Ex gratia payments to patients who were infected with Hepatitis C as a result of NHS treatment with blood or blood products

Notes of a meeting held on 30 July 2003

Present Andrew MacLeod (Scottish Executive)
Bob Stock (Scottish Executive)
Richard Gutowski (DH)
David Reay (DH)

Brief background

Following the decision by the Scottish Executive to make ex gratia payments to patients in Scotland infected with Hepatitis C via contaminated NHS blood and blood products before the introduction of heat treatment/screening, and subsequent to correspondence between the Minister for Health in Scotland and the Secretary of State for Health, a meeting was convened to discuss DH collaboration on this issue.

Salient issues

It was agreed that the following issues required resolution before work on a compensation scheme could begin –

- Scope. Rather than individual provincial schemes, a UK wide scheme was favoured by both the Scottish Executive and DH. This would be easier to administer, ensure equity and precedents were already in place.
  Action – the scheme will be developed on this basis, subject to Ministerial approval.

- Devolution. Although the Scottish scheme is within devolved competence, the position with regards to Wales and Northern Ireland is less clear. If a UK wide scheme is developed, its jurisdiction in the devolved provinces will need to be clarified and mechanisms of joint funding defined. Wales and NI are not aware of developments so far and a decision about the timing of their involvement is yet to be taken. Concerns were raised that there may be a legal obligation to share information.
  Action – lawyers from both DH and the Scottish Executive will be asked to provide guidance on financial, legal and constitutional issues with a view to seeking Ministerial approval of a UK wide scheme and a decision as to when to involve Wales and NI.

- Scotland. The Minister for Health in Scotland is under pressure from the Scottish Parliament to make an announcement as to when a compensation scheme will be established in Scotland. In view of SofS's request for solidarity, the Scottish Executive has asked DH for a holding line to ensure consistency and for the Minister for Health's Parliamentary Committee appearance on 9 September.
  Action – A revised line is being drafted by DH special advisers and this will be shared with Scotland. The Executive feels it is important this reflects a positive/progressive position.

- Finance. Estimates of the potential cost of a scheme have been prepared for England and Scotland but resources have not yet been identified in England. The implications of funding claims in Wales and Northern Ireland are also still being considered.

Action – Finance division in DH is exploring options to secure resources.

Proposed parameters of the scheme

1. It was felt that the scheme should be administered independently and that Government should be distanced from the disbursement process. Two options were proposed on how the scheme might be developed. The first was to establish a scheme under the umbrella of the Macfarlane Trust, a UK arms-length body compensating haemophiliacs who have contracted HIV via contaminated NHS blood and blood products. The second was to constitute an entirely new trust as was done for the vCJD compensation scheme.

2. The former option was preferred for reasons of simplicity and because of the successful management of the Macfarlane Trust. It was thought that the Macfarlane Trust would be amenable to this proposal, especially as it already administers the smaller Eileen Trust (which provides payments to non-haemophiliacs who have contracted HIV via NHS blood and blood products). The Eileen Trust could serve as a model for the new scheme.

3. An eligibility criterion for awards and the extent of supporting evidence submitted need to be determined. Where it exists, it is envisaged that claimants will generally be given the benefit of the doubt (eg. because of lost/destroyed medical records etc). But it is not expected that relatives, dependants and/or the estates of patients who have died will receive payments, even if they died between the announcement of the scheme and its launch. This approach would mark a change in precedent, as similar Trusts do compensate the 'personal representative' of eligible deceased patients.

4. The level of awards would be based on the Scottish model already speculated to the Scottish Parliament. Those qualifying would receive a £20,000 payment, followed by a further £25,000 should their disease progress to a medically defined trigger point. Medical advice will be sought to provide a clear definition of the trigger. Estimates suggest that the cost of such a scheme in England alone would be around £210m.

5. The initial £20,000 payments would not be made to patients who are co-infected with HIV and who have received awards from other Government sponsored schemes such as the Macfarlane Trust. However, this group would be eligible to claim the £25,000 award should their condition progress to the trigger point.

6. Eligible patients who cleared the disease spontaneously (approx 20%) would receive no payments, those who cleared after treatment would receive the £20,000 payment only and those who receive a liver transplant would receive both awards. Those patients eligible for awards who had successfully sued the NHS or private supplier or reached an out of court settlement, would have the settlement deducted from the amount awarded by the proposed scheme.

7. Following preliminary discussions with DWP and according to Inland Revenue precedents, it is envisaged that awards will be disregarded in respect of social security payments and income tax contributions. Macfarlane Trust awards are already disregarded and although social security disregard requires amendment to legislation, DWP advice suggests this is a simple process. Disregard for income tax purposes would require an amendment to the IR's General Rules, but not legislation.

8. The constituting of a trust would require the appointment of trustees and inclusion of an appeals process. Trustees would most likely be appointed directly by SofS in consultation with Ministers from the devolved administrations and by voluntary organisations with an interest (eg. the Haemophilia Society). Demographic make-up would be an important consideration. DH is seeking legal advice as to whether a formal appeals process is necessary.

Issues arising from the Scottish Executive proposals

The following action was agreed –

- DR to collect relevant figures for haemophiliacs in England and dates of introduction of screening and heat treatment etc of blood in England and liase with Finance in respect of awards made based on these figures
- DR to also collect figures for Wales and NI (pending legal advice on whether an ex gratia payment scheme is a devolved issue)
- DR and BS to obtain medical advice re. definition of medical trigger of 2nd payment and then provide estimates of (or confirm) numbers progressing to this stage
- DR and BS to seek medical and policy advice on extent of supporting evidence supplied by claimants and present options
- DR to consider implications of potentially contentious proposals (such as not making awards to 'personal representatives' of deceased patients, payments to co-infected patients and those who have been treated for Hep C)
- DR to forward note of discussions with Dept of Health lawyers to BS
- DR to confirm DWP disregard position with regards to Scotland post-devolution
- DR to begin work on UK discussion paper that will highlight areas requiring Ministerial decisions
- DR and BS to ensure Malcolm Chisholm is informed of developments in England and has a consistent line to take for his appearance in front of the Scottish Parliamentary Health Committee on 9 September and to keep SofS updated
- DR to ensure that SE request for a positive/pro-active stance is reflected in the line to take

Next steps

- A constructive dialogue has now been opened between DH and Scottish Executive officials. This will ensure the sharing of information, co-operation and consultation between our two Departments to aid a joint approach.

- The discussion paper tabled by the Scottish Executive will be expanded to make provision for a UK wide scheme. This will outline the development process and structure of the proposed scheme and form a basis from which an announcement can be made and scheme rolled out.

- The scheme will be advanced as above subject to the resolution of the issues laid out at the start of this note. A rough timetable would see –
  - an update to SofS on 29 August suggesting ways forward (in association with briefing for the Minister of Health in Scotland for his appearance in front of the Scottish Parliament's Health Committee on 9 September);

- then a decision shortly afterwards by SofS to inform Wales and NI of the scheme and invite them to join;
- followed by Treasury agreement and a joint Administration announcement of the scheme in the Autumn and
- the commencement of a scheme in the Spring.