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|  | **Scottish Infected Blood Support Scheme**  Practitioner Services  Gyle Square  1 South Gyle Crescent  Edinburgh  EH12 9EB  **Email: NSS.SIBSS@nhs.net**  **www.nhsnss.org/SIBSS** | N H S NATIONAL SERVICESLOG |

Minutes

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

Date: 23rd April 2020, 10:30 -12:00

Location: via teleconference

Attendees:

Martin Bell (MB) 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)

Sam Baker (SB) Scottish Government

Tommy Leggate (TL) Scottish Infected Blood Forum

Joyce Donnelly (JD) Scottish Infected Blood Forum

Leon Wylie (LW) Hepatitis Scotland

Apologies:

Dan Farthing-Sykes (DFS) Haemophilia Scotland

Michelle Kivlin (MK) Scottish Government

David Goldberg (DG) NHS National Services Scotland - Health Protection Scotland

1. **Welcome and Apologies**

Apologies were noted from DFS, MK & DG.

MB welcomed everyone to the meeting and took the group through the agenda.

1. **Actions from previous meeting held 12th December 2019**

The group went through the previous minutes;

Unsuccessful Applications (Appeal Criteria) – LW asked if applicants who had previously taken drugs were automatically refused and if this was stated as the primary source of infection without considering the possibility of blood transfusion infection.  He added that it seemed 2 different standards were being applied.  SR advised that during review, for drug users, the appeals Panel viewed the evidence on the basis of ‘balance of probability.’ If the probability was that drug use was more likely to be the source over a blood transfusion, they would be unsuccessful.  On the occasion where there was no evidence either way, the probability would be that the infection had come from previous drug taking.

Complaint re appeal - a complaint regarding an appeal outcome had been sent via the SIBSS team and Scottish Government. SR advised the last appeal considered by the Panel had been successful and an award made.

1. **Scheme Update**

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

* Total number of beneficiaries – 540
* Applications processed Apr- Mar - 119
* Value of payments made Apr - Mar- £9.4m
* Unsuccessful applications Apr – Mar – 11
* Reasons – natural clearer, did not meet criteria, deferred stage 2
* Deceased Apr - Mar – 19

Deceased – TL asked if it was possible to have a breakdown of the deceased figures.

**ACTION 035 – SR to anonymise and send out with the minutes**

New Applicants – SR reported that the majority of new applications had been made up of haemophiliacs. There had been an increase in those who were severely affected who had been referred by a GP/Consultant. She added that all those who had applied had been successful.

Co-infected/HIV – TL asked SR if the figures could be split into detail for co-infected/HIV and if the figures were higher or lower than England. SR advised the figures had been combined due to data protection and the small numbers. LW advised he did not feel that this had to be broken down further due to the low co-infected numbers. SR confirmed no new people had come forward as co-infected – numbers static.

Partners Infected – TL asked if the figures had stayed static. MB confirmed he could not recall signing off any.

Support Grants (One Offs) – TL asked what the requests had been for. SR reported that one had been for psychological support and the other was for help with a mobility car deposit. She added that most requests than came in were for psychological support. TL asked if it could be confirmed that members would receive fair payment, i.e. all would not receive any less support than they would have from the previous UK schemes. SB confirmed that the scheme overall was making sure all members were getting at least the same. She advised the non-restricted support and assistance grants such as income top-up and living costs supplement were more generous, but there was more focus on the increased annual payments (which are clearly not restricted in terms of how they can be spent), rather than one-off grants. SB clarified that when SIBSS was set up it was decided that one-off grants should be focussed on supporting costs associated with the impact of a person’s HCV or HIV. TL asked if this information had been updated in the Policy. SB confirmed the Policy was available on the SIBSS website and SR agreed to check the guidelines.

**ACTION 036 – SR to check Policy guidelines wording to ensure it is clear on this**

Payments – SR reported that a second application had been received at the end of the year, this would be reflected in the April 2020 figures. She advised that a lot of new applications had been sent in previously with lump sums but there had been no applications in March, which may be due to Covid.

**New Panel Member** – SR reported that a new panel member had joined, Professor Clifford Leen who was an HIV specialist.

