

# Minutes

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

**Date:** 17<sup>th</sup> February 2017, 14:00-16:00

**Location:** Meeting Room 17, 2<sup>nd</sup> 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
Dan Farthing-Sykes (DF)	Haemophilia Scotland
Steven Fenton (SF)	NHS National Services Scotland
David Goldberg (DG)	Health Protection Scotland
Tommy Legate (TL)	Scottish Infected Blood Forum
Sally Richards (SR)	NHS National Services Scotland
Joe Schofield (JS)	NHS Greater Glasgow & Clyde
Grant Sugden (GS)	Waverley Care
Petra Wright (PW)	Hepatitis C Trust
Leon Wylie (LW)	Hepatitis Scotland

Observers

Sam Baker (SB)	Scottish Government
Robert Girvan (RG)	Scottish Government
Grainne O'Brien (GO)	NHS Lothian

Apologies:

N/A

## 1. Welcome and Apologies

DK welcomed the Group and opened up the meeting with introductions from the attendees and gave an overview of the Agenda. All proposed attendees were present.

## 2. Terms of Reference for group

DK introduced the Advisory Group Terms of Reference (ToR) document and opened the meeting up for questions or comments related to the document. TL asked about the schedule of Advisory Group meetings and suggested that meeting every six months may not be sufficient around the launch of the new scheme. DK said that he was happy for the meetings to be scheduled on a more frequent basis in the first instance to allow for continued development of the scheme after launch. JS suggested the addition of a diagram to highlight the responsibilities of the Advisory Group and the Appeals Panel, to show exactly what each of the groups is responsible for.

TL discussed those described as being “Stage 0”, where evidence of how the Hepatitis C infection occurred is absent, or sufficient evidence cannot be provided and explained that this group are perceived to have fallen through the cracks. DK expressed an interest in finding out more about this group and how the scheme could assist them going forward.

The Group discussed whether the scheme would then be open to receiving fresh applications from those that had not been accepted onto existing schemes, or did not meet the criteria for moving from ‘Stage 1’ to ‘Stage 2’ Hepatitis C payments. It was agreed that the scheme would be open to receiving new applications from people in these circumstances. It was acknowledged that each application would be considered on a case-by-case basis with consideration being made to the availability of records. It was highlighted that the medical criteria set out for the scheme is similar to that of the existing schemes; however this would be considered as part of the forthcoming clinical review.

DK informed the Group that the ToR would be reviewed and updated with any changes proposed at each meeting.

**Action 001** – DK to update the frequency of meetings and add an organisation chart as an Annex to the Terms of Reference document.

### **3. Financial Review Report – key points**

DK discussed the key points within the Financial Review Report. Proposal 4 relates to the support and assistance grants and it was explained that this will be an ongoing area for review following the launch of the scheme and will be discussed at future meetings of the group. Application forms for the Support & Assistance Grants were being drafted, with members of the group expressing an interest in viewing the draft forms. SF would send the group the draft grant application forms for review.

DK introduced the Appeals Panel and discussed the membership of Panel. TL explained that existing beneficiaries had expressed the opinion they had been treated in an impersonal and unfriendly way when going through appeals in relation to Skipton Fund decisions. TL said that many have a lack of trust in current system and the procedures involved, and feel they are not treated with dignity.

DK highlighted the importance of the new scheme setting a positive culture in its contact with beneficiaries and asked what the scheme could do to change current perceptions of such schemes? This was discussed by the Group and the overall opinion was that this could be achieved by adhering to the intentions set out to assess applications against the ‘balance of probabilities’ and exercise consistency and transparency when communicating decisions.

It was suggested that the Appeals Panel could include someone closely related to the infected beneficiaries and not only medical professionals and lay people, but it was also noted that the Panel had to be seen to be completely independent. JS furthered this by suggesting that the Appeals Panel meetings could include a nominated observer from the Advisory Group. It was agreed that this could be considered occasionally, although it was noted that an applicant may not want an additional person there, particularly given the potentially sensitive discussions about their medical history so it could only happen where the applicant was content with this.

The composition of the panel was discussed and some concerns were noted. DK gave an overview of Proposal 5 “Further Work” and highlighted that work is in progress on many of these points, with some items being taken forward out with the new scheme.

**Action 002** – SF to send the draft Support & Assistance Grant application forms to the Advisory Group members for review and feedback.

