR negative (A PCR test establishes whether the virus is still active and needs treating), are those with cirrhosis and these patients should remain under the care of a specialist who will advise what monitoring they require.

As part of the 2017 consultation the Government stated: *“Going forward, we will keep the scientific literature under periodic review for possible inclusion of other hepatitis C related complications to the stage 2 criteria based on life expectancy”*.

12. Is there a specific reason beneficiaries receive support for dental treatment? Are we at increased risk of dental problems, and does this need to be monitored?

EIBSS Response: Hepatitis C has been known to cause oral health issues and thus was included within the scheme specification, as the scheme provides discretionary support to cover costs that have been brought about as a result of infection or its treatment and are otherwise unable to be met. These issues are most likely to be linked to cirrhosis, so should be considered as part of monitoring.

13. Do EIBSS hold data on beneficiaries who may have died before EIBSS was established, and were members of the previous schemes?

EIBSS Response: EIBSS confirmed we only hold data of beneficiaries where explicit consent was given for their information to be transferred to EIBSS, for support payments to continue.

EIBSS do not hold data of beneficiaries who did not sign explicit consent for their records to be transferred to EIBSS when Skipton Fund, Macfarlane Trust, Eileen Trust, MFET and Caxton Foundation ceased.

14. How can I retrieve my medical records?

EIBSS Response: Information can be found on the EIBSS website here:

<https://www.nhsbsa.nhs.uk/who-can-join-scheme-and-how-apply/requesting-medical-records>

15. How much are bereaved partners paid?

EIBSS Response: Bereaved partner payments are paid at the same rate as their partners; and receive 100% equivalent payment for first 12 months then reducing to 75% following the 1st year anniversary of their passing.

16. Do I need to appoint a lawyer to represent me for the Inquiry and to receive Compensation?

EIBSS Response: Beneficiaries do not require a lawyer to act on their behalf as they can receive any information about the Public Inquiry directly via the Inquiry website.

Information can be found on the IBI website:

<https://www.infectedbloodinquiry.org.uk/about/legal-representatives>

However, this did create some discussion between the beneficiaries at the focus groups; A law firm had given an update to a beneficiary about possible outcomes of the Inquiry, indicating they could also file a lawsuit against the government, but the law firm would deduct 15% payment of any settlement.

Another beneficiary stated that in terms of having a lawyer for the Inquiry, it is their choice and also any lawsuit to the government is their choice but not required, and if any beneficiary still wanted a lawyer, then it is advisable to wait for the outcome of the Public Inquiry.

Another beneficiary also talked through the objectives of a campaign group he is part of and that any beneficiary is welcome to join.

Charity organisations and Campaign groups can be found on the Public Inquiry website here:

<https://www.infectedbloodinquiry.org.uk/about/core-participants>

17. Discretionary Payments for Employment Training – can it be reviewed and increased?

A request was made for a change to the Employment Training criteria, to increase and also include further / higher education and Degrees, as this would assist in gaining employment in current job market.

EIBSS Response: MR confirmed this request will be passed to DHSC and will feedback the outcome of this question to beneficiaries.

DHSC Response: There is no set maximum for the Employment Training grant which can already be used to pay for adult further education courses. There are no plans to extend this payment to Higher Education courses as separate funding arrangements already exist. You can find out more information from <https://www.gov.uk/get-undergraduate-student-loan>

The Skills for Life campaign has information about training courses to help people improve their skills to get the job they want. More information can be found at <https://skillsforlife.campaign.gov.uk>. This is run by the National Careers Service which provides information, advice, and guidance to help people of all ages make decisions on learning, training, and work – visit <https://nationalcareers.service.gov.uk> or call 0800 100 900.

18. £900 limit for counselling – can it be increased / uncapped?

A request was made for an increase / limit removal of the £900 available for counselling. Unfortunately, some people require weekly counselling sessions and can cost around £70 per session. This limit would only cover around 13 weeks of the year, so more funds should be made available for counselling.

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

MR confirmed this request will also be passed to DHSC and will feedback the outcome of this question to beneficiaries.

DHSC Response: We are working with the EIBSS team and NHS England and Improvement to consider how the current psychological support offer could be improved. In the meantime, beneficiaries with greater need should contact EIBSS to apply for discretion to be applied in their case.

19. Is there any specific psychological support available to beneficiaries, like the other schemes?

A request was made for EIBSS to provide additional psychological support as this is highly required by beneficiaries and there should be more funding for psychological support for beneficiaries.

EIBSS Response: MR confirmed that investigative conversations are ongoing with the Devolved Administration schemes, but they are all structured differently, depending on the Country.

As the NHSBSA who administer the EIBSS scheme is an organisation who provide at scale administration and payment related support, they are not able to be part of a patient healthcare journey. NHS England and Improvement (NHSE&I) are responsible for the provision of local psychological support and are being consulted with, to investigate possible future support options.

DHSC are in discussions with NHSE&I to understand all possible psychological options within England, no timescales are available for this.

20. Can we change the scheme name from England Infected Blood Support Scheme (EIBSS)?

A request was made asking if the name of the EIBSS scheme can be changed due to the stigma it attracts, especially when making applications and having to disclose where payments come from, as a quick search online explains what EIBSS means.

EIBSS Response: JB explained all information sent from EIBSS to beneficiaries is in the strictest

of confidence, plain envelopes used, and payments made to beneficiaries' bank accounts state that the payments are from 'NHSBSA Hosted 6' and not EIBSS.

No suggestions were made regarding alternative names.

MR confirmed this request will also be passed to DHSC and will feedback the outcome of this question to beneficiaries.

DHSC Response: There are no current plans to change the name of the Scheme. There are a number of regulations in place so that payments from EIBSS are not taxed or counted as income for certain means tested benefits. For these payments to be discounted it is essential that they are attributed to an Infected Blood Support Scheme.

21. How much has EIBSS operating costs increased this year, to deliver the Parity Payments?

EIBSS Response: MR stated that the operational costs would not be available until after the end of the Financial Year. However, as EIBSS is a directed service by DHSC, it is not resourced and funded like the previous Alliance House Organisations. Three additional staff were recruited temporarily to assist with the changes required following the Cabinet Office announcement in March 2021, to ensure the changes could be delivered as requested.

22. Can Scheme assessors on the EIBSS team attend future focus group meetings?

A request was made for the EIBSS scheme assessors to attend the focus group meetings so that beneficiaries can meet them and put a face to the name of their EIBSS scheme contacts.

MR explained that due to the current workload and how the EIBSS scheme operates this may not be possible but would investigate any option where this might be possible for future focus groups.

MR also confirmed that future focus groups would be held digitally until further notice, whilst the current COVID guidance is in place.

HE, JB & MR thanked everyone for attending the focus groups.

*Minutes, questions and answers finalised and published on 25 February 2022.

Updated Q10 response on 23 March 2022