

Minutes

Meeting: Scottish Infected Blood Support Scheme – Advisory Group

Date: 25th August 2017, 14:00-16:00

Location: Meeting Room 17, 2nd Floor, Gyle Square, Edinburgh

Attendees:

David Knowles (DK)	NHS National Services Scotland - Practitioner Services (Chair)
Sally Richards (SR)	NHS National Services Scotland - Practitioner Services
Kelly Watt (KW)	NHS National Services Scotland - Practitioner Services (Minutes)
David Goldberg (DG)	NHS National Services Scotland - Health Protection Scotland
Tommy Leggate (TL)	Scottish Infected Blood Forum
John Rice (JR)	Scottish Infected Blood Forum
Dan Farthing-Sykes (DF-S)	Haemophilia Scotland
Petra Wright (PW)	Hepatitis C Trust
Leon Wylie (LW)	Hepatitis Scotland

Observers:

Robert Girvan (RG)	Scottish Government
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Apologies:

Grant Sugden (GS)	Waverley Care
Joyce Donnelly (JD)	Scottish Infected Blood Forum
Bill Wright (BW)	Haemophilia Scotland
Sam Baker (SB)	Scottish Government

1. Welcome and Apologies

DK welcomed everyone to the meeting and took the group through the agenda for the afternoon. Apologies were noted for SB, BW, JD and GS. It was noted that Joe Schofield had left NHS Greater Glasgow & Clyde and would not return to the group. There would be no replacement for Joe on the group as it was felt there was no-one available with sufficient experience to take on the role.

2. Scheme Update

SR updated the group on the scheme progress. She advised that there had been nearly 60 (58) applications in the 1st Quarter which had been turned around within the agreed 2 week turnaround time. Spend was estimated to be £1.8 million in the 1st quarter (around £3million in total so far). It was noted that only 8 apps had been declined with the main reasons being that applicants did not meet the clinical or evidential criteria.

SR advised that her team continued to take quite lengthy and emotive calls from beneficiaries. These had reduced significantly but were still hard to deal with for her team. DK added that callers wanted to explain their circumstances in detail and that staff valued the opportunity to speak to applicants in person.

DK asked if representatives at the meeting had received any feedback. TL noted that people can find the process difficult for lots of reasons and some found filling in forms and dealing with medical terminology difficult. DK noted that scheme staff were very happy to assist applicants in completing applications.

SR advised that there had been changes made to the scheme criteria following feedback from members; long term partners would now be included to give them the same eligibility to regular payments as widows and civil partners. The Scheme document would be updated in due course.

It was noted that the Scheme Appeals Panel had met and heard 2 appeals recently. Everyone agreed that the process had worked well and thought it was advantageous that applicants had the opportunity to attend in person. DK noted that the Scheme had also learned some lessons around logistics which would help future appeals. SR also noted that the scheme guidance on what Estates can claim had been clarified following the appeal.

SR proceeded to provide a copy to each of the group of the facts of figures so far from the Scheme. DK asked the group not to publish the information on the group's respective websites as there was confidential and sensitive information contained within.

3. Scottish Government Update

RG noted that the recently announced UK inquiry was still in the early stages of being set up. There was still some uncertainty what type of appeal would be established. It was noted that the scheme had been asked to contact scheme members and notify them of the consultation.

TL asked if there was an intention to review the thresholds for the income top up, as the levels paid were £2 below the living wage. RG noted that the overall structure of what beneficiaries were paid was kept under review and that would include the thresholds.

4. Clinical Review

DG reported that there had been a lot of progress since the last Advisory Group meeting in May 2017. He advised that he had met with most of the patient reps on the group which had given him a greater understanding of the patient experience.

He said that to compile his report for the Cabinet Secretary there were four pieces of work still to be completed;

- Wide ranging scientific literature review, this had been going well. Completion hoped in the next 2-3 months.

- The experience of patients would be very important to illuminate the scientific literature. DG advised he would seek to interview 15-20 participant testimonials who were happy to participate. Completion around December/January anticipated.
- Consider the clinical perspective; speak to specialists, nursing to get their perspective on stage 1 disease. Everyone agreed this part could be done by questionnaire. To be completed before February 2018.
- Contextual information, detailed anonymised information on the numbers impacted. DG outlined proposal to link the SIBSS data to data held on the HEP C database, approval from the Public benefit Patient Privacy Panel would be needed. Patient representative groups were supportive of this being done. Details to be reviewed around Jan/Feb 2018.

DG advised that the initial report would come back to the Advisory Group and that he hoped to have the initial draft by February (final date for submission to Cabinet Secretary April 2018).

The issue of the delay in patients being informed of their diagnosis was discussed. TL suggested that patients should be asked about dates and that there were 4 key dates that would provide important context: Infected Date; Tested date, diagnosed date, informed date.

The Clinical Review Group will consider the evidence in two meetings during Jan/Feb.

Action 012 - Both TL and DF-S asked that the stage 1 widow's voice needed to be considered. They would help to identify widow's who would be willing to speak to DG.

5. Newsletter Content

DK advised that possible content so far included; a photo of the Advisory Group, Scheme Facts & Figures, Guidance Changes, Contact Details, and an update on the UK enquiry.

Action 013 - The group agreed that a piece on the Clinical Review should also be included. RG agreed to provide an intro piece from the Scottish Government.

It was hoped that the Scheme Newsletter could be published in September 2017

6. AOB

No other business was discussed.

Next Meeting: To be confirmed – suggested date to be before December 2017

**Scottish Infected Blood
Support Scheme**

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Action Log

Scottish Infected Blood Support Scheme – Advisory Group
25th August 2017, 14:00-16:00, Meeting Room 17 Gyle Square, Edinburgh

ACTION NO.	ACTION DETAILS	OWNER	DATE RAISED	TARGET DATE	UPDATES	STATUS
010	Advisory Group members to consider and forward suggestions of websites offering support that could be made available to beneficiaries.	All	05/05/2017	16/06/2017	25/08/17 - Ongoing	Open
011	BW and TL to provide the scheme with details of the SIBF/Haemophilia Scotland meeting in October.	BW / TL	05/05/2017	16/06/2017	25/08/17 - Ongoing	Open
012	TL and DF-S to help to identify widow's who would be willing to speak to DG	TL/DF-S	25/08/2017	ASAP		Open
013	Newsletter - RG agreed to provide an intro piece from the Scottish Government	RG	25/08/17	ASAP		Open