

**Scottish Review of Financial Support Schemes:
minutes of first meeting, 11 June 2015,
14.30-16.30, Scottish Parliament (Cm Rm 1)**

Attendees

Shona Robison, Acting Chair – Cabinet Secretary for Health, Wellbeing and Sport.
Alice Mackie - Campaigner, HIV.
Bruce Norval – Campaigner.
Bill Wright - Chair, Haemophilia Scotland.
Dan Farthing-Sykes - CEO, Haemophilia Scotland.
Jeff Frew - Campaigner, blood transfusion.
Petra Wright - The Hepatitis C Trust (Scotland).
Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF).
Tommy Leggate – SIBF/independent consultant.
Andy Cowe – SIBF.
Gareth Brown – Scottish Government.
Robert Girvan – Scottish Government.

1. Welcome, introductions and apologies

No apologies were recorded. The Cabinet Secretary (CS) noted that she wanted to keep the process focused on the financial review and not diverge into tangential issues – there was a short timescale to complete a complex piece of work.

2. Chair and membership

The CS noted that it was acceptable for deputies to attend the meetings. For the key organisations (Haemophilia Scotland and Scottish Infected Blood Forum) she would envisage a maximum of three attendees in total per organisation to keep the meetings manageable and focused.

The CS informed the Group that Ian Welsh of the Alliance had agreed to Chair the process, and would lead future meetings subject to the Group's agreement. She noted that it was preferable for the review to be independent, although she would keep in touch with the discussions and would try to attend some of the later meetings as the thinking developed.

The Group confirmed that they were content with the appointment of Ian Welsh as Chair. Scottish Government officials would brief Ian, and set up any introductory meetings, in order for him to be able to take over as Chair from the next meeting.

The CS asked if there were any additional suggestions for key membership of the Group. The Group confirmed they were content with membership.

3. Draft Terms of Reference

The draft ToR had been shared for the agreement of members. Robert Girvan outlined the development of the ToR so far.

The Scottish Infected Blood Forum spoke to the detailed ToR (6 pages) they had produced as an alternative. The CS noted that ideally, for simplicity, she wanted to keep the ToR as concise and high-level as possible. The detail of the SIBF draft ToR was useful, but much of it was more appropriate for integration into the work plan (such as development of principles) and

agenda for future meetings. It was agreed that RG would share the detailed document with the new Chair for consideration.

It was agreed that the bottom three bullet points from the draft Government ToR would be removed. The summary document would be adopted as the working ToR, although the Chair would also want to consider them with the group at the next meeting.

It was agreed that it was more appropriate for Patrick McGuire of Thompsons solicitors to function as an expert witness, rather than a permanent member of the Group.

TL commented that given the Penrose report reception, it would be important that the review was perceived as truly independent.

It was noted that although hepatitis C infection had often been the focus of discussions in the past, financial support considerations for those infected with HIV would have equal weight within the review. There was no legal impediment to the Scottish Government taking responsibility for the HIV payments schemes in the future.

BW asked how other policy concerns stemming from the Penrose report would be progressed. While these were important, it was agreed that these would be dealt with via different channels. The Group's purpose was the financial review, and to conclude swiftly it had to be focussed on that work. BW added that there would have to be clear identification of what additional work on the report needed to be done and how that would be taken forward; along with a tight but realistic deadline to demonstrate progress by Haemophilia Day 2016.

With regard to the 4th bullet point on stakeholder engagement, it was noted that there would have to be a mechanism for patients/families to feed their views into the review. It had previously been suggested that Hamish Macdonald of Dogstar productions could help facilitate this consultation via roadshows etc. The Chair would also want to consult directly with those involved – this may necessitate a hybrid approach incorporating one to one meetings. PD commented that the SIBF may want to take separate action to consult their membership. DF agreed to consolidate views and feedback to the Group on the potential characteristics of the consultation exercise. It was agreed that the Group would orchestrate the consultation. Funding would be made available by the Scottish Government to support the exercise. It was agreed that the consultation had to start quickly if the Group was to complete its work by the autumn.

