Martin Harvey

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Sent: 10 November 2003 17:55
Subject: Hep C scheme

Moira

Martin and I had a "secret" meeting at the Dept of Health this afternoon. The secret is that people such as the Haemophilia Society were not involved and we were being given an advance warning of what is now planned.

The position now is that most of the key elements of the scheme have been agreed between the various health department officials, the main outstanding point being whether or not the Macfarlane registrants (the "co-infected") are eligible for payments on the same basis as those mono-infected.

We have said all along, and repeated today, that the use of our resources and expertise is conditional on this eligibility. The official involved has to convince the Sec of State (John Reid) that this must be included in the scheme. The Under-Secretary to whom he reports, Melanie Johnson, has agreed to it, but it is Reid's call.

Given that, the intention is to make a public anouncement of the exact scheme within 2 - 3 weeks. Some hopes, since there are still some key medical issues unresolved, but we have to accept their intended timetable.

The official concurred that now is the time for BLP to talk to the DoH lawyers. The critical points of the scheme as far as the operating vehicle is concerned appear to be as follows:

- there will be a fixed tariff - a rate for being Hep C positive on 29 August (the date of the original announcement) plus an additional payment, claimable at any time from now into the as-yet-undefined future, for meeting a medical trigger point (also still undefined) indicating liver damage or disease
- there will be a further, smaller amount payable now to anybody who had by 29/8 cleared the Hep C virus as a result of taking the drug regime; should this clearance prove to be transitory, those involved would then be eligible for balancing payments to give them the same amounts as they would have received had they not apparently been cleared
- there are some 6,000 believed to be eligible, of whom about 2,800 are haemophiliac, the balance having been infected through transfusion (rather than through blood products). It is assumed by the officials both that not all those eligible will claim and that there will be some claimants who were probably infected through some other route (eg drug abuse) but about whose medical history there is sufficient ambiguity that it will be impossible to refuse them. I am not clear whether these figures are UK-wide or English, or a mixture.
- the scheme is estimated to cost the English DoH £200 million, including those payments to be made far into the future. We do not yet have the assumptions on which the cost estimate is based.
- the idea is to give the new vehicle the whole sum at the outset and tell the operators to get on with it. There would be no certainty of re-plenishment of depleted funds other than that, the politicians having financed the scheme once, they would have no political case for refusing further fuding if their initial assumptions proved to be wrong. (I am reporting, not commenting!).
- the operating costs would come out of the capital sum rather than be funded by a separate DoH budget allocation (it seems that they are finally thinking along this route for MFT, which I first mooted 2 or 3 years ago).
- there would be no payments to bereaved families, or to those who have cleared the virus naturally. The first of these, in particular, is regarded as unacceptable by the Haemophilia Society and its political allies, so there might be continued campaigning on it. This could put certain MFT Trustees in a difficult position. For my part (as a Society-appointed Trustee) I can live with the NHS making ex gratia payments, with no admission of liability, to people it has harmed who are still alive and are or will be incurring costs as a result of their infection, while ignoring what would seem a bit more like compensation who have been bereaved (even in those cases where such bereavement has resulted in real financila hardship).
- as I have said before, the scheme will be funded by each of the 4 national health departments according to a formula we have not (yet) seen, presumably based on estimates of numbers of claimants
- it is apparently agreed by the DWP that payments from the new vehicle will not count against benefits entitlement and will be tax-free. (I am not convinced that the DWP can make commitments on tax; nor do I believe that they have considered aspects such as the taxability of income arising from the investment of sums received from the new vehicle).

I have said that the sum of these considerations to me makes your recommendation of a corporate vehicle irresistible - I cannot see many people queueing up to be Trustees of a Trust that could run out of money with legitimate obligations still unfulfilled.

I have no idea whether the MFT Trustees as a whole will continue to be prepared to go along with this scheme. It has some advantages for us, in giving us the opportunity to upgrade systems and other things, and mayeb move into slightly larger premises, without calling on MFT's constrained operating budget. Willingness to help the DoH might also have some benefits, although I suspect political memories are fairly short.

On the assumption that we are going to be involved, please would you get in touch with the DoH official involved, who will in turn refer you to the appropriate DoH lawyer(s). The contact is Richard Gutowski, Blood Group Policy, Department of Health, Room 633B, Skipton House, 80 London Road, London SE1 6LH; his Email is richard.gutowski@ GRO-C

Gutowski himself keeps talking of a Trust and of Trustees. I suspect that this is habit, not something that he is getting from his legal people.

I would be much happier if BLP were in control of determining the sort of vehicle to be used and of drafting its key documents, but I have not made that an absolute condition of our participation, so I shall have to hope that you can negotiate your way into it.

One issue that the nature of the vehicle clearly affects is the tax status of its investment returns, which it would seem could be quite significant if there were a substantial proportion of the initial capital to be set aside for later conversions from infection to disease. Again, we have no idea of the assumptions that would enable us to work out what this proportion might be. (Equally we have no idea how much money might be coming into the scheme from the non-English bits of the Union, although I guess at no more than £30 million).

That is all that I can think of at the moment. I hope you will feel that there is a workable scheme here; at least as important, I hope you have a chance to straighten things out if you think it is in danger of going off the rails already.

Best regards

Peter