FOR FOR DECISION

SC02(XX)

SCOTTISH CABINET

FINANCIAL AND OTHER SUPPORT FOR PATIENTS WHO HAVE CONTRACTED HCV FROM BLOOD TRANSFUSIONS ETC; RECOMMENDATIONS OF EXPERT GROUP

MEMORANDUM BY THE MINISTER FOR HEALTH AND COMMUNITY CARE

Purpose

1. To discuss and agree a proposed Scottish Executive response to the recommendation of the Expert Group on Financial and Other Support that people who suffer from Hepatitis C as a result of blood transfusion or treatment with blood products receive ex gratia compensation.

Timing

2. The Group submitted their interim recommendations to me on 4 September. These had been expected by 31 July, so we may expect early Parliamentary interest.

Background

- 3. The underlying issue is that numbers of people acquired Hepatitis C (HCV) through blood transfusions or treatment with blood products provided by the NHS, before the problem was identified and remedial action taken. It has not been policy to pay compensation in this sort of situation where there is no fault attributable to the NHS. People infected after 1 March 1988 (when the Consumer Protection Act came into force) are entitled to compensation, regardless of fault. However, many are denied such recourse either because they were infected before this date (this includes all haemophiliacs) or because of the 10 year time bar provision.
- 4. The Health and Community Care Committee's "Report on Hepatitis C" recommended that the Executive set up a mechanism for providing financial and other appropriate practical support to all people who had contracted HCV from blood or blood products provided by the NHS in Scotland. We agreed in December to reject this approach and instead to set up an Expert Group, chaired by Lord Ross, to advise (i) on whether the Executive should alter its general approach to provide compensation when the health service has no legal liability and (ii) whether current dispute and compensation systems could be improved.
- 5. Following discussion with HCCC and a debate in parliament, we agreed that the Group's remit (Annex A) would require it (i) to consider the situation of patients who had contracted HCV and/or HIV from 'blood' as part of its wider considerations, and (ii) make recommendations on whether any recommended changes should be applied retrospectively.
- 6. In its preliminary report the Group concludes that 31 July is an unrealistic deadline for it to decide whether the general approach should be changed. It has since decided that it will not make a recommendation in its final report in favour of a general no-fault compensation scheme for health service injury in Scotland. However, it may still endorse the making of ex gratia payments in more limited circumstances e.g. in ad hoc schemes for specific injury

scenarios. Initial indications are that the outcome of an investigation chaired by the English CMO will be to reject no-fault compensation as method of dealing with health service injury.

7. Nevertheless the Group has recommended that the Executive provide compensation to the "HCV from blood" patients (Annex B). Like the HCCC they argue that there is a 'moral injustice' and that this group should be treated on a par with those who acquired HIV in similar circumstances, and for whom support arrangements already exist with public funding via the Macfarlane Trust.

Legal implications			
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Discussion

- 9. I need not rehearse in detail the difficulties that all this gives rise to:
 - rejection of the recommendation will bring political difficulties in the Parliament;
 - implementing the recommendation would involve considerable expenditure that would have to be met from the existing health budget, at the direct expense of services to patients;
 - it would be a departure from our previous policy of not making payments where the NHS has no legal liability is a potentially very dangerous precedent;
 - making payments of this nature (as with Attendance Allowance and free personal care) is likely to result in the loss of social security payments to the recipients,

[DN: Further information to be added from DWP.]

- there is a risk that the Executive could be seen to be acting outside the terms of the Scotland Act.
- 10. On the other hand, when the matter was debated in Parliament in January of this year, there was a high degree of cross-party agreement in favour of providing financial and other support to "HCV from blood" patients.
- 11. The Group has also made recommendations about the operation of the Scottish Legal Aid Board and on issues such as the accessibility of information on HCV. I think we should be

able to respond positively on these matters as I understand matters are already in hand to progress these issues.

Options

- 12. Putting aside the question of whether powers to act here are reserved or devolved, I do not feel it would be right to accept the recommendation as it stands for the reasons given above. I see the options as follows:
 - A) Decline to respond to the recommendation until the Group provides its complete view on ex gratia payments for health service injury and the Executive can consider the recommendation in that context.

