From: Karen Simpson
Health Protection Branch

INV/68/2011

Date: 7 February 2011

To: 1. Dr Mitchell √[EM 7/2/11]
2. Michael McGimpsey

TELEPHONE CALL WITH EDWINA HART AND NICOLA STURGEON RE CONTAMINATED BLOOD

Summary

Issue:	Minister's discussion today with Edwina Hart and Nicola Sturgeon about the review of financial support provided to those affected by contaminated blood.
Timescale:	Urgent: phone call scheduled for 3.30 pm
FOI Implications:	This note is fully disclosable.
Presentational Issues:	None
Recommendation:	Minister to note the briefing below including lines to take

Detail

1. Minister has agreed to discuss the review of financial support provided to those affected by contaminated blood with Edwina Hart MBE, Minister of Health and Social Services, Welsh Assembly Government, and Nicola Sturgeon the Scottish Cabinet Secretary for Health and Wellbeing at 3.30pm today.

2. Anne Milton, Under-Secretary of State, DH, wrote to Minister on 13 October 2010 about a short internal review of financial support for people affected by contaminated blood. (COR 1145/2010). Ms Milton pointed out that some aspects of the review would be relevant to

England only and others would touch on matters that have wider implications, such as the level of payments made to those infected with hepatitis C.

3. Northern Ireland adopted the same position as the Scottish and Welsh health departments, and did not participate in the formal review but asked to be kept informed of the recommendations of the review and to be consulted on any proposals that would potentially have an impact on the devolved administrations.

4. The findings of the review and England's response to the recommendations were announced by Andrew Lansley on 10 January.

5. The Health Departments in Northern Ireland, Wales and Scotland only had sight of the Government response on the same day. There was no consultation with DA Health Ministers before the announcement, and despite written requests from the devolved administrations, officials were not kept informed or provided with an advanced sight of the report, before the announcement.

Compensation schemes for individuals in the UK

6. There are currently three ex-gratia payment schemes in operation in the UK: (i) the McFarlane Trust, (ii) the Eileen Trust and (iii) the Skipton Fund. The MacFarlane Trust and Eileen Trust provide ex-gratia lump sum and discretionary payments to, respectively, haemophiliacs and others who contracted HIV from infected blood and blood products, and their dependants. An annual payment of £12,800 is paid to each infected individual and is administered on a UK basis.

7. The Skipton Fund was announced on 29th August 2003 to make payments to people infected with hepatitis C from infected blood and blood products. A first stage payment of £20,000 is available to those who are eligible for payment under the scheme. For successful recipients of the first stage payment whose hepatitis C infection has led

to advanced liver disease there is a second stage payment payable of £25,000.

8. There is no central funding allocation for the Skipton Fund: each UK country contributes what they need to pay annually into the fund to meet their own needs. In Northern Ireland approximately £3m has been paid out to 120 individuals.

9. The Fund is currently only available in respect of people who died after 29 August 2003. No payment can be made in respect of those with hepatitis C contracted from contaminated blood who died before the Skipton Fund was established.

Compensation for individuals in the Republic of Ireland

10. Substantial public inquiries were undertaken in Canada (the Krever Commission) and Ireland (the Finlay and Lindsay Tribunals), both resulting in significant reform of the systems for supply of blood and blood products and the establishment or modification of compensation schemes.

11. The Irish Hepatitis C and HIV Compensation Tribunal was established by the Irish Government in 1995 to provide compensation for those infected with Hepatitis C via blood or blood products and its remit was extended in 2002 to include infection with HIV. It has a statutory basis in the *Hepatitis C Compensation Tribunal Act 1997,* the *Hepatitis C Compensation Tribunal Act 2002* and the *Hepatitis C Compensation Tribunal Amendment Act 2002.48.*

12. The size of awards is assessed in accordance with the principles of civil claims for damage and Tribunal decisions can be appealed in the High Court. The Irish Hepatitis C Compensation Tribunal does not aggregate its data in a form which enables it to provide a figure for an average payment to an infected individual in Ireland. However, officials in RoI Ireland have estimated that costs are in the region of <u>£750k per person infected</u>.

