Scottish Review of Financial Support Schemes: minutes of sixth meeting, 8 October 2015, 10.30-14.30, Royal College of Physicians

Attendees

Ian Welsh, Chair – Alliance Scotland.
Alice Mackie - Campaigner, HIV.
Bruce Norval – Campaigner.
Bill Wright - Chair, Haemophilia Scotland.
Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF).
Liz Ferguson – SIBF.
Mary McLuskey – SIBF.
Tommy Leggate - SIBF/independent consultant.
Petra Wright - The Hepatitis C Trust (Scotland).
Patrick McGuire – Thompsons solicitors.
Susan Murray – Central Legal Office.
Gareth Brown – Scottish Government.
Robert Girvan – Scottish Government.
Naureen Ahmad - Scottish Government.
Marion Cairns – Scottish Government.

Welcome, introductions and apologies

1. Apologies were recorded from Dan Farthing-Sykes, Jeff Frew and Norma Shippin.

Action Points

2. Infectious disease specialist – GB noted that given that a more simple scheme was currently being proposed, without detailed medical assessment, he had not prioritised this action at this point. BN had raised some questions regarding multi-viral infection and specific health implications for haemophiliacs. BN noted that there was emerging evidence with regard to hepatitis G and hepatitis E exposure which could have more serious implications in the future. He said that the impact of treatment should also be explored in more detail. BW commented that although the survey favoured a simple scheme, it was primarily a qualitative not a quantitative exercise, aimed at gathering context. PD noted that there was a time imperative for the group to make its recommendations and many of those infections (65%) were due to blood transfusions. These additional health concerns did not apply to them to the same extent. BN reiterated his view was that there should be two separate schemes to account for these differences.

3. Tax issues – SM said that the key difference with regard to tax implications for damages payments was that periodic payments were tax free. With a lump sum any interest generated was subject to tax. For example, with a £5 million settlement someone may choose to take a £1m lump sum and the rest in periodic payments paid for their lifetime. She commented that life expectancy was always a fundamental issue in large settlements.

4. Vale of Leven – It was noted that the Vale of Leven settlements for survivors and bereaved families were negotiated directly between CLO and solicitors. BN said that the context was different as the deceased did not leave behind infected children and partners.

Minutes of previous meeting

5. The minutes of the previous meeting on 7 September were agreed as accurate.

Consulting with affected people – survey results

6. Dan Farthing had provided a final analysis of the survey responses that had been circulated for consideration. IW reflected on the final analysis of the survey. He noted that there was no clear recommendation that could be extracted from the results, but a simpler and speedier solution was preferred. There was not a clear preference for a Scottish solution although more were in favour of this than not. Similar to the interim results, there was a preference for an equal distribution of funding without testing or targeting. There was also some support for prioritisation based on health/liver damage and disability. As expected, there was less support for means testing or needs based assessment.

7. PD commented that he had attended three of the regional meetings and there was a strong feeling that a Scottish scheme was preferred. He suggested that people from outwith Scotland may have responded. RG said that DF had not indicated any evidence of that and the number of responses seemed proportionate. BN noted that the Department of Health had recently met with the Haemophilia Society and patient groups from Wales and Northern Ireland. BW said that the survey represented a snapshot of current thinking among the wider community. IW commented that the recommendations would have to be ready to present to the national meeting, with a rough draft ready for the next review group meeting.

Planning for 31 October National Event

8. IW noted that as requested, the venue was changed to the more central location of the Station Hotel, Perth from 11am to 4pm on Sat 31st October.

9. Dan Farthing had provided a suggested format for the event which had been circulated to the group. He presented two options, the key difference being whether to split into smaller groups with facilitators or not. GB commented that he not think it was appropriate for SG to present the draft recommendation proposal – this was a product of the group. This may call into question the ownership and legitimacy of the recommendation with stakeholders. Discussions may also be constrained or aggravated by the presence of SG officials. IW said that he would be happy to present the recommendations.

10. The group agreed that option 2 was preferred as it was more suitable for the room that had been booked.

Updated scheme proposal

11. GB reiterated the group's conclusions and views that were articulated at the last meeting and presented an updated proposal based on them. The initial suggestion had involved regular Stage 2 payments increased to the Scottish median income; an increased and more flexible discretionary fund; and a new intermediate stage for those with moderate HCV disease progression. The updated proposal strengthened provision for bereaved spouses. Where the primary recipient had died, the increased annual payments would convert into a pension for surviving spouses. Again, this proposal had not been tested with Ministers and was being offered to stimulate discussion and points of agreement.

12. BN said that based on advice he had received from PM and in common with damages arrangements, the pension should be 75% of the relevant annual payment. He commented that every victim should get a basic payment for injury over and above the financial support the rest of the scheme contemplates. The minimum for that should be £50k – this would be in line with the Ross recommendations. With regard to gauging moderate liver disease, PW said that this could be hard to diagnose accurately. AM commented that it would help if

everyone started on a level footing – all Stage 1's could potentially transition to the higher lump sum.