This is likely to leave us facing an identical situation in January – merely delaying the decision.

B) Accept the recommendation in principle but with a reduced scope – with emphasis on addressing difficulties faced by survivors who are suffering serious long-term harm, rather than providing compensation.

The most obvious model would be to establish a discretionary Trust (along the same lines as Macfarlane). Macfarlane provides monthly payments to survivors based on an assessment of what they need in order to cope with the effects of living with their infection.

Adopting this monthly payment element would target those most severely affected and would have no up front cost. This would be attractive to some MSPs although others would argue that, lacking the lump sum payments originally made under Macfarlane, it still does not address the inequity with equivalent HIV patients.

Payments might only be made to people who had developed cirrhosis, liver cancer or liver failure as a result of the HCV infection – including those who had redress under CPA prior to the announcement of the scheme but failed to raise an action within time bar limits. The dependants of people already deceased and survivors with non-specific symptoms such as fatigue would not be covered by the scheme.

The continuing annual cost should have dwindled to a minimal level by about 2040. However, we should still be out of step with England and the difficulty about social security payments would also still apply.

C) Reject the recommendation outright on the basis of principle (as we rejected the recommendations in the HCCC report), also making the point that, unlike Macfarlane, such a scheme would have to be funded from existing health service budget – at the direct expense of services to patients.

Our arguments for this approach were not well received in Parliament when this issue was last debated. MSPs cited Macfarlane, the Vaccine Damage Payment scheme and the vCJD Trust as examples of ex gratia payment schemes that already provided precedents in this area.

UK Implications

13. The Whitehall view is against any compensation scheme for Hepatitis C. Any decision to offer compensation in Scotland could expose English Health Ministers to renewed pressure

from MPs and English pressure groups. The UK government would also be concerned about any scheme which had an impact on social security entitlement.

Presentation

14. I propose that we publish the Expert Group report, along with our response, at an early opportunity after the October recess. The HCCC takes an extremely close interest in this issue and if publication were timed for Wednesday 6 November, this would offer me an early opportunity to discuss this with them. See Annex D for further discussion on presentation.

Financial Implications

15. The cost of implementing the scheme recommended by the Group is likely to be between £62m and £89m (depending on numbers who finally contract HCV, degree of progression of the illness, and take up – assumed to be 31%). The cost of implementing the scheme outlined in Option B is likely to be between £1.25m/yr and £4m/yr (depending on the proportion of infected people who develop cirrhosis or other serious liver damage).

Conclusion

Realistically, I think our choice is between the second and third of the above options. Option C is correct but would create an enormous outcry.

I am therefore driven to conclude that option B is the least bad option, although there are financial and Westminster difficulties attached to it.

MALCOLM CHISHOLM 30 October 2002

ANNEX A

PRELIMINARY RECOMMENDATIONS OF THE EXPERT GROUP ON FINANCIAL AND OTHER SUPPORT

REMIT OF THE EXPERT GROUP

- To consider circumstances in which a system of financial and other support might be available to people who have been harmed by NHS treatment in Scotland in circumstances where there is unlikely to be liability on the part of NHSScotland and to apply general principles which are consistent, equitable and transparent for all.
- The situation of patients who have contracted HIV and/or Hepatitis C from blood transfusion or treatment with blood products should form part of the wider considerations.
- Preliminary recommendations should be made by the end of July 2002 and should include whether the current system should be changed and, if so, what changes should be made and whether any of these changes should be applied retrospectively.
- Consideration should also be given to the current dispute and compensation mechanisms in Scotland for dealing with negligence and fault-based compensation to determine if there is room for improvement. Any recommendations should be brought forward by the end of December 2002.

Notes

In considering the above-

- 1. The group should note the existing approach that "the NHS does not pay compensation when it has no legal liability for the harm suffered by the patient" and consider whether this is appropriate
- 2. Any recommendations should be based on achieving a workable balance between the following tests:

Any alternative arrangements should:

- a) not inhibit innovation and creativity in NHSScotland
- b) be consistent with efficient health service operation
- c) represent a fair deal for all patients
- 3. The group should take into consideration the findings of the Review of Clinical Negligence by the Department of Health in England taking due account of any factors that are likely to affect their applicability to the Scottish situation. It should also look at the approach to medical compensation adopted in the Republic of Ireland.
- 4. The group should take into consideration the findings of the Review of Mediation in the Health Service in Scotland by the Royal Society of Edinburgh, and the Scottish Executive Report on the Evaluation of the NHS Complaints system.