#### 4. Scottish Infected Blood Support Scheme – project update

SF presented the work done to date on establishing the new scheme and first discussed the work being done to arrange for the existing beneficiary data to be transferred to the new scheme. It was explained that the existing schemes had been given advice that suggested they would have to seek explicit written consent from every beneficiary. SF explained that this has meant that beneficiaries who are registered with more than one UK scheme would receive multiple letters to obtain their consent.

The group acknowledged that some beneficiaries on multiple schemes may not realise that they should respond to all of the consent letters being sent out. SF asked that any members of the group who had contact with existing beneficiaries encourage them to return all consent letters as soon as possible. DF informed the group that he has put information on the Haemophilia Scotland website to advise beneficiaries what they should do if they receive the consent forms.

SF explained that payments from the existing UK schemes were not taken into account for tax purposes, or for assessing means-tested benefits or council tax reductions. He went on to explain that the Scottish Government was seeking similar exemptions for the new scheme from HMRC, DWP and Scottish Government colleagues. SB explained that positive progress was being made and that all exemptions were expected to be in place in time for the scheme making its first regular payments to beneficiaries.

PW enquired as to whether there would be a standard letter available, as exists currently, which beneficiaries could present to benefits agencies and other organisations. It was explained that an explanatory document would be made available via the scheme website and could be issued to beneficiaries on request.

SF informed the group of the drafting of new application forms for the scheme, which was also mentioned earlier in the meeting.

SF updated the group on progress with the new scheme website, highlighting that the new pages sit within the NHS National Services Scotland website ([www.nhsnss.org/SIBSS](http://www.nhsnss.org/SIBSS)) and were being designed to be easy to navigate. The website would include scheme information and application forms which could be downloaded for completion.

PW asked if there would be a section covering Frequently Asked Questions. SF explained that the content was being designed to answer the key questions applicants and beneficiaries may have and there would be the possibility of adding in a FAQ section if regular questions were identified following the launch of the scheme.

SF told the group that any beneficiaries could contact the scheme and ask for advice on how to complete the forms, with the scheme being happy to send printed forms to people who don't have access to print them from the website.

DF said that he would forward the details to the new scheme of all of those that approach Haemophilia Scotland with any questions or concerns, or those that haven't received any correspondence from the existing schemes.

The Group discussed whether there would be an official launch for the scheme in April. SB agreed that some form of press release for the launch of the scheme could possibly take place, and this would be considered further.

**Action 003** – DF to forward details to [NSS.SIBSS@nhs.net](mailto:NSS.SIBSS@nhs.net) of anyone that contacts Haemophilia Scotland with any enquiries regarding the new scheme.

## 5. Scottish scheme criteria and draft guidance for beneficiaries and applicants

SB gave the group an overview of the Scheme Document and the additional guidance documents that had been circulated ahead of the meeting. She informed the group that the Scheme Document is somewhat technical and was drafted as such due to legislation requiring the document to detail exactly who is eligible.

*The Scheme Document is available for review at the Scottish Government website at <http://www.gov.scot/Topics/Health/Services/Blood>*

*The guidance documents will be made available on the scheme website at [www.nhsnss.org/SIBSS](http://www.nhsnss.org/SIBSS) closer to the launch of the scheme*

SB informed the group that the Scheme Document covers the eligibility of the applicants and outlines the criteria for each qualifying person. SB went on to explain that although the document still refers to 'Stage 1' and 'Stage 2' in relation to those with Hepatitis C, going forward this will now be referred to as 'chronic' and 'advanced' Hepatitis C. TL asked if this change in terminology opens the door for new categories to be introduced. SB answered that the document would be subject to review and is not static, so could potentially change depending on the outcome of the clinical review.

PW asked about the eligibility criteria and the distinction between country of residence and county of infection. SB said that the existing schemes were based on country of infection, but that the Smoking, Health and Social Care (Scotland) Act 2005 requires that applicants can only be eligible if they are resident in Scotland. Therefore, this requirement will need to be more strictly enforced under the new scheme as a result of its establishment.

DG also highlighted the possible interpretation of the criteria related to those who have cleared their Hepatitis C infection through treatment, and suggested that the wording could be changed to highlight that they will still be eligible to apply by changing 'is infected' to 'was infected'. PW added that this would help to prevent people making a decision to not seeking treatment in order to apply to the scheme. SB agreed that this could be misunderstood and would review the wording of the document.

LW raised the criteria specifically related to secondary transmission and injecting drug users. SB informed the group that numbers of secondarily infected people was fairly low and this was worded as such to try and prevent people from not taking necessary precautions to prevent spread of infection. JS suggested that any uncertainty related to secondary infection where instances of injecting drug use were noted could be covered by the appeals process.

