

PS/John Reid
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From: R M Gutowski

Date: 1 July 2003

Cc: As attached

COMPENSATION SCHEME FOR HEPATITIS C

1. Following your meeting on 25 June you asked for a joint submission on the issues around setting up a Compensation Scheme for Hepatitis C sufferers in England. This submission has been drafted following discussions with The Scotland Office, Department of Work and Pensions and the Treasury. You also asked for advice on the position with regards to Wales, therefore, it would seem best to begin with the legal advice on the devolution issues involved.

Devolution

Wales

Am still concerned about where this money will come from

2. Whether the power to establish a scheme for the payment of compensation to persons infected with Hepatitis C is devolved to the Welsh Assembly is determined by whether the scheme can be established under a devolved statutory function. Only specifically devolved statutory functions can be exercised by the Assembly, although section 40 of the Government of Wales Act does give the Assembly power to do anything (including the acquisition or disposal of any property or rights) which is calculated to facilitate, or is conducive or incidental to, the exercise of any of its functions.

From is surely just out of the question.

3. Legal advice is that the establishment of a charitable trust for the relief of poverty or distress among people with haemophilia does not rely on powers which have been devolved to the Welsh Assembly. The conclusions are that it is not thought a compensation scheme along the lines of the one proposed for Scotland could be made under either of those powers.

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4. Legal advice is that the Secretary of State would be exercising common law powers in setting up such a scheme and these have not been devolved. The options are therefore the devolution of new powers to the Assembly or for a single scheme covering England and Wales, possibly with a separate part for Wales containing different provisions.

Northern Ireland

5. The position in Northern Ireland is essentially similar to that in Scotland. When the Northern Ireland Assembly is sitting, it may make provision in relation to any matter which has not been excepted or reserved. When the Assembly is suspended, such provision can be made under the provisions which apply for the government of Northern Ireland during the suspension. No exception or reservation would appear to apply to a compensation scheme for Hepatitis C as both health and social security are devolved matters.

WAY FORWARD

6. There would appear to be three possible ways of setting up a Scheme in England which will need to be considered by Officials during the Summer::

- a) extending the remit of the MacFarlane Trust,
- b) extending to remit of the Eileen Trust
- c) setting up a brand new Trust from scratch.

Extending the MacFarlane Trust

7. The Trust was set up by the Government in 1988 to administer a fund for haemophiliacs infected with HIV through contaminated blood products. To date 1,240 haemophiliacs have received payments plus 39 infected dependants. The Trust started life with a £10m fund which, until a couple of years ago, was topped up by the Department on an ad-hoc basis. It now has an annual budget of around £3m. In addition the Department meets the Trust's administrative payments from section 64 Scheme. These will reach £287k per annum by 2004/05. The Trust has a Chairman and five Trustees appointed by the Haemophilia Society and two Trustees appointed by the Secretary of State.

8.. To extend the remit of the Trust to cover haemophiliacs who have contracted Hepatitis C would necessitate a Deed of Variation to the Trust Deed which SOL advice should not be a problem. The Chairman, Chief Executive and Trustees would also need to agree to such a move and the Charity Commission would need to raise no objection.

9. The Trust is of course a UK body. Therefore, before reaching a final view on extension in relation hepatitis C there could be advantage in testing whether the Scottish Executive would wish to see the Trust discharge a scheme on behalf of Scotland too. This could benefit equality of treatment for the payment regimes and the social security disregards plus the taxation issues. However negotiations would need to take place as to where the money for Scottish payments would come from. The same considerations would apply for Wales and Northern Ireland.

Extending The Eileen Trust

10. The Eileen Trust was established by the Government in 1993 to assist non-haemophilias who contracted HIV through contaminated blood products. The Eileen Trust provides similar services to the MacFarlane Trust but on a much smaller scale. It currently gives support to about 30 people. So far the Trust has made payment of £730,000. The Trust's current funds total £5500,000 sufficient to keep it going at least until 2006/07..

11. The existence of the Eileen Trust could set a precedent for another trust under the umbrella of the Macfarlane.

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Set up New Trust

12. There would appear to be two ways to take this option forward. Set up a New Trust under the existing umbrella of the MacFarlane Trust or set up a new self-standing Trust. The benefit of using the MacFarlane Trust is that an existing structure is in place. The level of extra support required will be determined not only by the single payments envisaged by Scotland but the extent to which extra claimants come forward.

13. The alternative would be to set up a new Trust independent of the MacFarlane. This would be time consuming in having to find and appoint a new Chairman and Trustees and Executive support and device a structure to make the payments. We would also need to budget for any start up costs

Preferred Option

14. It would appear on the face of it that the preferred option would be to consider using the existing MacFarlane Trust structure and we would work with the devolved administrations to see how this could best be taken forward.

