Scottish Review of Financial Support Schemes: minutes of fifth meeting, 7 September 2015, 14.00-17.00, Royal College of Physicians

Attendees

Ian Welsh, Chair – Alliance Scotland.
Alice Mackie - Campaigner, HIV.
Bruce Norval – Campaigner.
Bill Wright - Chair, Haemophilia Scotland.
Dan Farthing-Sykes - CEO, Haemophilia Scotland.
Jeff Frew - Campaigner, blood transfusion.
Philip Dolan – Convenor, Scottish Infected Blood Forum (SIBF).
Liz Ferguson – SIBF.
Patrick McGuire – Thompsons solicitors.
Susan Murray – Central Legal Office.
Gareth Brown – Scottish Government.
Robert Girvan – Scottish Government.
Marion Cairns – Scottish Government.

Welcome, introductions and apologies

1. Apologies were recorded from Petra Wright, Mary McLuskey, Norma Shippin and Tommy Leggate. It was agreed that a document provided by BN regarding HCV and extra-hepatic conditions would be circulated to the Group.

Membership

2. IW said that he was still pursuing a meeting regarding the request for Group membership.

Action Points

3. Interim payments – following the discussion regarding an interim recommendation at the last meeting, GB advised that the Cabinet Secretary had written to the UK Public Health Minister to raise the issue of making increased Winter Fuel payments as a possible interim measure, while awaiting a decision on the £25m transitional funding previously announced by the Prime Minister. Any increase in payments would have to be agreed by all four Ministers. It was agreed that the letter would be circulated electronically. PD commented that it would be more appropriate to distribute the money via the Skipton Fund given that some people had not registered with Caxton due to discontent with means-testing. RG noted that registering was a personal choice – Caxton was primarily for those suffering the most financial hardship, including families that would not be registered with Skipton. Skipton had carried out a recent look-back exercise to encourage registration with Caxton.

4. Infectious disease specialist – BN had raised some questions and these would be passed to a specialist for comment.

5. Tax issues – SM said that she would pick up this action point at a later meeting.

6. Pensions - RG provided an update on the average public sector pension amounts. He confirmed that under those arrangements the continuing pension for a widow or widower is one half of your pension. While the average public sector pension in 2009-10 was £7,800, once you factored in pensions paid to dependents, the figure fell to £6,500. 10% of public

sector workers received annual pensions of £17,000 or above. 1% of workers got payouts of £37,000 a year - two thirds of those were NHS doctors and consultants.

Minutes of previous meeting

7. The amended minutes of the previous meetings on 28/29 July and the minutes of 28 August were agreed as accurate.

Consulting with affected people – survey and engagement plan update

8. DF had provided a short summary of the outcome of the regional meetings for agreement to publication. BN noted that you could potentially identify who some respondents were in the longer report. DF confirmed that the long report was not for publication. The Group approved the summary document for publication.

9. DF thanked the Alliance staff for preparing the survey response analysis at very short notice. A selection of comments had been extracted, focusing on particular losses. He said that it would be helpful to test a few of the consultation points with further sub-sets of interested people. BN noted that some of the most vulnerable people may not have responded. DF commented that the survey was not robust in term of methodology, it was a qualitative exercise primarily to gather context and not a quantitative exercise where the numbers of respondents was critical. The free text was an important factor. He said that further activity was required to test the results and members should send him any further questions they thought appropriate to do this and clarify the data. DF hoped to deliver a further update by the next meeting.

10. JF commented that he was receiving regular phone calls giving anecdotal evidence from 6 or 7 people who were not capable of responding. He would pass this information onto DF.

11. DF advised that he intended to schedule the 31 October national meeting from 11 – 4, to allow for two sessions of two hours. This would take travel time into account. PD said that people did not want a bus from Glasgow – this could be cancelled. He also asked for a venue in the centre of Perth rather than the St Johnstone football ground. It was agreed that an alternative venue would be investigated.

Potential scheme models

12. GB reiterated the Group's discussion to date. He said that in presenting a potential model, his intention was to exemplify the progress through a scheme proposal. GB noted that there was a divergence of views of across the Group and wider community and his intention would be to identify key principles during the discussion where agreement could be reached. BW commented that there was the potential to build diverging principles into the scheme if they were not agreed beforehand. It was agreed that principles could be clarified as the model was tested. This would be a high-level presentation with examples to provoke discussion.

13. For discussion, GB presented an initial suggestion for a new model involving 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. This proposal had not been tested with Ministers and was being offered to stimulate discussion and as a starting point.

14. PD noted that historically many of the Skipton Fund decisions about whether an individual was eligible for payment or not were determined by the attitude of the hepatologist in question. A high percentage of people were rejected. GB said that the existing appeals

mechanism could be improved under a new scheme to involve patients or lay people to some extent, as well as including mechanisms for a second opinion by a different clinician. PM commented that you could have a tiered appeals process, with the option of arbitration - potentially independent medical assessment and legal advice. The possibility of a contractual scheme was noted, featuring different degrees of involvement of legal representatives. BN said that extra-hepatic conditions should be recognised by the scheme, with a good appeals system. Opinions on assessment could be taken account of as the medical evidence evolved. PM said the key point was that people had sufficient trust in a fair hearing and confidence in the process.

