

URGENT

FOR DECISION

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17/4/09.

MS(PH)

From Liz Woodeson

Date 17 April 2009

Please let me know how you would like to progress regarding meetings with Baroness Thornton

Cc. attached Phil Hope.

Lord Archer's report – Response to recommendations

1. We understand that you are keen to respond to Lord Archer's report in the most positive way possible. We have sent several submissions covering different aspects of his recommendations. As requested, this submission now pulls together the position on each recommendation in response to the steers you have given us so far. I have not repeated the background and detail as these are covered in earlier submissions.

The Recommendations

2. The full text of Lord Archer's recommendations is at Annex A.

Rec 1) A statutory committee to advise on the management of haemophilia

3. You have already agreed that you do not want a statutory committee.

4. Alternative option - There is an existing UK wide partnership - the Haemophilia Alliance - between patients, haemophilia doctors and others involved in their care such as nurses, physiotherapists and social workers. This Alliance is jointly chaired by the Haemophilia Society and the haemophilia doctors' organisation. We could propose that the Government will seek advice from the Alliance on matters relating to the care of haemophilia patients and will meet formally with the Alliance twice a year (and fund the cost of those meetings).

Cost – approx £10,000 per year to cover meeting costs. Could be met from within existing budgets.

Pros: likely to be well received as a second best option.

No downside for DH.

Rec 2) Haemophilia patients and their partners to receive any tests recommended by the statutory committee

5. If we recognise the Haemophilia Alliance as a Government advisory committee as suggested above, then we could accept this recommendation and implement any testing they recommend.
6. Cost – none at present as we believe that haemophilia patients already receive all relevant tests. Future costs unlikely to be higher than they would be anyway as it is highly likely that any new relevant tests would be offered to haemophilia patients in any case.

Rec 3) All blood donors to receive the same tests (recommended by the statutory committee)

7. We cannot accept this recommendation as another advisory committee – SaBTO (Safety of blood, tissues and organs) - already advises on tests for blood donors. They are obliged to take cost effectiveness into account as testing all blood donors for something is potentially very expensive.
8. Alternative option – we could agree to refer any recommendations for tests for blood donors to the advisory committee on the Safety of Blood, Tissues and Organs.

Cost – none, as we would do this anyway.

Rec 4) Free prescriptions and free access to other services “not freely available under the NHS including...GP visits, counselling, physiotherapy, home nursing and support services” for those infected

9. You have already agreed that the issue of free prescriptions will be dealt with as part of Professor Gilmore’s review.
10. We clearly could not accept that GP visits, counselling, physiotherapy and home nursing are not already available under the NHS where needed.
11. “Support services” are more problematic as these could include social care services such as domiciliary care which are means tested. We cannot make any change here as charging is a matter for local authorities and they have discretion over whether and how much to charge. However DH guidance to local authorities on charging for social care services already advises them to take account of the specific needs and costs associated with the person’s condition or disability – this would include any additional costs related to HIV or Hepatitis C.

Rec 5) Secure future of Haemophilia Society by adequate funding

12. The core funding for the Haemophilia Society has been tapering off and is down to a last payment of £30k for 09/10. (They are of course also eligible for project funding and are due to receive £80k over the next two years.)
13. Option 1 – reinstate ongoing core funding of £100k per year
Pros: would satisfy Lord Archer and Haemophilia Society
Cons: colleagues responsible for third sector funding advise against this as agreed ministerial policy is to end core funding for all third sector organisations.

14. **Option 2**- give a one off "development grant" of £100k this year to give them more time to secure alternative sources of funding.

Pros: would be in line with treatment of other third sector organisations, a few of whom have received similar one off grants. Recommended by policy colleagues with responsibility for third sector funding.

Cons: Unlikely to satisfy Lord Archer and the Society.

15. **Option 3** – agree ongoing core funding of £100k for five more years
Pros: this would probably be accepted by Lord Archer and Haemophilia Society as a reasonable second best option.

A relatively cheap way of responding positively to one of the key recommendations. Could be found from existing budgets. *Liz has said £100k can be found in her programme budget.*
Would sugar the pill if we are not able to respond as positively as they would like to the other financial recommendations (see below).

Cons: could result in pressure from other third sector organisations for a similar deal on the basis that they are equally deserving.

Should you choose this option - would you like to meet with Phil Hope?

Yes please ✓

16. **Annual meetings** – you have already said you would like us to formalise our relationship with the Haemophilia Society and meet with them annually. We do already meet with them on an informal ad hoc basis. It would be no problem at all to have a formal annual meeting in addition and we can include this in the response.

