# Minutes

**Meeting:** Scottish Infected Blood Support Scheme – Advisory Group  
**Date:** 22nd December 2017, 13:00-15:00  
**Location:** Meeting Room 18, 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 – *Teled*  
- Tommy Leggate (TL)  
  Scottish Infected Blood Forum  
- Joyce Donnelly (JD)  
  Scottish Infected Blood Forum  
- Petra Wright (PW)  
  Hepatitis C Trust

### Observers:
- Sam Baker (SB)  
  Scottish Government

### Apologies:
- Grant Sugden (GS)  
  Waverley Care  
- Robert Girvan (RG)  
  Scottish Government  
- Dan Farthing-Sykes (DF-S)  
  Haemophilia Scotland  
- Leon Wylie (LW)  
  Hepatitis Scotland

## 1. Welcome and Apologies

DK welcomed everyone to the meeting and took the group through the agenda for the afternoon. Apologies were noted for RG, DF-S, LW and GS.

## 2. Actions from previous meeting held 25th August 2017

The group went through the previous minutes and they were agreed.

### Action 014 – SR agreed to liaise with NSS IT to check the amount of hits to the SIBSS website.

## 3. Scheme Update

SR updated the group on the scheme progress. Statistics shared below:
- Applications Processed - 184
• % Processed within 2 weeks - 100%
• Value of payments made to date - £5.3m
• Total number of beneficiaries – 507
• Unsuccessful applications – 15
• Deceased since April - 15

The group then looked through the number of beneficiaries on the scheme. PW asked SR if there had been any problems reported with regards to undertakers for any beneficiaries who had died. She advised that currently, across Scotland, undertakers were refusing to wash or dress any deceased people who had Hep C. The group were dismayed at this and SR reported that there had been no feedback. SB advised that it was possible to contact the Inspector of Funeral Directors to find out why this was the case.

The group looked through the number of applicants processed and it was noted that only 14 had been declined so far. SB explained that the budget for SIBSS was £6million which had been surpassed by the number of new applicants.

4. NSS Audit

DK explained to the group that he had planned to request an internal audit on the SIBSS Scheme due to the amount of new processes and large amounts of money involved. This had now been carried out the audit had been positive with only 5 minor recommendations (listed below);

- Restrict users on Zendesk to either submit or approve new details, but never both. Ensure that the system is set up with clear segregation of duties, automated where possible.

- NSS should request that the former scheme administrator pass on any files they have on the recipients that have since transferred to SIBSS.

- Implement a more robust conciliation review with evidence of review and approval. This could be by printing and signing the submission, or even by emailing the submission to the Scheme Manager and having an approval by email before it is submitted.

- An action plan should be agreed with the outgoing scheme administrator to ensure relevant data is not lost.

- The procedure document should be handed over and managed by the Quality Management Team, and the SIBSS team should ensure it is informed of any appropriate updates in good time.

DK advised that the report had been discussed at the NSS Audit and Risk Committee and the full report was available for the group to view if required. TL agreed that it was a good report.

5. Scottish Government Update

SB reported the following; Records – She advised that there was still no movement from Skipton with regards to releasing the records to Scotland, however, paper records were available to patients via a subject access request. This had to be requested before the professional bodies shut down at the end of March 2018. They then had 40 days to respond to the requester. She was unsure if there would be a cost associated.
Action 015 - SR and DK agreed that the information would be added to the SIBSS webpage and a letter sent to beneficiaries.

Macfarlane Trust – SB reported that one of the professional bodies had reserves left and were currently looking into starting a Grant Scheme for any people already registered with Macfarlane. She added that the SIBSS Scheme would make an exception regarding any extra payment for any beneficiaries in this case if they wished to apply.

Action 016 - SR and DK agreed that information regarding this exception would communicated to ex MacFarlane Trust beneficiaries directly.

6. Clinical Review Update

DG took the group through his proposed Terms of Reference (paper attached for reference).

CRI of Hep C Grp ToR V0 6 Draft

He advised that the HCV Clinical Review Group had met for the first time recently and discussed the Terms of Reference and Workplan. He advised he would present his findings of the study at the next Clinical Review Group meeting on 22nd January 2018.

7. AOB

6-month Review – TL reminded the group that it had been agreed that a 6 month review of the group would take place. To date this was yet to happen. The group agreed that an official review would not take place, however, this would, instead be discussed at the next SIBSS Meeting in April 2018 and a response drafted for the SIBSS website.

Next Meeting: 27th April 2018 at 1pm.
### Action Log

**Scottish Infected Blood Support Scheme – Advisory Group**  
22<sup>nd</sup> December 2017, 13:00-15:00, Meeting Room 18 Gyle Square, Edinburgh

<table>
<thead>
<tr>
<th>ACTION NO.</th>
<th>ACTION DETAILS</th>
<th>OWNER</th>
<th>DATE RAISED</th>
<th>TARGET DATE</th>
<th>UPDATES</th>
<th>STATUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>010</td>
<td>Advisory Group members to consider and forward suggestions of websites offering support that could be made available to beneficiaries.</td>
<td>All</td>
<td>05/05/2017</td>
<td>16/06/2017</td>
<td>25/08/17 – Ongoing 22/12/17 - Ongoing</td>
<td>Open</td>
</tr>
<tr>
<td>011</td>
<td>BW and TL to provide the scheme with details of the SIBF/Haemophilia Scotland meeting in October.</td>
<td>BW / TL</td>
<td>05/05/2017</td>
<td>16/06/2017</td>
<td>25/08/17 – Ongoing 22/12/17 - Ongoing</td>
<td>Open</td>
</tr>
<tr>
<td>012</td>
<td>TL and DF-S to help to identify widow’s who would be willing to speak to DG</td>
<td>TL/DF-S</td>
<td>25/08/2017</td>
<td>ASAP</td>
<td>Done through random selection</td>
<td>CLOSED</td>
</tr>
<tr>
<td>013</td>
<td>Newsletter - RG agreed to provide an intro piece from the Scottish Government</td>
<td>RG</td>
<td>25/08/17</td>
<td>ASAP</td>
<td>Done</td>
<td>CLOSED</td>
</tr>
<tr>
<td>014</td>
<td>SR agreed to liaise with NSS IT to check the amount of hits to the SIBSS website.</td>
<td>SR</td>
<td>22/12/2017</td>
<td>ASAP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>015</td>
<td>Information on access to paper records (via subject access request) to be added to SIBSS website and a letter sent to beneficiaries</td>
<td>SR</td>
<td>22/12/2017</td>
<td>ASAP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>016</td>
<td>Macfarlane Trust Grant Scheme Applicants - SR and DK agreed that information regarding this exception would be communicated to ex MacFarlane Trust beneficiaries directly.</td>
<td>SR</td>
<td>22/12/2017</td>
<td>ASAP</td>
<td></td>
<td></td>
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</tbody>
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