ANNEX B

PRELIMINARY RECOMMENDATIONS OF THE EXPERT GROUP ON FINANCIAL AND OTHER SUPPORT

EXPERT GROUP RECOMMENDATION ON HCV COMPENSATION

We were asked to consider as part of wider considerations 'the situation of patients who have contracted HIV and/or HCV from blood transfusion or treatment with blood products'.

Presently people who have contracted HIV through receiving blood, blood products or tissue from the NHS benefit from the arrangements via the Macfarlane and Eileen Trusts, whereas people who contracted HCV under exactly similar circumstances do not. We believe that infection with HCV brings about adverse effects for the people involved similar to those experienced by people infected with HIV. Furthermore, the way in which people were infected with HCV was exactly the same as those who became infected by HIV. We feel that this represents an inequity that should be addressed by introducing new arrangements.

We considered evidence on a scheme which might operate on broadly similar principles to that of the Macfarlane and Eileen Trusts. This would mean recommending that each person who could demonstrate that they were infected with HCV as a result of receiving blood, blood products or tissue from the NHSScotland, would receive a lump sum ex-gratia payment. We also considered evidence from the publication by the Scottish Executive entitled 'Hepatitis C: Essential Information for Professionals' which suggests that:

• around 20% of those infected with Hepatitis C will clear the virus at the acute stage.

Of the 80% who do not:

- around 20% may never develop physical symptoms;
- 60% will develop long-term symptoms of liver damage with the potential to progress to cirrhosis, liver cancer or liver failure.

CONCLUSIONS

We conclude that we should have regard to the loss suffered by the individual in recommending new arrangements for Hepatitis C sufferers. Furthermore, we conclude that the support arrangements for people suffering from the disease should be improved.

We consider that our recommendations below are consistent with our remit. We gave consideration to whether the recommendation for a discretionary Trust would represent a 'fair deal for all patients' as indicated in Note 2(c) of our remit. The proposed arrangements address an inequity between two groups of patients who were harmed by exactly the same set of circumstances (i.e. the inadvertent provision of blood, blood product or tissue contaminated with a virus). We therefore feel that the recommendation does satisfy this test.

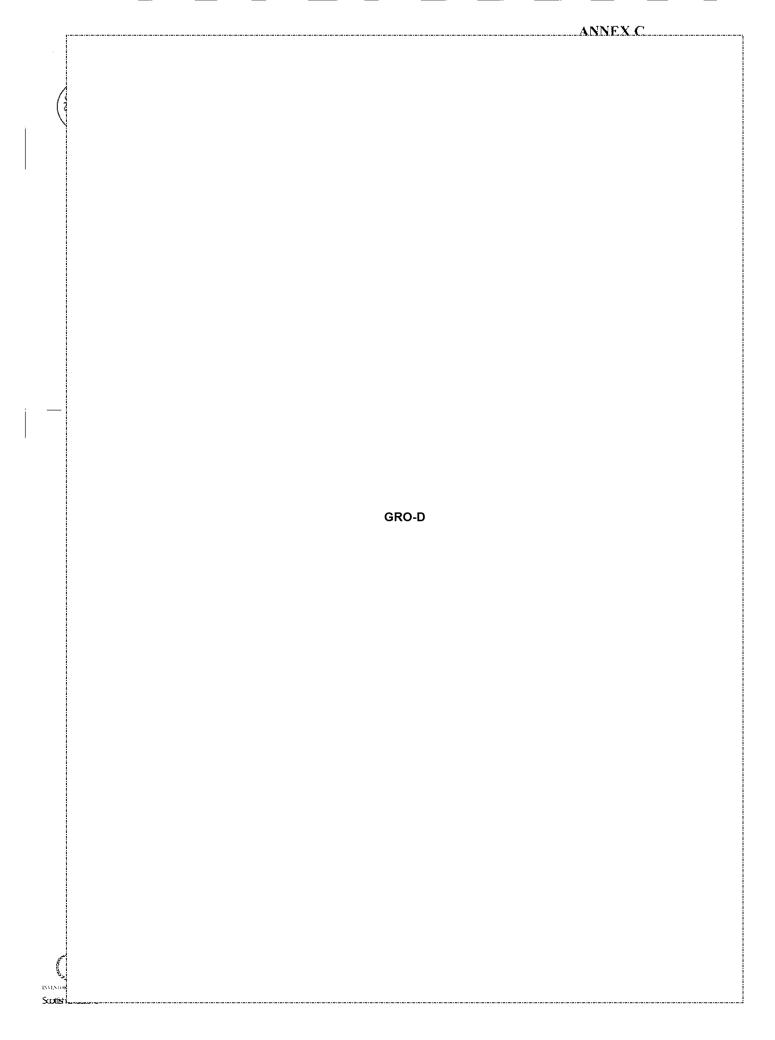
We appreciate that spending resources of this nature inevitably means that money is being used which would otherwise be spent on health care in general. However, we feel the circumstances justify the introduction of these new arrangements for Hepatitis C sufferers.