13. SM noted that in settlements liability is often not accepted – it is more about recognition of harm and mitigating the risk of legal action. BW noted that there were still unanswered questions from the Penrose Inquiry and the risk of further litigation. He said that strategic mistakes had been made by Government. BN commented that the ex gratia money that had been paid out to date should be written off.

14. IW said that the drafting of the recommendation proposal should be channelled through him. BN said that ideally those affected would want to avoid civil litigation, although there were still outstanding questions around the use of prison plasma and the licensing of the Protein Fractionation Centre.

15. With regard to the ongoing pension payment, BW said that the 50% precedent for salary based pensions was not appropriate. The 75% precedent set by the Damages (Scotland) Act 2011 was more appropriate for this context, given that it was about recognition of harm. BN noted that if someone had died directly due to extra-hepatic conditions then this indicated that they should not be in Stage 1 in the first place. New evidence regarding the implications of extra-hepatic conditions was constantly evolving. IW said that the fine detail of implementation would be dealt with later. A review process after 2-3 years would make sure the scheme was still fit for purpose. PD said the 50% or 75% pension issue needed clarification. IW said this could be recognised in the recommendation. AM noted that carers had lost out on their own pension. GB commented that there were infected people with no significant health impact or minor impact. AM said that those co-infected at Skipton stage 1 should automatically move to stage 2 due to the additional immune implications of the viral interactions. BN said that it may be difficult to access truly independent medical advice in Scotland as many specialists were involved in the historic infections. GB said that the definition of health effects could be wide-ranging to encompass psychological impacts, treatment side-effects etc.

16. PD said that the recommendation would have to spell out what was being offered to those at stage 1 Skipton. He noted that due to ageing many health impacts can be dismissed by clinicians and said that this kind of assessment was just another form of testing, with inherent subjectivity. GB commented that there would be a transparent appeals process. AM noted that there was the potential to incentivise people to not pursue treatment. TL commented that people still had to justify their claim – this could cause anger. BN said that in line with the recommendations of the science committee on vCJD, there should be a specialist medical team looking specifically at this area. He noted a lack of trust or confidence in clinicians due to the infections. AM said that the additional intermediate lump sum could be predicated on pursuing treatment. It was noted that the assessment process would take time given the number of stage 1 people. GB said that he recognised that people could be treated successfully and still have significant ongoing health impacts.

17. BW said that those receiving treatment were generally at liver disease stage F3/F4 – interferon treatment could potentially be used as a marker for additional payment. With regard to natural clearers BN said that there were still increased risks of cancer and other diseases. There could still be reservoirs of the virus in the body. He noted that a specialist team could regularly update the global research information. There was a need for further longitudinal studies and research and the new scheme could be involved in that.

18. BW asked that the number of Stage 1 living people be brought to the next meeting for consideration. On the subject of insurance, BN said that the cumulative risks of haemophilia, HCV etc made some people uninsurable. The only way they would get insurance would be for the Government to underwrite them. BW said that the categories for

discretionary payment were attractive, but assessment could be problematic in some areas. Again, GB noted that any appeal panel could involve peer representation. IW said that any charity would require spot-checking for audit purposes if making those kind of flexible discretionary payments. There would also need to be appropriate resources for administration of the fund. With regard to the suggestions of a contractual agreement, GB commented that such handling contracts can generally be dissolved by either party at any time – the Government or agency in question. PD noted that people generally did not want means-testing and any appeals committee would have to have wider membership than ex-NHS staff. BN said that a discretionary fund would need higher funding in the first 3 years. It was agreed that the updated presentation would be circulated to the group for information. BN reiterated that 75% of the annual payment should go to the spouse upon death on the basis of recognition of harm.

19. On the subject of converting the annual payments into a single lump sum, GB said that he would need to know what the final proposal was first, but could certainly consider this option. TL asked if the intention was still to cost model the proposal for individual cases – people representing different categories could be canvassed for examples. It was agreed that around five different archetypes would be modelled upon the final proposal. This would be one page setting out what they currently received and what they would get under the proposed model.

20. IW said that he would try to bring an interim recommendations paper to the next meeting for consideration. He would also consider the PM points. IW said that he could not rerun the Penrose Inquiry with regard to culpability and fault, but could certainly note that the group felt there were outstanding issues. BW said that the new scheme would need to be reviewed after 1 year – this could also address the ongoing Penrose concerns. BN said that the new scheme should be collecting beneficiary data from day one to inform the evidence base. IW said that he would be happy to meet with PM one to one to discuss his proposals.

21. AM commented that she was still concerned that any lump sum using life expectancy as a marker could disadvantage those with only a few years left. The key thing was to give people a choice in the way they receive the money. BW said that the sum could be calculated from the point of impact. BN said this could be as far back as 1965 if you take into account the history of the PFC and the absence of appropriate licenses. He noted that everyone would expect some kind of lump sum offer at the 31 October meeting. GB said that there was an issue around the expectations of the community. He recognised that some people would want a lump sum but noted that many would actually receive less in real terms under such an arrangement. TL commented that many of the infected had been in debt most of their life. The proposal needed buy-in from the whole community.

Next meeting

22. The next meeting would be on 16 October at 10.30 in Victoria Quay, Leith, Edinburgh.