13. As well as being entitled to claim compensation, Irish patients infected with HIV or Hepatitis C via blood or blood products may use a government-subsidised scheme to purchase life insurance, mortgage protection and travel insurance with no disease-related premium. The total cost of administering this scheme in 2009 was £950,000.

14. Those with Hepatitis C are also entitled to hold a Health Amendment Act Card which provides free access to a range of health services. Similar insurance and healthcare provisions for UK victims of contaminated blood were recommended by the Archer Report.

15. It should be noted that in Ireland there was a significant problem with Hepatitis C contamination of Anti-D serum (given to women with certain blood types to prevent haemolytic disease of the newborn) in addition to problems related to blood transfusions and treatment of haemophilia.

16. Successive UK Governments including the current Government have argued that the situation in Ireland is not comparable to that in the UK because the Irish scheme had been established on the basis that an official enquiry there had shown wrongdoing by a government agency, i.e. it is a compensation scheme based on fault. No such wrongdoing has been shown in the UK and therefore the UK ex gratia payments scheme was appropriate.

17. It would cost in excess of £3 billion to replicate the Irish scheme in the UK. It will be impossible to find that amount of money without a severe impact on other essential programmes.

Detail of the review and recommendations in England

18. The measures that DH (L) are proposing to implement for England seek to address clear discrepancies between the provision of ex-gratia payments to those infected with hepatitis C and those infected with HIV through NHS-supplied blood transfusions and blood products.

19. There are no annual payments for those infected with hepatitis C and there are no discretionary payments to those infected with hepatitis C or their dependants. Further, payments were not made in respect of individuals infected with hepatitis C who died before 29th August 2003. The review recommended that this be changed to enable a posthumous claim to be made on behalf of those who died prior to 29 August 2003.

20. The review paper demonstrated the case for greater similarity between *ex-gratia* payments for HIV and hepatitis C infection is based on the arguments that the impact on quality of life of living with chronic hepatitis C is at least as great as that of living with HIV. In addition, those who are living with chronic hepatitis C are now more likely to die prematurely if they develop severe liver disease. Dependants of an infected individual can experience financial hardship, irrespective of whether the individual was infected with HIV or hepatitis C, and whether the infected individual is still alive.

21. Based on the advice of the expert review team, the recommendations that DH England are taking forward can be summarised as follows.

    a. A recurrent flat rate annual payment of £12,800 to be introduced for each living person who is infected with hepatitis C who has developed serious liver disease. The payment will be provided to Stage 2 recipients only. This will bring the payment made to people with hepatitis C into line with the annual payment made to people with HIV. The payment will be CPI linked and, like the current ex-gratia payments, will be disregarded for the purposes of calculating income tax and eligibility for calculating other state benefits.

    b. A discretionary fund to be established to support infectees and their dependents in greatest need. This will include dependants of infected individuals who have died. These discretionary payments may be made to individuals with chronic hepatitis C infection, as well as those who have developed serious liver disease (stage 1 and stage 2 recipients). It is expected that this fund will be means-tested.

c. A payment to be made posthumously in respect of those individuals who died before 29 August 2003. How much will be paid will depend on the levels of payment the person would have been eligible for if they had been alive on 29 August 2003 (i.e. either at Stage 1 or Stage 2). The stage 1 payment will be £20,000 and Stage 2 £50,000. The payment will be made to the individual's estate.

d. A further lump sum payment of £25,000 for those with the most serious hepatitis C-related illness, increasing the amount they receive at stage 2 from £25,000 to £50,000. This payment will apply to all successful Stage 2 applications – past, current and future, including those who died before 2003.

e. To provide funding to selected national charities to provide additional access to counselling for people infected with both hepatitis C and HIV. DH have provided £100,000 per annum for those charities in England.