We recommend the following:

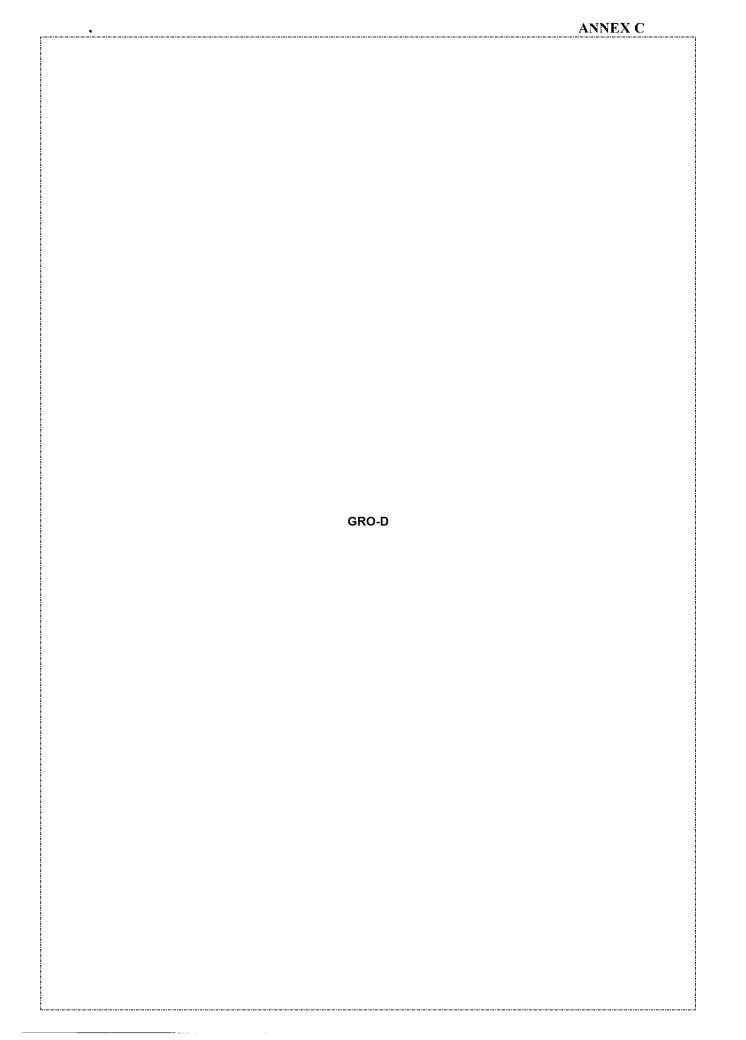
The Scottish Executive should establish and fund a discretionary Trust as a matter of urgency that will make ex gratia payments to all people who can demonstrate, on the balance of probabilities, that they received blood, blood products or tissue from the NHS in Scotland and were subsequently found to be infected with Hepatitis C virus*, as follows:

