

Minutes

Meeting: Scottish Infected Blood Support Scheme – Advisory Group

Date: 5th May 2017, 14:00-16:00

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

Attendees:

David Knowles (DK)	NHS National Services Scotland (Chair)
Sharon Carson (SC)	NHS National Services Scotland (Minutes)
Joyce Donnelly (JD)	Scottish Infected Blood Forum
Steven Fenton (SF)	NHS National Services Scotland
David Goldberg (DG)	Health Protection Scotland
Tommy Leggate (TL)	Scottish Infected Blood Forum
Sally Richards (SR)	NHS National Services Scotland
Bill Wright (BW)	Haemophilia Scotland
Petra Wright (PW)	Hepatitis C Trust

Observers:

Sam Baker (SB)	Scottish Government
Robert Girvan (RG)	Scottish Government

Apologies:

Dan Farthing-Sykes (DF-S)	Haemophilia Scotland
Joe Schofield (JS)	NHS Greater Glasgow & Clyde
Grant Sugden (GS)	Waverley Care
Leon Wylie (LW)	Hepatitis Scotland

1. Welcome and Apologies

DK welcomed the Group and opened up the meeting and gave an overview of the agenda. DF, JS, GS and LW had given their apologies for the meeting, and DK welcomed BW as a representative from Haemophilia Scotland standing in for DF-S.

DK reviewed the action log from the last meeting and informed the Group that all of the actions have been completed; including the drafting of an organisational flow chart for the scheme that was shown to the group.

2. Updates on the launch of the scheme

SF gave an overview of the activities that had taken place since the last meeting of the group. SF explained that the transfer of beneficiary data took place on 9th March 2017, which didn't give the scheme a lot of time to review and prepare the data prior to launch.

However, this was achieved and the beneficiary data was successfully migrated to the new secure database that was built specifically for the scheme.

SF explained that the consent approach taken by the UK schemes meant that if someone had a relationship with more than one of the schemes, they were asked to provide their consent to each scheme individually.

Once the data was migrated, the scheme took steps to prepare welcome letters that were scheduled to be sent to beneficiaries in a prioritised order. These letters were sent between 23rd March and 7th April 2017.

The scheme therefore successfully launched on Monday 3rd April 2017 as planned and there was a press release issued by the Scottish Government to communicate this.

SF confirmed that all of the necessary exemption legislation had been put into place with HMRC, DWP and the Scottish Government and all have come into effect. SF explained that regular payments from the scheme would be made on the 15th of each month, so for the first month's payments these were scheduled for Thursday 13th April 2017, as this meant payments would arrive with beneficiaries before the Easter weekend.

SF gave the Group information on the number of beneficiaries that had been transferred to the new Scottish scheme and provided an overview of the initial payments made over the first month of the scheme. Suggestions were made by the group as to how this financial information could be better broken down for future meetings. The Group discussed the number of widows/widowers registered with the scheme and it was suggested that this number would increase as further widows approached the scheme. SF explained that steps had been taken to ensure all widows who were due regular payments have been contacted by the scheme and those payments have been put in place.

The Group discussed beneficiary data potentially still held by the UK schemes at Alliance House and whether they had data that was still to be transferred to the Scottish scheme. SF explained that the scheme was continuing to receive data from beneficiaries who were late in returning their consent forms to the UK schemes, however there are still some people that have not given consent for their data to be transferred.

SF will contact Alliance House and enquire about the number of identified Scottish beneficiaries whose details still have to be passed to the Scottish scheme. The Group discussed the steps that have been taken to promote and make the new scheme more visible and encourage people to approach the scheme if they believe they may be entitled to support. The Group discussed the possibility of organising another press release to highlight this and to encourage potential beneficiaries to come forward. DG speculated as to whether there could possibly be a role for clinicians to promote and raise awareness of the scheme. DK therefore suggested that an article could be placed in the Practitioner Services newsletter that is issued to GPs, with further suggestions around additional promotion through the patient groups and other possible campaigns.

DG asked if the scheme had data on how many people had joined the scheme within recent years. SF informed him that the data held by the scheme should allow this to be checked. BW mentioned the look back exercise that took place previously and thought that this could help identify numbers.

Action 007 – SF to review how financial data could be better broken down for future meetings of the group.

Action 008 – SF to check how many new members have joined the UK schemes in recent years.

Action 009 – SF to ask UK schemes at Alliance House for the number of identified Scottish beneficiaries who still have to consent for their details to be transferred to the Scottish scheme.

3. Amendments made to the scheme criteria

DK gave an overview of changes that had been made to scheme criteria as a result of feedback received from SIBF and Haemophilia Scotland. It was confirmed that the minimum available One-Off Grant has been reduced from £500 to £200. The previous restriction on widows, widowers and partners only being able to receive **either** the Living Costs Supplement or Income Top-Up has also been removed. This information has been updated on the guidance documents and application forms available from the scheme website.

SB informed the Group that there was also a request made to review the threshold levels for Income Top-Up support and that this would take place around October, with a view to any potential amendments being in place for the next financial year.

4. Scheme website

SF gave an overview of the scheme website that is available at <https://nhsnss.org/SIBSS> which exists within the main NSS website. The site can be accessed by typing the address, by clicking the link on the NSS home page, as well as being found very easily via internet search engines. The website was specifically designed to be simple and easy to use with minimal text. Application forms and guidance documents for the scheme are available via the website should anyone wish to get more detailed information on the scheme.