22. DH (L) is setting up a separate agreement with the UK Skipton Fund to administer the payments. DHSSPS sought legal advice on this matter and there are no issues for DHSSPS on DH (L) using this vehicle, and if the three Devolved Administrations agree to keep in parity with England, this agreement can be extended.

Position in Northern Ireland

23. DHSSPS officials are currently considering the report of the expert review, including the financial and legislative implications of the recommendations for Northern Ireland.

24. Approximately £309k is needed recurrently and £1.4m for one-off payments for claimants in Northern Ireland. DH (L) intends to make as

many payments as possible under recommendations 3 and 4 in the 2010-11 financial year. DHSSPS Finance has advised there is no budget cover in DHSSPS for this financial year to implement these new financial measures. In 2011-12 the total costs to be incurred would need to be funded from the ‘residual demand’ allocation. Finance has advised there will be many competing pressures on this budget, and difficult decisions on what can and cannot be funded will need to be taken.

25. Dr Mitchell and Karen Simpson met with Mr GRO-A, an influential patient representative in Northern Ireland, at his request, on 2 February to discuss whether these measures will be introduced in Northern Ireland. Mr GRO-A has been Treasurer of the McFarlane Trust, Financial Director of the Skipton Fund and Vice President (Programs) of the World Federation of Haemophilia.

Position in the other parts of the UK

26. At a teleconference on 13 January, officials from Scotland and Wales informed DH that they are keen to keep parity with England and are advising their Ministers accordingly.

27. The Scottish Health Minister met with patient representatives on Thursday 3rd February to discuss the review report and its findings this week. In feedback from officials the patient representatives did not feel enough is being done for those in receipt of Stage 1 payments and there is a dislike of any discretionary payments which people have to apply for (and which will have an income based approach as per HIV payments).

28. Scotland has adopted the Skipton Fund as a legislative scheme under section 28 of the Smoking, Health and Social Care (Scotland) Act 2005. Any new financial measures require a change in legislation for Scotland.

29. Edwina Hart met with representatives from the Haemophilia Society on 31 January to discuss the contaminated blood review. She is sympathetic to their view that the package England is introducing does not go far

enough. She has asked her officials to look at the compensation scheme in the Republic of Ireland. Ms Hart also had a brief telephone conversation with the Minister last week on the issue and raised an issue with regards the Skipton Fund as the vehicle for making payments. Officials have not been able to discover anything specific on this, however it is known that there has been considerable support from the patient representatives for the payments to be administered by the Department of Work and Pensions (DWP). The review team considered the possibility that the ex-gratia payments might be made through the DWP, but came to the conclusion no tangible benefit to be gained from doing so. The mechanism for administering the schemes is now well established through the Charitable Trusts, and incorporates the necessary health expertise to determine eligibility.

Recommendation

30. I recommend that the Minister note this briefing including the proposed lines to take below and the key facts and summary of the key issues attached.

Proposed lines to take

(1) Andrew Lansley's announcement on the financial measures for England following the expert review of contaminated blood

- Disappointed that I was not consulted or given sight of the report before the announcement was made on 10 January.

- Currently considering the report of the expert review, including the financial and legislative implications of the recommendations for Northern Ireland.

- Already facing severe cuts because of pressures on the service and budget constraints.

(2) Engagement with patient representatives

- My Deputy Chief Medical Officer met with Mr GRO-A, an influential patient representative in Northern Ireland to discuss the review. Mr GRO-A has been Treasurer of the McFarlane Trust, Financial Director of the Skipton Fund and Vice President (Programs) of the World Federation of Haemophilia, but has since retired due to ill health.

(3) Whether the Republic's compensation scheme should be copied

- The situation in Ireland is not comparable to that in the UK because the Irish scheme had been established after an official inquiry there had found there had been wrongdoing by the Irish National Blood Transfusion Service Board, a government agency.
- The figures suggest that parity with the Irish scheme would cost the UK over £3 billion. If I were to put in place similar arrangements for Northern Ireland opportunity costs would be significant in terms of the impact on essential services.

(4) Whether payments should still be administered by the UK Skipton Fund.

