

Hepatitis C financial assistance scheme

Issue

1. Following your meeting with Michael Connarty MP (Chairman of the All Party Group) and the Haemophilia Society on 29 October, you asked for estimates of the cost of extending the scheme to those people who are co-infected with HIV, who cleared the hepatitis C virus (HCV) following treatment and to dependants of those who have died prior to the announcement of the scheme.
2. These groups were not included under the initial eligibility criteria agreed by SofS in October but not made public, and Mr Connarty and the Haemophilia Society raised concerns that without their inclusion, they would not be able to endorse the scheme.

Recommendation

3. We suggest you ask SofS to agree to amend the draft eligibility criteria for the proposed hepatitis C scheme to –
 - make eligible for the initial £20,000 payment those people with HIV co-infection
 - make eligible for the initial £20,000 payment those people who have cleared HCV following successful drug therapy.

Timing

4. Urgent – you asked for this note in time for your stock take meeting with Secretary of State on 11 November.

Background

5. We have taken this opportunity to revise the original cost estimates for this scheme. These were made on the basis that up to 8,500 potential claimants would be eligible for payments under the initial draft eligibility criteria. This suggested that a budget of between £162.5m and £212.5m would be required depending on the number of eligible

claimants making applications (£162.5 = 50% take-up, £212.5m = 100% take-up).

6. Updated estimates and a more comprehensive analysis of these figures appears to show them to be an over-estimation due to double counting and inclusion of some non-eligible groups. Our further analysis appears to show that the original calculations included those patients that have cleared the virus with treatment and those who are co infected with HIV. These are two of the key concerns of both the Haemophilia Society and the All Party Group. Subject to more detailed calculations being carried out it would appear that we could offer to include these within the proposed scheme without incurring any additional costs.
7. Estimated cost of extending scheme to –
 - People with HIV co-infection - ~£12m
 - People who cleared HCV following treatment - unknown, but see below
 - Dependants - >£154m

However these figures still need to be finalised.

8. The ~£12m required to extend the initial payment to co-infectants should fall within the difference of the original and revised total cost estimates caused by the above double counting, therefore representing no actual increase in cost. This group is already eligible for the second payment under the draft eligibility criteria.
9. The figures used to calculate the total number of potential claimants made no allowance for those people who cleared HCV following treatment. We have therefore assumed that these people have already been included in our calculations and as such it would represent no additional cost to include this group.
10. The cost of extending the scheme to dependants (>£154m) would at least double the cost of the scheme and remains unaffordable within the existing budgets of all the four Health Departments.

Wider impact of making suggested revisions to draft eligibility criteria

11. The Haemophilia Society and the All Party Group have four outstanding concerns regarding the proposals and draft eligibility criteria for the scheme –

- The proposed payments are lower than those recommended by the Scottish Executive Expert Group and their own expert working group recommendations
- No payments are being made to dependants
- People who have cleared HCV following drug therapy are not eligible
- People who are co-infected with HIV will not be eligible for the initial £20,000 payment

12. With the figures above in mind we are therefore in a position to negotiate with the Society and the All Party Group and would be able to accommodate the last two demands at no extra cost. However, agreeing to the first two demands would –

- Embarrass the Scottish Executive who have already announced the size of their awards and that they will not make payments to dependants
- Be unaffordable within the existing four health budgets
- Require SofS's agreement to amend the proposals and draft eligibility criteria

Advantages/Disadvantages of extending scheme to include co-infectants and successfully treated patients

13. Advantages -

- DH is able to include these groups at no extra cost to original estimates
- DH would be seen to be listening to the arguments put forward by the Haemophilia Society and the All Party Group and the needs of the people it represents.
- DH would expect the All Party Group to be more supportive of the Scheme than they had previously indicated.
- DH agreement would undermine and marginalise the Haemophilia Society's lobbying position
- The Macfarlane Trust, whose only non-negotiable demand is that co-infectants are included, would be satisfied and have today confirmed that they would be prepared to administer the proposed Scheme if this condition was met.

- Disadvantages –
 - Payments to successfully treated patients may be viewed as compensation for past suffering and could set a precedent for other patients groups who have undergone unpleasant, but successful, drug treatment
 - Whilst the Department for Work and Pensions is happy to introduce a social security disregard for those eligible under the draft criteria, extending a similar disregard to successfully treated patients would be more difficult to justify. This may also set an untenable precedent.
14. It may be possible to placate these issues by stressing that the original philosophy of the scheme was to provide ex gratia payments to all of those who developed chronic hepatitis C as a result of inadvertent infection from blood or blood products. This would emphasise the fact that payments are not being made on the grounds of past or current suffering, but on compassionate grounds because this is the right thing to do. DWP have indicated that this is a viable option.

Conclusion

15. There remains little scope for satisfying the Haemophilia Society's demands in full. Their request that DH considers increasing the size of awards and that dependants be eligible for financial assistance are unsustainable on the grounds of affordability. However, extending the eligibility criteria to include co-infectants and successfully treated patients would not require additional funding.
16. By agreeing to extend the scheme, the Society would be appeased by what they and their members will see as a partial victory. More importantly, if Ministers agree to include co-infectants, the MacFarlane Trust will sign up to the scheme.
17. The devolved administrations have indicated that they would also be willing to extend the eligibility criteria of the scheme to include co-infectants and successfully treated patients but have not cleared this with their respective Ministers.

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