MS(PH) From: Rowena Jecock

Cleared by: Ailsa Wight

Date: 1<sup>st</sup> June 2009

Copy: As attached

## Government response to Lord Archer – next steps

1. Reaction to the Government package announced in response to Lord Archer's report has been limited, but negative. The main areas of criticism are:

- Although we are increasing the payments to HIV patients from an average of £6,400 a year to a flat rate for everyone of £12,800 per annum this was considered to be nowhere near enough (Lord Archer described it as "tossing a bone to a dog")
- That we should be increasing payments now to hepatitis C patients and their dependents – rather than just promising a review of the Skipton Fund in five years time.
- The level of payments should be closer to the amounts paid in Ireland which are claimed to be an average of £1m per person (for both HIV and hepatitis C sufferers) and up to £5m per person in some cases.
- 2. You have asked us for more detailed information as to why the situation here is different from Ireland, together with possible options for handling the criticism around the Skipton Fund.

# Why Ireland is different

- 3. The Government here has never accepted any liability. We believe that people were offered the best treatment available at the time and that as soon as blood screening tests were available they were implemented. There were attempts to bring litigation against the Government by those infected with HIV in the early 1990s but these were withdrawn following legal advice to the plaintiffs that they were unlikely to win their case. The Macfarlane and Eileen Trusts were established at that time for those infected with HIV, with levels of payment determined between Trustees and claimants. All the payments made in the UK, including through the Skipton Fund for hepatitis C, are therefore ex gratia goodwill payments only.
- 4. In Ireland by contrast there was large-scale contamination with hepatitis C of a blood product used in pregnant women, and a judicial

inquiry found that 'wrongful acts' were committed by the Irish Blood Transfusion Service. The Irish Government set up a hepatitis C compensation scheme in 1997 for the infected women following this conclusion, because of the threat of litigation (which the Irish Government believed it would lose). The compensation scheme was later extended to all people infected with hepatitis C through blood products and blood transfusion, as some infected women had donated blood and so infected others. **Annex A** contains a Hansard extract from 2004, which contrasts the position in Ireland with that in England for hepatitis C.

5. Haemophiliacs with HIV in Ireland initially received similar ex-gratia payments to those in the UK, but successfully campaigned to be included in the more generous hepatitis C scheme.

## Skipton Fund – payments for those infected with hepatitis C

- 6. We have announced that we will review the Skipton Fund in five years when it will have been in existence for 10 years. You are worried that we will not be able to maintain this position and that we may need to announce a review of the Fund now if we come under sustained pressure. If so, it will be important to keep this to an internal review so that we maintain control of it.
- 7. If we do announce a review, we will be pressed to say how long it will take and there will be an expectation that it would be no more than about three months, if that. We also need to be clear that the outcome would have to be increased funding as it simply would not be possible for the review to conclude that funding should remain the same. We would therefore need to determine what the options for increased funding might be, and whether they are affordable, ahead of any announcement.
- 8. The Skipton Fund makes stage 1 payments of £20k to people infected with hepatitis C from contaminated blood, and stage 2 payments of £25k if they go on to develop serious illness such as cirrhosis or liver cancer. The key options for increasing payments are:

#### Option 1

Give all stage 2 claimants £12,800 per annum while they are alive. Estimated cost – **up to £10m per annum recurrent** (Note – this could increase as more people progress to stage 2)

#### Option 2

Give all Skipton Fund claimants £12,800 per annum while they are alive.

Estimated cost - £52m per annum recurrent

# Option 3

Double stage 2 payments to £50k for all past and future cases. Estimated cost - £19.3m one off plus £2.5m per annum recurrent (Note – there will be costs in future years as more people progress to stage 2)

#### Option 4

Double stage 1 payments to £40k for all past and future cases. Estimated cost - £81.2m one off plus £2.3m recurrent (Note – there will be costs in future years as new claimants come forward)

#### Option 5

In addition to, or instead of, these options we could rectify the anomaly whereby the estate of an infected person who died before August 2003 received nothing, while the Skipton payments are made into the estate of a person who dies after that date. This would benefit those who benefited from the deceased's estate, including widows and dependents. We do not have reliable figures but estimate that there could be up to 1,200 estates eligible for £45k each. Estimated cost – up to £54m one off (assuming current level of

#### Option 6

payments)

Rather than giving each estate the full amount of £45k we could try and cut this total down by giving them only a stage 2 payment of £25k. This would inevitably be criticised.