- I believe the mechanism for administering the scheme is now well established through the Skipton Fund, and incorporates the necessary health expertise to determine eligibility.

cc Dr Michael McBride

Dr Elizabeth Mitchell
Seamus Camplisson
Adrian Murphy
Lynn Campbell
Paula Shearer
Karen Simpson
Lynsey Stewart
Claire Baxter
Philip Robinson

Key Issues

1. The Health Departments in Northern Ireland, Wales and Scotland only had sight of the Government response on the same day. There was no consultation with DA Health Ministers before the announcement, and despite written requests from the devolved administrations, officials were not kept informed or provided with an advanced sight of the report, before the announcement.

2. To keep in parity with England approximately £309k is needed recurrently and £1.4m for one-off payments for claimants in Northern Ireland. DHSSPS Finance has advised there is no budget cover for this financial year to implement these new financial measures. In 2011-12 the total costs to be incurred would need to be funded from the 'residual demand' allocation. Finance has also advised there will be many competing pressures on this budget, and difficult decisions on what can and cannot be funded will need to be taken.

3. Ms Hart is currently seeking further information on the compensation scheme in Ireland following a meeting with the Haemophilia society.

4. During his Inquiry, Lord Archer recommended that payments should be at least the equivalent of those payable under the Scheme in Ireland.

5. Successive UK Governments including the current Government have argued that the situation in Ireland is not comparable to that in the UK because the Irish scheme had been established on the basis that an official enquiry there had shown wrongdoing by a government agency, i.e. it is a compensation scheme based on fault. No such wrongdoing has been shown in the UK and therefore the UK ex gratia payments scheme is appropriate.

6. The Department of Health estimate that it would cost in excess £3 billion to replicate the Irish scheme in the UK. The package of measures recommended by the review is considered a balanced package of support; is within the range of representations made by those affected during the course of the review, and, given the current fiscal context, meets the principles set out for conduct of the review.

Key Facts

- There are currently three ex-gratia payment schemes in operation in the UK: (i) the McFarlane Trust, (ii) the Eileen Trust and (iii) the Skipton Fund.

- The MacFarlane Trust and Eileen Trust provide ex-gratia lump sum and discretionary payments to, respectively, haemophiliacs and others who contracted HIV from infected blood and blood products, and their dependants. An annual payment of £12,800 is paid to each infected individual and is administered on a UK basis.

- The Skipton Fund provides lump sum payments to people infected with hepatitis C from infected blood and blood products

- A first stage payment of £20,000 is available to those who are eligible for payment under the scheme. For successful recipients of the first stage payment whose hepatitis C infection has led to advanced liver disease there is a second stage payment payable of £25,000.

- In Northern Ireland approximately £3m has been paid out to 120 individuals, with 23 individuals receiving stage two payments.

- In the Republic of Ireland the approximate average cost of a settled claim for an infectee has been approximately £750,000 including court costs.

- As well as being entitled to claim compensation, Irish patients infected with HIV or Hepatitis C via blood or blood products may use a government-subsidised scheme to purchase life insurance, mortgage protection and travel insurance with no disease-related premium.

- To keep in parity with England approximately £309k is needed recurrently and £1.4m for one-off payments for claimants in Northern Ireland.

Costing for contaminated blood payments, UK and NI, 2011/12

(Estimates for NI are based on proportion of claimants in NI compared to UK.)

Recurrent Funding	**UK**	**NI**
Recurrent payments to bring hep C into line with HIV	£12.4m	£256k
Hep C discretionary funding	£2m	£50k
Funding for charities to provide counselling	£0.1m	£2.5k
Total Recurrent Funding	**£14.5m**	**£308.5k**
One-off lump payments		
Additional lump sum for hepatitis C stage 2 claimants	£22.5m	£525k
Pre-2003 catch-up programme	£35.7m	£892.5k
Total one-off funding 2011/12	**£58.2m**	**£1.418m**
Total Funding 2011-12	**£72.7m**	**£1.726m**