Rec 6a) Financial assistance should be increased and take the form of prescribed periodic payments.

17. **Skipton Fund** (for those infected with hepatitis C) – You have already decided that this should be left alone at present but that we should make a commitment to review the fund in 2014 ie. 10 years after it was set up. ✓

18. **MacFarlane and Eileen Trusts** (for those infected with HIV) – You have indicated that you would like these to be changed to remove discretionary payments and give prescribed periodic payments. There are 584 registrants with these schemes and they currently receive average payments of £6,400 per year each.

19. **Option 1** – to provide every recipient with the same annual payment we would need to level up. If you were to give them each £10,000 per year this would cost around £5.9m pa – **a total increase of £2.1m per year.**

20. **Option 2** – You might prefer to double the current average payment from £6,400 to £12,800 per annum. This would cost around £7.6m pa - **a total increase of £3.8m per year.**

Pros: These suggested increases in per annum funding are relatively small. Finance advise that finding the additional funding would be difficult given the more challenging financial climate that the Department is facing, but that it should be possible through re-

prioritisation. However of the two, they would much prefer Option 1. Agreement from both SofS and HMT will be needed.

Cons: Any increase could lead to renewed pressure from other groups eg. Thalidomide patients, vCJD families etc.

Rec 6b) Anomalies between and within schemes should be removed

21. We understand you would like to see harmonisation of eligibility within the Skipton Fund.

22. Skipton Fund - The most significant anomaly is that partners and dependents of those who died from Hepatitis C before 29 August 2003 when the fund was set up do not receive any payments. We do not have data on numbers who died before the cut off date. Best estimates suggest there could be 1200 of them. To make payments to their dependents equivalent to what the infected person would have received **would cost up to £54m one off**. (explanation at Annex B)

Pros: This is by far the most significant anomaly and correcting it would be welcomed.

Cons: It is a very large sum and reaching agreement with HMT and the DAs would be challenging. Finance colleagues advise that it is not impossible - but that you would need to make a strong case to SofS. SofS would need to be convinced as to why this should be funded over and above other pressing priorities. The funds would have to be spent this year ie. 2009/10 as there would definitely be no money next year. This would be difficult to achieve as we do not have contacts for these people – we would publicise the scheme through appropriate channels and invite them to come forward (which in itself could be a problem as it could mean the scheme was vulnerable to abuse and false claims). This option would not address anomalies between the schemes (because Skipton Fund beneficiaries would still not receive recurrent payments as MacFarlane and Eileen recipients do) so it would only go part way towards meeting Archer's recommendation for harmonisation. It could also be perceived as very unfair to give £20-45,000 to people whose spouses/partners died more than six years ago, and no increase financial assistance to living beneficiaries of the Skipton Fund.

I think this is an important consideration.

Rec 7) Access to insurance by providing premiums or setting up separate scheme

23. The ABI (Association of British Insurers) has assured us that insurers do not treat haemophiliacs or those infected with HIV or hepatitis C differently from people with other pre-existing conditions. In all cases, a person's premiums are determined through assessment of their risk of illness/death.

24. We have asked the ABI for an indication of how much extra a haemophiliac's premiums would be if they were infected with HIV and/or hepatitis C. *Liz assures me that they are chasing ABI on this issue and the ABI aim to get back to the team within 2 weeks.*
25. If you agree increased payments as at 6a) above, then these should enable those infected with HIV to pay the increased premiums (subject to confirmation of the amounts by ABI). This would allow us to respond positively to this recommendation.
26. It would not however help those infected with hepatitis C. We will consider this when we get further information from ABI. However, since Skipton Fund recipients do not get recurrent annual payments – and you have indicated you do not want to make changes to the Skipton Fund at present - it is difficult to see what we could do about this.

Rec 8) A look back exercise to identify any others who may be infected

27. We can accept this recommendation.
28. Cost - the haemophilia doctors' organisation has indicated this would cost around £50,000 and they would be willing to do it. The money can be found from existing budgets.

Engagement with the Haemophilia Society

29. We had an initial discussion with the Haemophilia Society when Lord Archer first published his report. They confirmed then that the most important recommendation from their point of view was for increased financial assistance for those infected.
30. We have not spoken to HS since then as we believe careful handling will be vital. We would not want to raise their expectations unduly. Nor would we want to give them more time to work up objections to our proposals.
31. Bill handling is also relevant here. As you know, Lord Morris (chair of the Haemophilia Society) has tabled an amendment to the Health bill to achieve the first of Lord Archer's recommendations ie. a statutory committee. On the advice of the Bill team we have already suggested that you meet with Lord Archer and Lord Morris ahead of Report Stage on 28 April (Rowena Jecock's submission of 2 April refers.) *Attached*.