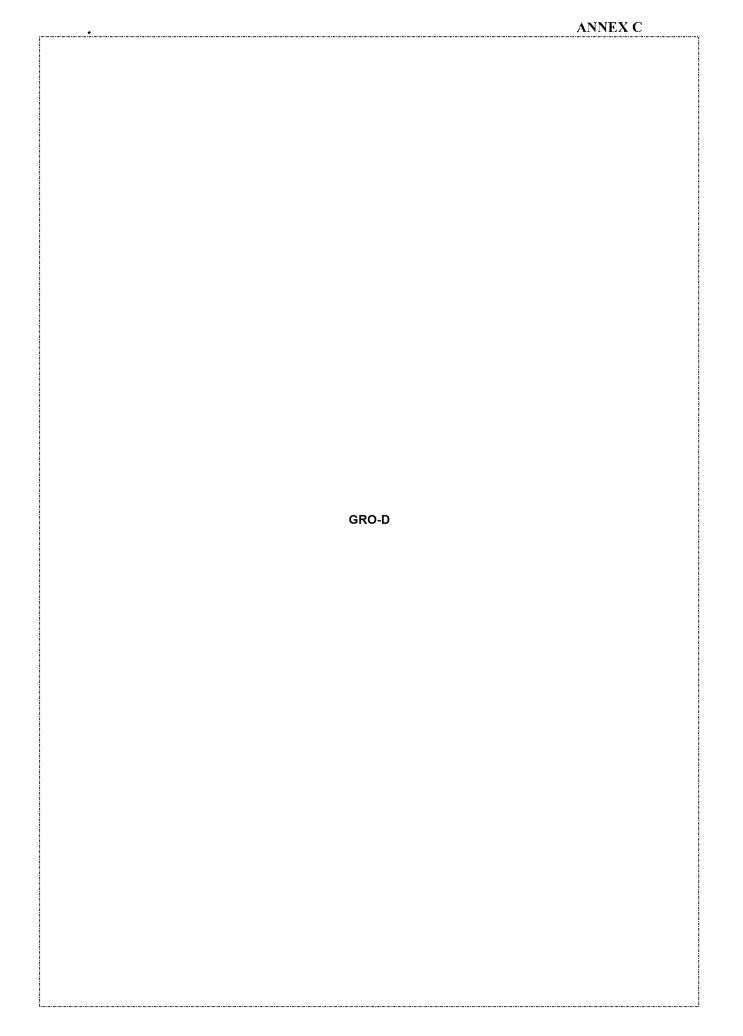
- a) an initial lump sum of £10,000 to cover inevitable anxiety, stress and social disadvantage;
- b) an additional lump sum of £40,000 to those who develop chronic hepatitis C;
- c) in addition, those who subsequently suffer serious deterioration in physical condition because of their Hepatitis C infection e.g. cirrhosis, liver cancer or other similar serious condition(s), should be entitled to additional financial support (on an ongoing basis if necessary) as may be assessed appropriate by the Trust. This financial support should be calculated on the same basis as common law damages taking account of the payments made under a) and b) above;
- d) where people who would have been beneficiaries of these arrangements are deceased and their death was <u>not</u> due to the Hepatitis C virus, the above payments should pass to their Executors. Where their death <u>was</u> due to the Hepatitis C virus, the Trust should provide for payments to be made to dependant children, spouses, partners or parents, as appropriate.
- e) people who receive any payment under legal liability arising from alleged negligence or breach of statutory duty, from the Scottish Ministers, or any of the constituent authorities of the NHS in Scotland, in respect of having been infected with Hepatitis C should not qualify for these arrangements;
- f) people who are already in receipt of payments linked to HIV infection from the Macfarlane Trust, Macfarlane Trust Special Payments Trust, Eileen Trust or the associated government Scheme of Payments should have these payments taken into account when additional financial support is assessed for the purposes of c);
- g) people who have become infected with Hepatitis C as a result of the virus being transmitted from a person infected by blood, blood products or tissue from the NHS in Scotland shall be dealt with by the Trust on a similar basis to those who have been infected directly in this manner