Estimated cost – up to £30m one off (assuming current level of payments)

- 9. Annex B gives details of how these options are calculated, plus pros and cons. The biggest problem is that they are all sizeable sums so finance colleagues have confirmed that any of these options would need to be agreed by Treasury.
- 10. The issue on which we receive most criticism is that families and dependents of those who died before August 2003 do not benefit (options 5 & 6). We would be heavily criticised for announcing any further funding that did not include this as a minimum, although there would be significant difficulties in verifying the eligibility of claims, given the time that has elapsed. The payments would, of course, go to all beneficiaries of the estate, not necessarily only to the group of widows and dependents. Implications for the devolved administrations will also need to be considered, as the Skipton Fund is UK-wide, and in Scotland, the eligibility arrangements specifically for payments are established independently in primary legislation.

11. Any increased funding we were to announce is of course likely to be criticised as insufficient, in exactly the same way that doubling the size of the HIV payments has been. You will want to consider very carefully therefore whether you want to do this, particularly in view of the size of the sums involved.

# Stakeholder views, and engagement, following publication of the Government response

## a) Macfarlane Trust/Eileen Trust

- 12. We have spoken to the Chief Executive of the Macfarlane and Eileen Trusts, and the Chair of the former, who advise that they are not campaigning organisations and cannot make a public statement of support for the increased funding, but nor will they criticise the position. They made the point that the recipient community will see the increased funding as little more than a 'catch-up exercise' for constrained funding over the past five years, and are unlikely to express gratitude for it.
- 13. We have opened discussions with the Trusts about implementation of the increased payments.

## b) Haemophilia Society

- 14. Feedback from the CE of the Haemophilia Society, is that members are particularly disappointed that the Government response does not address their financial needs. They do not consider the increase in their funding for those with HIV to be sufficient. The main grievance though, appears to be in relation to hepatitis C, where those affected believe the current financial relief provided through the Skipton Fund to be inadequate, and also unfair, particularly because of the ineligibility of widows/dependents of those who died before August 2003. The promised review of the Skipton Fund in 2014 has not been well-received because those now seriously ill with complications of hepatitis C are unlikely to benefit from it.
- 15. You are keen to ensure that the funding for the Haemophilia Society is used for activity that contributes to agreed outcomes in support of longer term sustainability to enable the Society to work towards a more secure future. We have discussed this with the Third Sector Partnership Team (TSPT), who advise that we can restrict how the monies are used through the formal grant agreement that will govern this award.
- 16. We plan to meet with the Society's CE on 11 or 12 June to discuss their use of the additional funding, and how we will work with the Haemophilia Alliance. There is a meeting of the Haemophilia Society Trustees on 13 June to discuss the Government's response, after which there may be a further statement from the Society.

# c) UK Haemophilia Doctors

17. The Chair of the UK Haemophilia doctors' organisation has confirmed that they will not make a public statement about the Government's response, but privately has said that he is disappointed only that nothing has been done to address the needs of those dependents not eligible for relief through the Skipton Fund. He is pleased with the proposal that Government work with the Haemophilia Alliance.

## Wider Handling

- 18. It is likely that debates will be secured in both the House of Lords (Lord Darzi's commitment of 28 April), and the House of Commons (Harriet Harman's comment of 21 May). Relevant Hansard extracts are at **Annex C.**
- 19. We will develop robust lines for parliamentary use, especially during the Second Reading of the Health Bill, which begins on 8 June. We will also work with COMMS in anticipation of further media interest.

Rowena Jecock
GTN GRO-C

Copy:

Penelope Irving Sarah Kirby Joanne Jones Marc McGonagle Catherine Hawes

Elizabeth Gunnion

Niall Fry

David Harper

Liz Woodeson

Richard Murray

Ailsa Wight

Jonathan Stopes-Roe

Debby Webb

Brian Bradley

Ted Goff

Olivia Butterworth

Catherine Pearson

Natalie Pemberton

Kate Pike

Judith Moore

Paula Cohen

Graham Kent

Simon Burke