Conclusion

32. We would welcome your views on the proposed responses to the recommendations set out here.

Liz Woodeson
Director of Health Protection

Copy:

Morven Smith
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Sarah Kirby
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Mike Davies
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Graham Kent (DH legal service)
Paula Cohen (DH legal service)
Sylvia Shearer (Scotland)
Caroline Lewis (Wales)
Karen Simpson (Northern Ireland)

SUMMARY OF RECOMMENDATIONS MADE BY LORD ARCHER

1. Establishment by Statute of a committee to advise Government on the management of haemophilia in the United Kingdom. It should have overarching responsibility for:
 - i) the selection, procurement and delivery of the best therapies currently available and recommended by NICE;
 - ii) readily available access to any necessary treatment relating to the condition itself or any condition arising from consequent therapy;
 - iii) all provisions necessary to address the financial and other needs of haemophilia patients.
2. Patients with Haemophilia who have received blood or blood products, and their partners, should be tested for any condition identified by the Committee described above.
3. Every blood donor should be similarly tested following the donation.
4. Those who have been infected should be issued with cards entitling the holder to benefits not freely available under the NHS, including free of charge prescription drugs, general practitioner visits, counselling, physiotherapy, home nursing and support services. The card should facilitate access to an NHS hospital bed and specialist services.
5. The Government should secure the future of the UK Haemophilia Society by adequate funding. This should be seen as a matter of urgency.
6. Direct financial relief should be provided for those infected, and for carers who have been prevented from working. The scheme should have the following characteristics:
 - a) It should be paid through the Department of Work and Pensions in the same way as existing statutory benefits, so that beneficiaries should receive their entitlements from the Government and not through intermediate sources such as the Macfarlane or Eileen Trusts, or the Skipton Fund. The Government would thus have direct responsibility to the individual beneficiary for providing the necessary resources.
 - b) Entitlements should be payable if infection is established within the appropriate time-frame. An appeal mechanism should be provided against rejection of a claim and the assessment of the amount due.
 - c) Entitlement should not be means-tested, but should take the form of an initial capital sum, followed by prescribed periodical payments.
 - d) There should be no distinctions dependent upon the reason for the treatment with blood or blood products.
 - e) The anomalies which at present apply according to the age when the recipient was first infected, or when the infection took place or, in the case of dependents, the date of death of the original patient

should be rectified. In particular, the Government should review the conditions under which the widow of a patient with haemophilia now becomes eligible for benefit from the Elileen Trust and from the Skipton Fund¹.

- f) Payments under the scheme should be disregarded for the purposes of calculating other benefits.
- g) There should be a table of amounts payable in the case of double or multiple infections.
- h) Payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland.

7. There is a need for some provision to ensure to patients access to insurance. This could be done either by providing the premiums, or by establishing a separate scheme for the patients in question.

8. In addition, a look back exercise should be undertaken to identify, as far as possible, individuals who may have been unknowingly infected by contaminated blood products and who might still not be aware of this.

Annex B

Bringing the eligibility criteria for partners/dependents of Skipton Fund beneficiaries in line with those for the MFT & ET

We do not have data on the numbers of people who died before 29 August 2003 from hepatitis C infections as a result of NHS treatment with blood or blood products before September 1991. According to the Archer report, a total of some 4670 cases of treatment-acquired hepatitis C infection have occurred. If, say, a quarter of them (i.e. 1200) died before August 2003, each of whom left a dependent, payments to their widow/ers or dependents could cost up to:

$1200 \times £20000 = £24\text{m}$ (stage one payment) plus, where indicated,
 $1200 \times £25000 = £30\text{m}$ (stage two payments) = £54m.

We do not envisage that this payment would be extended to the estate of a deceased, only to a person who was a partner or dependent at the time of death, and who (now) makes a claim on the Fund. We do not have a list of such potential claimants and it would be virtually impossible to identify them proactively, beyond placing suitable advertisements inviting them to come forward.

Any changes to the Skipton Fund would have to be agreed with the Devolved Administrations, especially with Scotland.

Estimated one-off cost of a payment to widow/ers or dependents: in the order of £54m