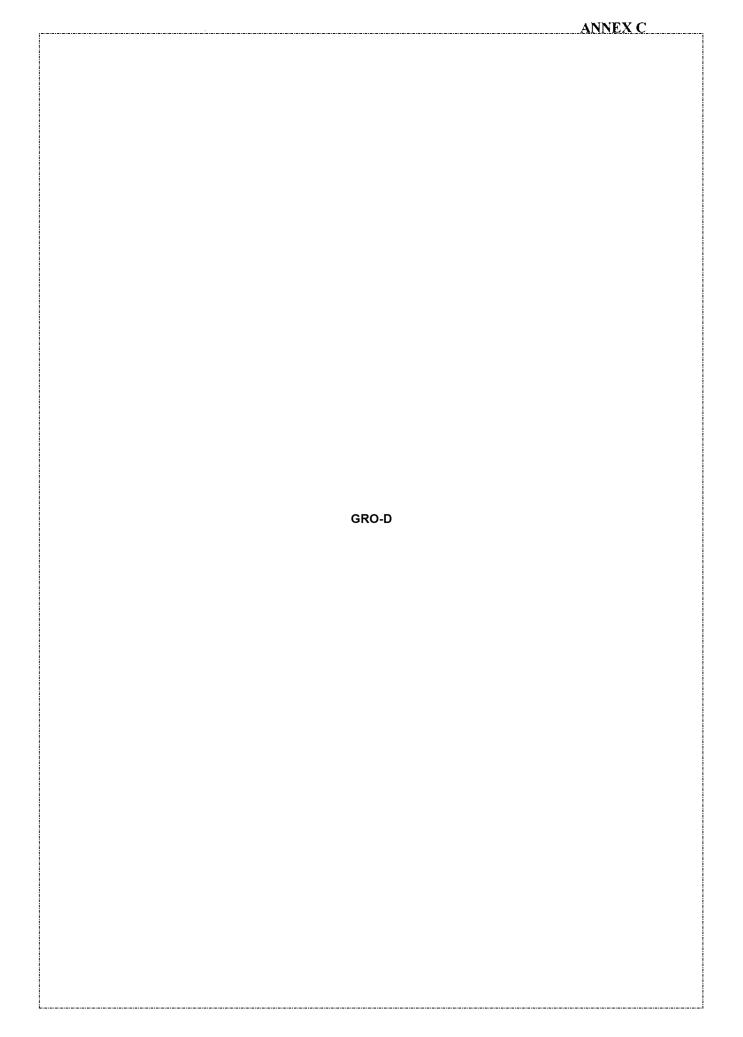
^{*} The Expert Group subsequently confirmed that their intention was that payments should only be made to people who had received blood, blood products or tissue <u>before</u> the dates when they were made HCV-safe.



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MEDIA HANLDING: HEP C COMPENSATION

Issue

The publication of the Expert Group Report on Financial and Other Support for Patients who have Contracted HCV from Blood Transfusions etc.

Timing

The Health Minister has given a commitment to discuss the report with the Health and Community Care Committee at the time of publication. The earliest opportunity to publish would be Wednesday 6 November.

Handling

The practical handling arrangements will require two stages.

- 1. The publication of the Expert Group report. The Group have not as yet stated whether they intend to host a press conference.
- 2. The Scottish Executive response.

The timeline proposed is:

1100 hours

Minister meets with the Health and Community Care Committee

Report of the Expert Group is published

12 noon

Scottish Executive response is published

Minister available for broadcast interviews

Minister undertakes one-to-one interviews with newspapers which have had a particular interest in this story e.g. Daily Record, The

Herald, The Scotsman, Daily Mail.

Key Messages

If the decision is to go with Option B (Fund)

 Remain to be convinced that there is a need to change our general approach to no-fault compensation;

- However, we share genuine concerns about the plight of hepatitis C sufferers who have been infected through no fault of their own;
- While we do not accept that it is right to make ex gratia lump sum payments we propose to fund a Trust that will provide monthly financial support to those who have serious long-term harm and who are experiencing hardship;
- The Executive does want to improve the support structures available to Hep C sufferers and help them achieve a better quality of life.

If the decision is to go with Option C (Reject):

- We are unable to look at the question of Hep C sufferers in isolation a compensation scheme must be consistent, equitable and transparent for all;
- We cannot provide support on an ad hoc basis;
- [However we are willing to reconsider if the Expert Group provides further advice in its final report];

Press Office October 2002