15. However any such move could put extra strain on Section 64 Grant used to support any extra administrative costs. Section 64 is not designed to support bodies such as the MacFarlane, where the Department has a long-term commitment to fund the whole of the organisations administration costs. The level of support currently needed by the Trust, leaving aside any top-up which may be needed as a result of Hepatitis C payments severely restricts the Department's ability to support the kind of voluntary groups the Section 64 scheme is intended to help.

Financial Implications

16. The scheme that the Scottish Executive is considering would cost up to £210m if a similar scheme were implemented in England which is the basis upon which we are working. This is a worst case and assumes that all those infected are identified and make a claim. If only 50% of the 5,000 unidentified people who are estimated to be infected make a claim the costs are likely to be in the order of £140m. If the payments detailed in the Scottish Expert Group proposals were accepted then the costs would be up to £600m.

17. The proposed Scottish Executive scheme would pay a lump sum of £20,000 to all people living who still have the virus and a further £25,000 to those who develop cirrhosis.

in England
18. There are around 3,500 people that we know have long-term hepatitis C infection from contaminated blood transfusions and blood products. The initial £20,000 payment would cost £70m for this group. On top of this there are around 5,000 people who may have been infected rough blood transfusions who we have not identified. If all these claimed, the cost would be an addition £100m. There proportion of these people that actually claim compensation will be dependent on

how pro-active we are in seeking to identify those infected. If only 50% of those infected actually claim compensation the additional cost would be £50m.

19. We estimate that, normally, around 20% of those with long-term hepatitis C infection will progress over time to develop cirrhosis. This would cost an additional £42.5m, making a total of £212.5m for the whole scheme. Current drug treatment reduces the likelihood of patients going on to develop cirrhosis, with overall success rates of around 40%. A more effective form of interferon (pegylated interferon) with overall success rates of around 55% is currently being appraised by NICE.

20. However, it is difficult to estimate what proportion of the group in question might be successfully treated with antiviral drugs. Some individuals may have already progressed to cirrhosis, others may already have been treated and cleared the virus, and it is not possible to say how many will have reached the disease stage at which treatment is indicated. It is likely, though, that successful drug treatment will have some impact in reducing compensation costs.

Possible Financial Pressures

21. The proposed scheme makes no provision for making payments to the dependants of people with Hepatitis C who have since died. The scheme proposed by the Scottish Expert Group did propose payments for dependants and it is possible that we will come under pressure to extend the scheme in such a way. This would increase the cost substantially. It is also possible that we will come under pressure to increase the value of the scheme towards that proposed by the Scottish Experts Group. Again, this could increase costs significantly. If the Scheme is administered by the MacFarlane Trust which pays dependants of HIV sufferers it would be difficult not to argue against similar provisions for Hepatitis C sufferers.

Funding the scheme

22. As the Law Officers have ruled that this is a health issue, the costs of the scheme in England would need to be borne by the Department of Health.

23. The Treasury have said that no additional funding would be available for a hepatitis C compensation scheme. Any such scheme would need to be funded from SR2002 settlements. We will need to work with the Devolved Administrations to attempt to reduce and/or re-profile the cost

Social Security Implications

24. The key social security issue is whether payments should be disregarded – ie ignored – in assessing means-tested benefits – Income Support, Income-based Jobseekers Allowance, Housing Benefit and Council Tax Benefit. Generally, Income Support or JSA entitlement would be removed altogether by a lump sum payment of £8000 or more, HB and CTB by a payment of £16,000 or more. The proposed hepatitis C payments would therefore be enough to remove benefit entitlement unless it was decided to exempt them.

25. Exemptions to the normal benefit rules must be justified. In policy terms disregarding any payments weakens the principle that means-tested benefits are awarded on the basis of need. Ignoring some payments but not others, without good reason, could also be discriminatory and open to legal challenge on human rights grounds. The proposed payments are arguably comparable to personal injury payments which are disregarded while held in a trust fund but not otherwise.

26. An exemption has however already been provided Macfarlane, Eileen Trust and variant CJD payments. These are completely disregarded on the grounds that the circumstances surrounding those payments are exceptional. If the Government believes that the equivalent considerations apply to the Hepatitis C payments it would be right to treat them in the same way for benefit purposes and disregard them

27. Providing a disregard will require amendments to secondary legislation if a completely new Trust is established. We will need to confirm whether amendments will also be needed if the existing Trusts are extended. Amending regulations could be made during the recess but time will need to be allowed for the processes involved, including the necessary consultation with the Social Security Advisory Committee and local authorities. Disregarding hepatitis C payments will mean foregoing benefit savings of £5 million a year that would otherwise have come from taking the payments into account. But there will be no increase in benefit expenditure.

Conclusion

28. At your meeting on 25 June it was decided that once further issues had been worked up then John Reid would communicate the decision that the Government would introduce a compensation scheme in England to the Devolved Administrations.

29. You are therefore asked to agree that once the devolved administrations have been informed that Officials from all interested Departments work over the Summer to devise an appropriate Scheme with a view to making an announcement in September.

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