1. **Scottish Government Update**

SB reported the following;

* Covid-19 - have been working together with HS and SIBF to ensure members are updated with information in relation to those at increased or highest clinical risk whenever there is a change to guidance. The most recent update was also shared via the SIBSS Newsletter.
  + currently waiting on further clarity from UK CMOs for those with decompensated cirrhosis, but it’s thought they will not require to be added to the shielding list (although will remain at increased risk, along with those whose cirrhosis is stable, so should stay at home wherever possible).
  + If anyone in the increased risk group has difficulties accessing food or medications, for example if they don’t have family or neighbours who can help, or if they need emotional support, there is a new national helpline available – 0800 111 4000 – which currently operates between 09:00 to 17:00 each day.
* agreed with SIBSS that anyone who is struggling to pay their energy bills due to needing to be at home more due to Covid-19 can apply for a discretionary grant from SIBSS to cover the increased heating costs. In addition, anyone who has unfortunately lost their job due to Covid-19 and is not able to take advantage of government support options, such as the furlough scheme, can apply for income top-up support from SIBSS.
* been feeding in to the questions asked by the SIBSS survey and look forward to using the results to improve the scheme.
* been taking forward work to look at expanding the Psychological Support service currently provided by NHS Lothian to consider if it could also provide support for those infected via blood transfusions and to wider family members who have been affected. Agreed that Scottish Government should wait for feedback from the SIBSS survey before deciding on the most appropriate model of support.
* published both the SIBSS amending scheme document, and also have provided a consolidated scheme document for information, on the Scottish Government website to reflect changes in relation to the inflationary uplifts to annual payments.

**Shielding Letters** - MB added that P&CFS were issuing shielding letters on behalf of the Scottish Government. A significant amount of letters were still going out to patients. It was hoped that they would reinforce patient engagement with their GPs.

1. **AOB**

**Survey Response** – JD advised that a quick turnaround for the survey response/data forms might not be possible during Covid due to the postage delays in certain areas. SR advised that the majority would be emailed out to scheme members. There was only around 100 that would have to be posted. Data, when received, would be analysed in June 2020.

MB thanked everyone for attending.

**Next Meeting:** 13th August 2020 at 10.30am.

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Scottish Infected Blood Support Scheme – Advisory Group

23rd April 2020, 10:30-12:00, via teleconference

| ACTION NO. | ACTION DETAILS | OWNER | DATE RAISED | TARGET  DATE | UPDATES | STATUS |
| --- | --- | --- | --- | --- | --- | --- |
| 017 | Group to have a think about a potential replacement for Grant Sugden. | ALL | 18/05/18 | ASAP | 29/08/18 – DK advised a subject matter rep was still required. DK/SR agreed to draft an advert paragraph to be placed in the newsletter. Ongoing.  11/04/19 – SR reported an advert had gone out in the newsletter with 1 interested party who was yet to respond. She agreed to look at putting another advert in the next newsletter. Ongoing.  22/08/19 – PW advised she potentially had a member in mind and would follow this up. DFS agreed to approach Miles again and report back to SR. Ongoing  12/12/19 – SR advised there had still been nil response. Ongoing  23/04/20 – No update. MB and SR to have a think about. Ongoing | CLOSED  (post mtg update 2/6/20) |
| 025 | Review/Evaluation of Self Assessment - Group to think about next steps, decide on requirements and how to make information available to the wider community.  Qualitative/Quantitative Review – March Decision point | ALL | 11/04/19 | ASAP | 22/08/19 – DFS agreed to ask BW to clarify. Ongoing.  12/12/19 –SR confirmed a long term review was due as the 3-year period was nearly up. The team agreed there was potential to send a questionnaire to members regarding the service. Ongoing.  23/04/20 – | Open |
| 029 (linked to 025) | MB and SR agreed to meet to discuss and pull together a possible survey/questionnaire proposal | MB/SR | 12/12/2019 | ASAP | 23/04/20 – | CLOSED  (post mtg update 2/6/20) |
| 030 | MK to raise 3 year review at 4 Nations Meeting to gage what is being done in other areas | MK | 12/12/19 | ASAP | 23/04/20 – SB advised MK had raised this at the 4 Nations Mtg. Northern Ireland were interested and SB had forwarded a copy of the 3-year review draft to them. CLOSE. | CLOSED |
| 031 | SR to provide a breakdown of 58 applications, the 5 declined and numbers moved from Moderate to Severe | SR | 12/12/19 | ASAP | 23/04/20 – CLOSE | CLOSED |
| 032 | SR to give an update on the death rates to the group | SR | 12/12/19 | ASAP | 23/04/20 – CLOSE | CLOSED |
| 033 | SR to send anonymised PowerPoint to the group | SR | 12/12/19 | ASAP | 23/04/20 – CLOSE | CLOSED |
| 034 | SR to put updated info on the SIBSS Counselling Service in the GP Practice Newsletter | SR | 12/12/19 | ASAP | 23/04/20 – CLOSE | CLOSED |
| 035 | SR to anonymise Deceased data and circulate with the minutes of April’s mtg | SR/KW | 23/04/20 | ASAP | Sent with minutes | CLOSED (post mtg update 2/6/20) |
| 036 | Support Grants - SR to check Policy guidelines wording regarding level of payments – does guidelines state members will not receive any lower than what they already receive? | SR | 23/04/20 | ASAP | Reviewed, minor adjustment to one off grant guidance reposted on website. | CLOSED (post mtg update 2/6/20) |
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