15. JF commented that some of those cases initially rejected due to lack of medical records were later successful on appeal due to the anecdotal evidence available. There were subjective judgements made on the quality and authority of the anecdotal evidence, such as if it came from a medical practitioner.

16. BN referred to the list of extra-hepatic conditions and noted that the intermediate HCV disease stage could also be fatal or contribute significantly to death. He said that any new disease staging process should also reflect employability and the adverse effects of treatment. BW commented that the current two stage system under Skipton was inadequate and many families were left behind. LF said that everyone's experience was unique and agreed that the side effects of treatment could be very debilitating. BN commented that the discretionary fund model could potentially work well for families. DF noted that there were a lot of objections to means-testing during the consultation. The point had also been raised that any scheme would have to be future-proofed against the budget decisions of future Governments. It would also have to take into account of those not yet diagnosed.

17. BN noted that there was currently no protection for savings and no incentive to save under the existing arrangements, given that some payments were means-tested. BN noted that there were increased care and domestic costs for the wheelchair bound, for example. PM commented that the term mean-testing had become toxic for beneficiaries and payments should just be described as discretionary, with a more flexible approach based on need rather than income. PD agreed that discretionary funding could be a useful tool if administered correctly by the decision-makers. DF said that this fund could be specifically for additional needs. GB agreed that the current discretionary criteria could be redrawn to make them more flexible and accessible. A list of core needs could be drawn up to guide the person's spend – they would sign up to this. BN commented that there would probably be a backlog of need with regard to home adaptations etc but after 2-3 years this would likely settle down to predictable levels.

18. BW said that context would be needed to justify the proposed amount in a discretionary fund. AM asked if such a fund would be a charity, noting that some beneficiaries had been told that their complaints could lead to the charity in question shutting down. PM noted that the charity trustees must work within the principles of charitable need but this could be interpreted in different ways, depending on the context. GB said schemes did not necessarily have to be set up as charities. AM said that if the regular payments were adequate this would cover additional caring costs etc and reduce the pressure on a discretionary fund.

19. On the issue of bereaved families BN said that security was important – they needed to know what finances they would have available in the future. A care pension could convert into 50% of the regular payment upon death. GB noted that you would have to define who gets the 50% payment. BN said this would be the carer or whoever gave up their job. PM noted that usually this would be the spouse or person with financial dependence on the deceased. BW commented that those who have suffered the most impact are clearly the deceased cases. They could receive a lump sum payment and a prescriptive annual

payment to ensure the widow/er was protected. BN said that if you were a living person who was directly affected you should be guaranteed some kind of pension. GB asked the Group if retrospective payments should be paid for those who died in the past. BN said that they should receive retrospective payments plus inflation. He noted that there was also a secondary group who had suffered psychiatric injury, pain and suffering. AM said that those who had remarried would have to be made aware of the new arrangements via publicity. BN suggested that any widows would receive the ongoing regular payment unless they had remarried. PM clarified that under civil damages arrangements, a widow/er would receive 75% of the pension. With regard to deceased cases, PD noted that there could be confidentiality issues as writing to the family could disclose the infection.

20. On the issue of the deceased, BW said that setting key eligibility dates could be problematic. BN noted that 1975 was the year cited by the Lindsay Tribunal and Krever report. AM commented that the bereaved were still suffering the same loss as an infected person. GB said that there could be an open-call regarding deceased cases to access annual payments. BN said that this was about the comfort of the dying as well, to ensure onward security. GB said that anyone could potentially reapply and received a fresh hearing with peer involvement in the appeal process. A solution could be found for the insurance issues, although this might take a bit more time to do. BN said that the only solution would be for the Government to become the underwriter.

21. BN said that it was his view that the scheme should encompass specific penalties/tariffs for specific recognition of faults – such as non-consensual experiments on haemophiliacs and unlicensed products manufactured by the Protein Fractionation Centre. This would reduce the chances of similar mistakes being made in the future. IW commented that the Group should be aiming to produce recommendations that Ministers could feasibly accept and the Group could not re-run the Penrose Inquiry.

22. SM commented that in damages cases you would work out the relevant care costs for a person and factor in life expectancy. Using the Ogden figures you would then come up with a figure to offer. PM said that you would multiply the relevant annual cost by life expectancy then discount via the Ogden tables. The claimant may or may not accept the offer and had the right to opt out or appeal. AM queried how life expectancy would be calculated, noting that the older you were then the less time you had left, potentially receiving less money. IW commented that it would ultimately be a matter for the individual whether they accepted a lump sum or opted for another arrangement. The Group agreed that a lump sum option should be included for deceased cases. PM said that the issue of injury and a figure for pain and suffering had still not been resolved. He pointed out that funeral costs were always covered in Scots Law. These were paid by the wrongdoer. He said that a lump sum should also reflect past losses. PD noted that in 1980 haemophiliacs were still not expected to live beyond middle age. He commented that the public would also have a view on any new arrangement and the Group would have to be mindful of the extent of their understanding and sympathy.

23. IW said that the initial models and principles presentation would be circulated for information and Scottish Government would refine and improve the proposal based on the Group discussions. An extra meeting would be scheduled before the next 16 October meeting. JF reiterated that there was a group of people who should have received Skipton payments but had not due to the destruction of medical records. BW said that the Vale of Leven precedent should also be considered.

Next meeting

24. The next meeting was to be arranged prior to the 16 October meeting.