It was noted that HIV patients would require discrete consultation methods – possibly one to one. The idea would be to access views from all categories of current and potential beneficiaries. BN commented that those infected via pooled plasma products had experienced different circumstances – changed patterns of disease and life expectancy. This should be recognised in the recommendations.

4. Timetable and key milestones

The draft timetable was provided for comments/discussion. It was noted that it would be further refined with the Chair once he started work. The CS asked that the Group try to achieve consensus on the key milestones in order to formulate the recommendations on time. If necessary, supplementary meetings could be organised on particular subjects.

With regard to cost modelling, it was agreed that sample case studies could be processed through the various proposed systems.

It was agreed that briefing and evidence would be sought from the Irish Tribunal. PD commented that Raymond Bradley was one of the Irish lawyers historically involved.

5. Meeting dates, format and rules/principles

The CS noted the need to establish a series of meetings to take this work forward. Attendees would be asked to pass their availability to Robert Girvan via a Doodle poll and he would seek to set meeting dates. It was envisaged that a meeting would take place every 3-4 weeks, but more could be scheduled depending on progress. Analysis and evidence gathering work would take place between meetings.

Members expressed a preference for fewer, longer meetings rather than more frequent given travel constraints. Meetings could be scheduled on consecutive days to allow for this. Given the amount of material to be considered, it was agreed that the July meeting format would be longer meetings on two consecutive days. Different venues could potentially be considered due to the Edinburgh festival (starts 7 August) etc.

It was agreed that a short factual note would be prepared after every meeting that could be shared with the wider community. The CS noted that she wanted to keep the process as open and transparent as possible, but there may be issues that members were asked not to share or discuss outside the group – particularly with regard to UK discussions. Members recognised the need for confidentiality on certain issues.

The CS said that she wanted to keep discussions as inclusive and productive as possible. If necessary, the recommendations to Scottish Ministers could account for various preferred options amongst different stakeholders.

6. Infected blood scheme statistics (for information)

The Group were provided with high-level statistical information on the numbers of people who currently received payments from the schemes. Robert Girvan briefly outlined this data.

It was agreed that further numbers would be sought on living HCV Stage 1 recipients still in contact with the Funds. RG noted that there had been a recent look-back exercise to establish the number of deceased as far as possible.

JF noted that he had collected anecdotal evidence over the years regarding Skipton Fund applications. It was agreed that data would be sought regarding successful/unsuccessful applications, how many of those went on to the appeal process and how many succeeded in their appeal or did not.

It was agreed that data would be sought regarding the proportion of those infected via plasma pool/transfusions and also the age of infection.

It was agreed that data would be sought regarding the number of Stage 1 beneficiaries who had died due to extra hepatic conditions – those who had died of the virus itself.

The disparity between the total deceased numbers and the low number of widows claiming support was noted – many more could theoretically come forward.

It was noted that those infected via plasma pool products could have been exposed to multiple viral infections. Medical advice would be sought on the impact of multiple viral infection from an infectious disease specialist. These viruses could potentially be passed on – additional familial infection.

It was pointed out that in the context of establishing Scottish schemes, if that is what the group recommended, cross-border issues may be particularly challenging – would claimants be

eligible via jurisdiction, place of infection, origin of implicated blood product etc? The CS noted that there were precedents that could be referred to with regard to free personal care, prescriptions etc. These areas incorporated rules around residence.

7. Interim/transitional payments

The CS referred to the recent PMQ statement regarding the transitional funding of £25m announced by David Cameron. The intention seemed to be to channel this through the Skipton Fund or Caxton Foundation to patients and families, but this was still not clear. The CS said that her intention was that Scotland would match any transitional payments – Scottish beneficiaries would not be disadvantaged.

The CS noted that the existing UK payment bodies were the only mechanism to distribute such transitional funding. She commented that the Group's main focus should be the review and a permanent improvement to the schemes rather than interim payments.

8. Any other business

It was agreed that travel and overnight expenses would be reimbursed if receipts were provided. Guidance would be circulated on claiming expenses.

9. Next meeting

Robert Girvan would collate availability via Doodle polls and try to schedule as many meetings in advance as possible. He would seek to do this with Ian Welsh, as Chair of the process.