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|  | **Scottish Infected Blood Support Scheme**  Practitioner Services  Gyle Square  1 South Gyle Crescent  Edinburgh, EH12 9EB  **Email:** [nss.sibss@nhs.scot](mailto:nss.sibss@nhs.scot)  [**www.nss.nhs.scot**](https://www.nss.nhs.scot/browse/patient-support-schemes/scottish-infected-blood-support-scheme-sibss) | N H S NATIONAL SERVICESLOG |

Minutes

**Meeting: Scottish Infected Blood Support Scheme – Advisory Group**

Date: 18th May 2018, 10:00-12:00

Location: Meeting Room 9, 1st 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 – ***Tele***

Tommy Leggate (TL) Scottish Infected Blood Forum

Joyce Donnelly (JD) Scottish Infected Blood Forum

Petra Wright (PW) Hepatitis C Trust

Dan Farthing-Sykes (DF-S) Haemophilia Scotland

Leon Wylie (LW) Hepatitis Scotland

# Observers:

Robert Girvan (RG) Scottish Government

# Apologies:

Grant Sugden (GS) Waverley Care

Sam Baker (SB) Scottish Government

# Welcome and Apologies

DK welcomed everyone to the meeting and took the group through the agenda for the morning. Apologies were noted for GS and SB.

It was noted that GS had expressed his concerns that he had only managed to attend 1 meeting and advised that he felt he would not be the best person to contribute to the work of the group.

Action 017 – The group agreed to think of a potential replacement for Grant Sugden.

# Actions from precious meeting held 22nd December 2017

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

# Scheme Update

SR updated the group on the scheme progress. Statistics shared below;

* Applications Processed - 231
* % Processed within 2 weeks - 100%
* Value of payments made - £6.8m
* Total number of beneficiaries – 510
* Unsuccessful applications – 18
* Deceased - 19

It was noted that unsuccessful applications numbers were due to factors including i.e. income being too high and outwith the scope of the scheme. SR advised that the split in Stage 1 and Stage 2 deceased was 60%/40%.

Action 018 – SR to forward info on age groups to the group.

Action 019 – Slides and Newsletter to be forward to the group.

SR advised the group that there had been a few issues with the Department of Work & Pensions regarding the scheme. The comms contact at DWP had been informed as well as local branches of the scheme so that beneficiaries were not contacted.

# Scottish Government Update

RG reported the following;

Records – He 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.

DFS advised that an announcement would be made soon with regards to the English enquiry terms of reference. RG added that the English Government would share this information with the Scottish Government as the enquiry was to be completed as a UK-wide fact gathering exercise.

# Clinical Review Update

DG provided an update on his findings from the review to the group. He advised the final meeting had been held on 17th May 2018 and had gone very well. He added that his next steps were to convey what had been agreed and finalise his report which he hope to have out week beginning 21st May 2018 for final approval. This would then be sent to the Scottish Government by week beginning 28th May 2018 for RG/SB to complete analysis before passing to Shona Robison (MSP) to look over and sign off.

He proceeded to take the team through the terms of reference of the report. He advised 2 separate meetings had been held specifically to look at these in depth and had concluded that there should be no formal individual assessment. He also identified that there was a large non-clinical impact as well as a clinical impact due to the infected blood.

# Survey

SR advised the survey would be emailed out to everyone with an email address and posted to those without an email.

# AOB

None

**Next Meeting:**  29th August 2018 at 1pm.

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| Action LogScottish Infected Blood Support Scheme – Advisory Group18th May 2018, 10:00-12:00, Meeting Room 9 Gyle Square, Edinburgh | **Scottish Infected Blood Support Scheme**  Practitioner Services  Gyle Square  1 South Gyle Crescent  Edinburgh, EH12 9EB  **Email: NSS.SIBSS@nhs.scot**  [**www.nss.nhs.scot**](https://www.nss.nhs.scot/browse/patient-support-schemes/scottish-infected-blood-support-scheme-sibss) | N H S NATIONAL SERVICESLOG |

| 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  22/12/17 – Ongoing  18/05/18 – 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  22/12/17 – Ongoing  18/05/18 – Ongoing | Open |
| 014 | SR agreed to liaise with NSS IT to check the amount of hits to the SIBSS website. | SR | 22/12/2017 | ASAP | 18/05/18 – SR reported this amounted to around 500 per month and agreed to get the report from IT. | Close |
| 015 | Information on access to paper records (via subject access request) to be added to SIBSS website and a letter sent to beneficiaries | SR | 22/12/2017 | ASAP | 18/05/18 - Complete | Close |
| 016 | Macfarlane Trust Grant Scheme Applicants - SR and DK agreed that information regarding this exception would be communicated to ex MacFarlane Trust beneficiaries directly. | SR | 22/12/2017 | ASAP | 18/05/18 - Complete | Close |
| 017 | Group to have a think about a potential replacement for Grant Sugden. | ALL | 18/05/18 | ASAP |  |  |
| 018 | SR to send info on age groups of the scheme to the group | SR | 18/05/18 | ASAP |  |  |
| 019 | Slides and Newsletter to be forwarded to the group | SR/KW | 18/05/18 | ASAP |  |  |