



# England Infected Blood Support Scheme (EIBSS) Quarterly Accountability Review Meeting

# **Minutes**

Meeting type: Meeting date/time: Location:

#### Attendees:

### DHSC

Tim Jones (TJ) Helen Got (HG) Thomas Reed (TR) Nigel Zaman (NZ) Joanne Hindmarsh (JH)

## Apologies:

Gill Eleanor Ikin Alastair EIBSS Quarterly Accountability Review Meeting Tuesday 21 January 2020, 11:00-13:00hrs Video conference

#### NHSBSA Dan Britton (DB) James Hardy (JRH) Linzi Fowler (LF) James Byers (JB) June Omadoye (JO) Hollie Edmondson (HE)

Chairs Introduction Thomas Reed welcomed everyone to the meeting and introductions were made.
Review of previous minutes and actions (Papers 1 & 2)
The action points from previous minutes held 22 October 2019 were reviewed;
01 – TR has shared the official treasury letter with Bahar and Eleanor. This action is now Complete.
<b>02</b> – TJ to write letter to NHSBSA setting out GLD's concerns about NHSBSA representation a the Infected Blood Inquiry. <b>Carried Forward</b>
<b>03</b> – TJ to provide funding letter for EIBSS 19/20. This action is now <b>Complete.</b>
<b>04</b> – MOU and specification approval – the agreement of the specification is still ongoing and has not yet been finalised. The first Joint Review Group (JRG) meeting which will be held Friday 31 January 2020 and the outcomes of the JRG will feed into the final draft of the specification for sign-off. The MOU will be looked at separately, as the priority is the specification agreement.
<b>05</b> – TR to include DHSC finance in future funding discussions. TR has noted this and finance are looped in to any funding discussions. This action is now <b>Complete.</b>
06 – Issue regarding missing 460 beneficiaries, to be discussed in this meeting. Carried Forward

#### General Update

TJ gave an update on Devolved Administrations– parity update. TJ informed the meeting that the Minister for the Cabinet Office, Oliver Dowden MP and DHSC Minister Nadine Dorries MP (Minister for this policy area) will meet with infected and affected representatives on Tuesday 28 January 2020. The meeting will be more about the parity, which could lead to operating a consultation across the UK which would probably include options along the spectrum of the parity.

TR updated that since the last meeting and general election, the Government and Ministers have returned to their original posts, which has meant that Nadine Dorries MP remains the Minister for EIBSS. There will be a reshuffle in February 2020, but no confirmation at the moment on whether this area will be affected.

#### Russell Cooke / legacy data arrangements

This was discussed at the last meeting, as this this in relation with the Alliance House data. All files from the 5 charities were taken over by, 3<sup>rd</sup> party solicitor Russell Cooke as data controllers. There are 460 beneficiaries who were registered with the Alliance House organisations but did not move over to EIBSS in 2017 because they did not provide explicit consent for their data to be shared with EIBSS when they were written to. This is regarded as an issue from risk / audit perspective. TR has been asked by the National Audit Office (NAO) in the last couple of weeks about this and they have been informed that this is in hand. The 460 beneficiaries need to be accounted for as they are part of the EIBBS budget. At present a financial buffer is maintained, in case the 460 beneficiaries materialise to re-join the scheme but this cannot continue. If these beneficiaries do show up, many of their payments will be backdated to the date of the application to the previous schemes, which would be a significant amount of money. Sadly it is likely that a number of this cohort will have passed away, but regardless they need to be followed up and accounted for.

DHSC explored the possibility of closing down the Russell Cooke agreement and spoke with JRH about NHSBSA taking over as Directors of Skipton Fund and thus becoming data controllers for this data, the advice from GLD was that it was not feasible, as the practicalities and risks associated with this were untenable. This would have included NHSBSA being required to maintain a separate team of staff from EIBSS operations, to act as data controllers of the legacy records.

TR confirmed that to get to the best result for these missing beneficiaries is to have a meeting with the all parties, to work the problem and hopefully come up with resolution.

**07 ACTION:** TR to arrange a separate meeting to workshop anything that can be done within the confines of Information Governance to resolve this issue.

#### DWP - PIP assessments

The Cabinet Office has raised the issue of PIP Assessments with DHSC and the affect that this recurring process has on beneficiaries. This issue was also raised at the last EIBSS focus group.

TJ's initial feedback to the Cabinet Office was that EIBSS takes the issues of the beneficiaries very seriously hence why they hold focus groups. The attendees agreed that a further meeting on these issues will need to take place to work through the issues that beneficiaries go through and what DWP can do to prevent these from taking place.

One such improvement is to advise beneficiaries that a letter confirming that the person is an EIBSS beneficiary can be provided, which will act as evidence to DWP for any questions of the source of EIBSS funding and possibly to negate the need for an PIP assessment to place or a simplified version of it. JB confirmed that EIBSS do have a letter template that has been provided on an ad hoc basis previously to beneficiaries.

