

HIM 16/1

To: Sammy Sinclair

From: R M Gutowski

Date: 17 June 2003

Copies: Graham Bickler
Vicki King
Gerry Robb
Zubeda Seedat

HEPATITIS C COMPENSATION

1. Your note of 17 June to Vicki King requests background and a line to take for S of S in advance of approaches from Malcolm Chisholm and Jack McConnell.
2. I have to say that your note summarises the priorities very well but perhaps the following can provide extra detail for S of S.

Hepatitis C Infection

3. Hepatitis C is a virus that can infect and damage the liver. The virus is found in the blood of people who have the disease. Hepatitis C is spread primarily by direct blood-to-blood contact with the blood of an infected person. Currently the main route of transmission in the UK is by the sharing of contaminated equipment by injecting drug misusers. Before the introduction of viral inactivation of blood products in 1984, and before 1991 when the screening of blood donors was introduced, some recipients of blood and blood products were inadvertently infected.
4. Many patients who acquire hepatitis C will live out their normal lifespan. Hepatitis C infection is cleared in about 20% of those infected, but persists in about 80% to become chronic infection. Some of those with chronic infection will have only mild liver damage, many with no obvious symptoms. About 20% of patients with chronic infection develop cirrhosis after 20-30 years. Of these, about 1-4% per year will develop liver cancer.
5. There are increasingly effective antiviral drugs that can prevent progression to serious liver disease in more than 50% of those treated. In October 2000, the National Institute for Clinical Excellence (NICE) published recommendations on the use of combination therapy (interferon alpha with ribavirin) for the treatment of moderate to severe chronic hepatitis C. A longer-acting type of interferon, pegylated interferon, is currently being considered by NICE and guidance is expected later this year.

Current Position On Compensation

6. Until recently the consistent position that the UK Government has taken, including the Devolved Administrations, with regards compensation payments to hepatitis C sufferers is that compensation or financial help is only paid to patients when the NHS, or individuals working in it, have been at fault. In the case of hepatitis C the NHS was not at fault because the screening of blood and blood products began as soon as a test became available. At the time many haemophiliacs were inadvertently infected. Attempts have been made to compare the position of haemophiliacs who acquired HIV through blood products and those who acquired hepatitis C in the same way where the Government did provide support. However the position was different, as at that time there was no effective drug treatment to offer these infected with HIV many of who were young adults and their life expectancy was short. Hepatitis C is different in that some patients will clear the virus themselves and drug treatments exist which clear the virus in around 50% of cases.
7. In November 2002 a report from an Expert Group presented to the Scottish Executive recommended that compensation be paid to infected patients whilst recognising that in law the NHS had no legal liability to make such reparation. Malcolm Chisholm then wrote to the Secretary of State for Work and Pensions indicating that he was considering setting up a lump sum compensation scheme and that the Scottish Executives legal advice was that this was a matter within devolved competence. This would distance Scotland from the rest of the UK on this issue. Department of Health Solicitors disagreed with the Scottish legal advice and the matter was put to the Law Officers:
8. The Law Officers have been asked:
 - a) Whether a hep C compensation scheme, whether in the form of periodic or lump sum payments, is within the devolved competence of Scottish Ministers;
 - b) If not, whether a narrow scheme, in the form of a single lump sum payment of each living infected person, would be within devolved competence;
 - c) Whether if the Scottish Executive introduced a scheme which the Law Officers thought was outside competence, they would consider it appropriate to either raise proceedings in the Court of Session or to refer the issue to the Judicial Committee of the Privy Council.
9. Law Officer's advice is expected any day now, and whichever way they rule both we and the Scottish Executive will need to abide by their ruling. The problem would be if they emerge with no definitive view and we

would then need to consider how to take things forward say with DWP and the Scottish Office.

Live to Take

10. Up to this point we have maintained a line to take and whilst awaiting Law Officers advice and we see no justification to move away from it:

"The report published on 6 November from the Scottish Expert Group on Financial and other Support was commissioned by the Scottish Executive and its recommendations on hepatitis C relate only to those people who contracted hepatitis C from blood or blood products provided by the NHS Scotland. It does not have implications for patients in other parts of the United Kingdom.

The Government's position remains as stated on many previous occasions in both Houses. We still do not believe that financial existence for people infected with hepatitis C through blood is justified."

11. If you require any further information please let me know.

R M Gutowski
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Social Security Implications

[For any of these options] it would be necessary to amend social security regulations if the Government wanted to ensure that payments were not taken into account as capital or income 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. There is some scope to disregard – ie ignore- personal injury payments but that would not necessarily apply.

Exemptions to the 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.

In this situation however it could be discriminatory not to disregard the payments. Macfarlane, Eileen Trust and variant CJD payments are already 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

Providing a disregard will require amendments to secondary legislation. These 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 £X million a year that would otherwise have come from taking the payments into account. But there will be no increase in benefit expenditure.

Social Security Implications

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.

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.

An exemption has however already been provided for 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.

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 a reduction in benefit expenditure benefit savings of around £5X million a year that would otherwise have come from taking the payments into account. But there will be no increase in benefit expenditure.