SF explained that the 'Further Support' page currently has links to the main support groups represented on the Advisory Group, plus the Haemophilia Psychological Support Service that was discussed at the previous meeting. DK explained that the page will be further developed as the scheme progresses with input from the Advisory Group and suggestions of types of support that should be shown are welcomed.

Action 010 – Advisory Group members to consider and forward suggestions of websites offering support that could be made available to beneficiaries.

5. Review of document – Guidance on Tax and Benefits Exemptions

This document is available on the SIBSS website at:

<https://nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/tax-and-benefits/>

It was explained that this document had been prepared to support beneficiaries who may be asked about payments received for the purposes of calculating income tax bills and benefits or Council Tax reductions. The Group reviewed the document and the feedback on the content and format was positive. SR informed the Group that she had received calls from beneficiaries enquiring about the effect payments would have on tax and benefits and this document had therefore proven useful.

SB said that a reminder had been sent to Councils to help to raise the awareness of the scheme with staff who deal with Council Tax reduction and housing benefit assessments.

6. Future communications with beneficiaries

DK asked the group for their thoughts on possible methods of communication between the scheme and beneficiaries. TL suggested that a customer survey could be conducted at the regular SIBF and Haemophilia Scotland membership meetings.

SF explained that all beneficiaries had been sent a Contact Preference form with their welcome letters and this had allowed beneficiaries to confirm the types and methods of contact that were best for them. SR confirmed there had been a positive response to the forms being returned, with most beneficiaries welcoming further contact from the scheme.

BW and TL discussed the joint SIBF/Haemophilia Scotland meetings and extended an invitation to the SIBSS scheme staff to attend, with the next meeting scheduled for October.

Action 011 – BW and TL to provide the scheme with details of the SIBF/Haemophilia Scotland meeting in October.

7. Clinical review

RG introduced the Clinical Review and gave an overview of the initial preparations, explaining that DG has already started work on this and was scheduling some preliminary meetings.

DG explained that the review will focus on Chronic (Stage 1) Hepatitis C, to explore the specific health issues associated with the infection. The review will address the eligibility criteria for those affected, with the review taking place over the coming year. DG will initially liaise with those affected, patient representatives, clinical and non clinical experts and this will take place over the summer.

DG informed the Group that he anticipated that collation of the information provided could lead to an appraisal of various options, including the development of some form of assessment tool. The long-term impacts of interferon treatment in some cases would also be considered through the review. However, the development of a tool might be challenging given the many variable factors to be taken into account and difficulty in assessing specific cause and effect.

The next steps following the summer meetings will be to liaise with SB and RG to finalise membership and schedule the first meeting for September. DG stressed the importance of the initial information. It is anticipated that most of the work will be completed by January 2018.

The Group discussed the proposed work and the anticipated timelines, with some concern expressed as to the ability to achieve the aims in the suggested timeframe. The Group discussed the sources of information that could possibly be considered and included in the study, expressing that they were encouraged with the approach outlined by DG. PW discussed the work undertaken by Graham Foster, Professor of Hepatology at Queen Mary University of London detailing the specific health impacts of the Hepatitis C infection, and DG acknowledged that he was aware of this work

Discussion turned to the makeup of the Clinical Review group and who should be part of the review, expanding on who the non clinical experts should be. DG intended that his could likely include academics, but this has not been confirmed yet. Members of the Group expressed some concern if the Review Group would only include those from an NHS or science/clinical background. DG welcomed any suggestions of potential Clinical Review Group members with appropriate expertise and it was confirmed that BW, PW and a representative from SIBF would be participating.

TL asked if it would be possible for anyone from the support groups to have some form of input toward the Clinical Review, if they were to express an interest in contributing? DG informed him that he would welcome suggestions and input, and discussed the possible formation of a small focus group which could be considered at some stage during the review process.

BW questioned whether the application forms and the medical questions in their current format were only interim forms until the assessment tool has been developed. SB and RG surmised that this would be dependent on the findings and suggestions of the Clinical Review.

8. AOB

No other business was discussed.

Next Meeting: To be confirmed – suggested date to be between 18th and 31st August 2017

Action Log

Scottish Infected Blood Support Scheme – Advisory Group
5th May 2017, 14:00-16:00, Meeting Room 17 Gyle Square, Edinburgh

ACTION NO.	ACTION DETAILS	OWNER	DATE RAISED	TARGET DATE	UPDATES	STATUS
007	SF to review how financial data could be better broken down for future meetings of the group.	SF	05/05/2017	31/05/2017	SF has reviewed the data that is available from the scheme database and the suggestions made by the group (e.g. separating out one-off lump sum payments). These are possible and will be taken into account when preparing the financial update figures for the August meeting.	Closed
008	SF to check how many new members have joined the UK schemes in recent years.	SF	05/05/2017	31/05/2017	The majority of scheme beneficiaries had joined the UK schemes by 2005. In the period 2006-2016 there were on average 12 new Scottish beneficiaries per year.	Closed
009	SF to ask UK schemes at Alliance House for the number of identified Scottish beneficiaries who still have to consent for their details to be transferred to the Scottish scheme.	SF	05/05/2017	31/05/2017	Skipton have confirmed that the following numbers had yet to return the consent forms they were sent earlier this year: <ul style="list-style-type: none"> • 57 Stage 1 beneficiaries • 1 Stage 2 beneficiary • 1 widow(er) 	Closed
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		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		Open