TJ stated that he was waiting for a clearer steer from the Infected Blood Inquiry around whether Page 2 of 4

they want the department to look into this issue further as a priority.

#### Feedback

With regards to the focus groups, TR wanted to know if after the focus group meetings, key points generated from the minutes are shared with beneficiaries, and currently we do not. The notes are shared with DHSC for visibility of the types of feedback provided. The requests for changes will now be fed in to the recently formed JRG and the outcomes of this will be communicated to beneficiaries.

TR asked whether EIBSS could investigate engaging with beneficiaries through surveys and newsletters, as regular sources of communication and feedback, as Scotland and Welsh schemes adopt this approach. JRH confirmed that EIBSS have previously surveyed beneficiaries but the questions would need to be reviewed, once the review is complete a draft question set will be shared with DHSC

**08 ACTION:** NHSBSA to draft survey questions and provide these to DHSC for agreement.

#### Finance Modelling

TR informed the team that he was involved in some modelling work with the DHSC analyst team on the structure of EIBSS services. The model relates to beneficiary flow of people entering and progressing through different stages of the scheme, beneficiaries who had sadly passed and how this ties in with finances, how much is spent, how much the DHSC currently pays and how much will be likely paid in the future towards the very end of the scheme. The analyst updated their assumptions around treatments as they realised that they have not updated the model with the latest Hep C treatments, and considered the impact this will have on beneficiaries' mortality rate and provision of payments whilst living. The model has now been updated and reflects the decreasing mortality rate, as beneficiaries will be living longer and receiving more payments over a longer time period.

With regards to HIV treatment and mortality, a similar exercise was done around this, updating on HIV treatment with the latest drugs changing every couple of years. TR explained that speaking with Hep C and HIV specialists / consultants, it is confirmed that the life expectancy and mortality rates are now broadly in line with the general population. The rationale for doing this is to model the long term financial affects to the scheme. The model will be a working project, as the information evolves, the model will too.

#### FOI Requests and Correspondence Handling

TR, queried if the method on how FOI (Freedom of Information) is handled through the DHSC & NHSBSA works well and should just continue as it is. JRH confirmed that the FOI method works well, he confirmed that if the request is for data about the scheme then the requestor should be directed to EIBSS, as we hold the data.

4	NUSPSA Updates
+	NHSBSA Updates
	Medical Assessors HE confirmed that the number of applicants has been positive, higher than any other previous recruitment for these roles. EIBSS are reviewing applications regularly to streamline the final shortlisting process upon advertisement closure. Our current medical assessor is assisting with identification of the applicants who are suitably qualified and experienced for the EIBSS role. Interviews will be held in February with the successful applicants to start beginning of March.
	The appeals panel chair advert has been published in the medical journal, with a mid-March closure date. The existing chair has agreed to assist with shortlisting and to provide a handover to the successful applicant. This is a lower risk recruitment, as there is a window of time available to the scheme prior to the next appeals panel being required.
5	Data Paper 3
	EIBSS Dashboard / MI Report

	JRH gave an update on the data. There are no amber or reds in the KPIs. All service levels throughout the month are green and progressing well.
	ACTION: JRH to update TR & TJ on the newly adapted KPI's, including background on how these were agreed.
6	Finance Paper 4
	Year to date JRH updated that the forecast is a recurring pattern i.e. High, low, low, High, as the high months relate to when the scheme makes quarterly payments. JRH confirmed that a slight overspend is predicted i.e. circa. £76m opposed to the budgeted £75 million, however monthly drawdown requests and reporting allow for the spend to be closely monitored in the later stages of the financial year.
	<b>09 ACTION</b> : TR to liaise with finance to see what process may be needed to fund the slight overspend.
	HG raised some specific questions about lines in the monthly finance report; JRH advised that it would be best for HG to speak with the author of the report directly.
	10. ACTION: JRH to provide HG with the NHSBSA Chief Accountants contact details.
7	Governance Paper 5
	Risk and Issues Register
	The Issue regarding the missing 460 beneficiaries, was discussed at agenda item three and the next steps will be taken forward as per ACTION 07.
	RED RISK- Lack of current medical assessors. Mitigating actions are in place i.e. the active recruitment exercise discussed at agenda item 4 but remains a red risk until the recruitment is complete.
	All other risks were reviewed and mitigation is appropriate.
8	Any other business
	a) Date of next meeting Tuesday 28 April 2020 at 11:00 to 13:00.
	b) TR asked if the group felt that from the known feedback from beneficiaries whether a public consultation would be welcomed and well received. JB confirmed that through focus groups meetings held, beneficiaries have made it known that they would like to get involved in any public consultation. TR confirmed that the DBSC will keep NHSRSA undeted if the
	in any public consultation. TR confirmed that the DHSC will keep NHSBSA updated if the public consultation does proceed and any assistance that may be required from NHSBSA.