DK asked if the Scheme Document had been finalised and signed off. SB informed the Group that it had been approved by the Cabinet Secretary with only the terminology related to transferring qualifying persons still being finalised.

SB introduced the group to the scheme guidance documents and gave an overview of the different categories, highlighting that changes could potentially be made after the clinical review process. SB informed the Group that Stage 1 widows/widowers can apply from April 2017 if they feel they a good case that there was a causal link between Hepatitis C and their spouse's death. SB added that if such an application was not successful then the applicant would still be able to apply for the available Support & Assistance grants.

The group discussed the types of evidence that may be required to be provided in support of a Support and Assistance grants application, in particular evidence related to those that may have passed away a while ago, especially for those who were co-habitees of an infected person. SB informed the group that those already recognised by existing schemes as a widow or partner would be considered as such by the Scottish scheme. However, those not already on existing schemes will have to provide some form evidence to prove that they were living with a deceased beneficiary if they were not married to/in a civil partnership with them.

The potential implications of GPs and other medical professionals beginning to receive forms for new applications was discussed, and whether they have been made aware of the possibility of receiving forms from the new scheme. DK enquired as to whether any notice of the scheme and the forms had been given through health board networks. DG informed him that health boards were aware.

The group was briefed on the application process for new scheme members who were infected and told that the applicant would fill in a section with their own details first. The form would then be given to the medical professional to complete the relevant sections related to the infection and then the form would be sent directly on to the scheme.

The issue of missing or lack of medical records was discussed and how those who did not have all of the relevant documentation to prove the source of a Hepatitis C infection would be able to apply to the scheme without this. It was explained that the new scheme would aim to make balanced decisions based on the balance of probabilities.

The group discussed the number of people that had applications rejected from existing schemes. RG informed the group that he believed approximately 15% of all Skipton Fund applications had been rejected.

DK gave an overview of the current procedures for retaining medical records and the timelines involved. It was anticipated that, as the new scheme is being managed by NSS Practitioner Services, the scheme would be in a good position to be able to advise applicants on how to locate and access medical records as they have responsibility for the transfer of medical records across Scotland.

The group discussed whether inflation would be considered in possible increases to regular payments. SB confirmed that there were no automatic rises to the payment levels at present, however the regular payment amounts would remain under review.

TL queried why interest accrued on lump-sum payments from the scheme/the existing schemes should be stated when declaring income for Support & Assistance Grant applications. SB agreed this need not be taken into account and the relevant guidance document and forms would be updated to reflect this.

**Action 004** – SB to review the wording of the scheme criteria document to consider changing the wording of ‘is infected’ to ‘was infected’ to reflect the eligibility of those who have cleared infection through successful treatment.

**Action 005** – SB/SF to review scheme documents and forms to ensure it is clear that interest accrued on the lump sum payments from the scheme/UK schemes will not be taken into consideration for the Support & Assistance grant applications.

**Action 006** – Advisory Group members to provide any further feedback they have on the guidance documents discussed.

## 6. Appeals Panel

The Appeals Panel was discussed at Item 3.

## 7. Haemophilia Service Psychological Support Pilot

GO introduced the Haemophilia Service Psychological Support Pilot and gave the group an overview of the pilot scheme currently underway to provide psychological support to those infected with Hepatitis C through the provision of blood products. The pilot has been looking at ways to expand to a national service and have been in discussions with the Scottish Government and the new scheme to potentially promote the service to scheme beneficiaries. GO informed that group that so far the scheme has been well received and positive feedback has been received from patients and staff.

RG informed the group that the pilot scheme was being discussed next week (week beginning 20/02/2017) at a steering group meeting to discuss if the pilot could be extended to a national service. JD said that it was important to have access to psychological support due to the impact a Hepatitis C infection has on a patient. TL thought that it was important to try and establish what types of psychological support were needed by beneficiaries.

DK talked about the about the debt management advice service that could be offered members of the scheme. RG informed the group that Scottish Government had sought advice and have been given details of potential services that could be used or accessed by beneficiaries. Details of these services would be publicised on the scheme website, as well as being promoted by scheme staff.

## **8. AOB**

The potential date of the next Advisory Group meeting was discussed and it was suggested the initial aim would be to meet in late April.

TL asked DG if there was any data and statistics related to the effectiveness of new Hepatitis C treatment drugs. DG and PW informed him that the effectiveness of new treatments is currently around 88-90%.

**Next Meeting:** To be confirmed for around the end of April 2017.