# OPTIONS FOR REVIEW OF THE CONTAMINATED BLOOD PAYMENT SCHEMES

## To inform discussion on 10 May 2013

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## Purpose of this paper

During PS(PH)'s attendance at the APPG on Haemophilia and Contaminated Blood on 17 April 2013, she expressed dissatisfaction with the current system of financial support, and has asked us to meet her.

This paper sets out our thinking so far on a broad range of possible options for reforming the hepatitis C payments system so that it better addresses the needs of those affected, particularly those people with chronic infection, suffering from a range of extra-hepatic conditions, which in some cases are severely debilitating, but where current scientific and medical evidence does not strongly demonstrate a causal link with hepatitis C infection.

However, there is no easy solution to this – all the options we identify are likely to cost significantly more than the current payments system.

## Introduction

As a result of NHS treatment with contaminated blood, or blood products, many thousands of people in the UK were inadvertently infected with blood-borne viruses (particularly hepatitis C and HIV) during the 1970s and 80s, before screening tests for blood donors and effective methods of viral inactivation were developed. Haemophilia patients were the largest identifiable patient group affected (around 5000). Liability has never been established, but successive governments have between them set up five ex-gratia financial relief schemes to support those infected. Campaigners have strong parliamentary support, and continue to press for compensation and a UK public inquiry. (In 2008, the Scottish Government announced a public inquiry into the deaths of a number of people in Scotland who had been infected as a result of their treatment, The Inquiry, chaired by Lord Penrose, is expected to report towards the end of 2013).

## Overview of the main issues

This government last reviewed payments in respect of hepatitis C infection in the autumn of 2010. Based on an expert review of clinical and scientific evidence on the natural history of chronic hepatitis C, in January 2011 SofS announced an enhanced lump sum and regular annual payments to people with cirrhosis and liver cancer, and set up the Caxton Foundation (a charity) to provide additional discretionary support to all those affected, based on need.

The attention of campaigners is currently focused on those people with chronic hepatitis C who do not meet the eligibility criteria for the enhanced lump sum and annual payments announced by SofS. The expert advice received in 2010 was that there is a wide spectrum of ill health associated with chronic infection. Many people experience few/mild symptoms, but others experience severe ill-health.. However, this is not reflected in the Skipton Fund eligibility criteria, because available evidence does not strongly support the attribution of these conditions to hepatitis C, although there may be an association, based on higher prevalence than in control groups. For more common conditions, such as type 2 diabetes, cognitive impairments and chronic fatigue, it is difficult to see how attribution might be demonstrated. However, we accept that these and other conditions may impact on QoL for some, and also on some individuals' ability to hold down a job or earn at their full potential. Ministers accepted that the needs of these people could be addressed through a discretionary mechanism (the Caxton Foundation), based on their financial circumstances. However, the Caxton Foundation has not had an auspicious start, and although it is working hard under a new Chair and CE to better meet the needs of its client community, it does not yet have systems of support in place that satisfy us that it is able to do what we intended.

Ministers agreed that the Advisory Group on Hepatitis (AGH) should continue to keep the evidence base on the natural history of hepatitis C infection under review, in order that DH can consider potential changes to the Skipton Fund eligibility criteria. The AGH's first report is due in the next few weeks. However, early indications are that it is unlikely to report new evidence which might merit changes to the eligibility criteria.

**Policy Objectives.**
The starting point for consideration of any changes to the eligibility criteria for hepatitis C payments and/or the wider system of ex-gratia payments, are the policy objectives that the Department is seeking to fulfil. The options for reforming the system outlined later in this document, can then be judged against these policy objectives.

1. To provide financial assistance/support, without admission of liability, to those people who experience significant loss of quality of life arising from HIV/HCV infection, as well as the partners, parents, carers, children and dependants of infected individuals, including those who have died.

2. A system that meets the needs of those affected to the greatest extent possible, within the context of the policy objectives as a whole. Providing most support to those people who need it most.

3. Not to provide on-going support to those who experience only limited loss of quality of life, and who can still work to support themselves (although to provide occasional support if/when necessary, eg when undergoing treatment).

4. Not to provide disincentives for seeking employment or treatment for their condition.

5. Reduce/do not create differences with HIV schemes.

6. The Skipton Fund eligibility criteria should be consistent with the clinical and scientific evidence base on the natural history of hepatitis C infection, [or suitable proxies for that evidence base].

7. The system should be financially sustainable and represent good value for money.

8. A consistent system across the UK.

## OVERVIEW OF OPTIONS FOR CONSIDERATION

**(more detail on each option in Annex B)**

| **Option** | **Title** | **Description (*and comment*)** | **Indicative Cost over lifetime of the scheme.** |
|---|---|---|---|
| Option 1 | The current system. | For HIV: annual payment of £14,191 and access to additional discretionary payments.<br>For Hepatitis C: initial lump sum payment for those with chronic infection, additional lump sum and annual payment of £14,191 for those who develop severe liver disease. Access to additional discretionary payments for all those affected. | £342.7m |
| Option 2 | The current system with an annual payment for Skipton Stage1. | As above, but those with chronic hepatitis C infection also receive an annual payment of, say, £5k.<br>(*Not evidence-based. Arbitrary level of payment. Will not satisfy campaigners*) | £715m |
| Option 3 | A tariff based system. | A single non discretionary body, would make payments according to fixed tariffs based on an individual's personal earned income. (*This assumes that a person's earning capacity is a reasonable proxy for their state of health*). The key difference with the existing system would be that people with chronic hepatitis C below a certain income would receive an annual payment of £14,191. | £807m |
| Option 4 | All infected individuals receive annual payment plus access to additional discretionary payments. | Annual payments of £14,191, to all infected individuals. The existing system of discretionary payments would continue as it is.<br>(*This is the campaigners' aim, but not evidence-based. It would mean people with mild disease who are able to work getting regular payments for life*) | £1.5bn |
| Option 5 | An independent Trust to disburse a fixed sum as a final settlement. | An independent Trust given a fixed sum to disburse as a final "settlement" to each infected claimant, and dependants/bereaved partners.. *(Could broadly model the vCJD Trust, to which DH gave a lump sum of £67.5m in 2001 to settle up to 250 cases. Even if settlement based on a basic sum as per vCJD Trust, admin costs/legal fees likely to be significant, but time-limited )* | £1.1bn, but DH could choose a lower settlement sum. |
| Option 6 | The Ireland Model. | A Tribunal to assess infected individuals, and the financial needs of partners, parents, carers, children and dependants of infected individuals. It would make payments proportionate to effect of ill health and losses arising from lost earnings. Irish model allows people to reapply as circumstances change. *(Admin costs/legal fees likely to be significant and ongoing)* | £1.13bn |

## ANNEX A

### Number of people involved – UK (England)

Around 3,400[1] (2,822) Skipton Fund stage 1 claimants still alive.
600[2] (479) Skipton Fund stage 2 claimants still alive (as at 31/3/13).
148 (117) Hepatitis C widows/other relatives registered with Caxton (as at 31/3/13).

378 HIV infectees still alive (as at 31/3/13).
120 HIV widows with Macfarlane Trust (as at 31/3/13).

[1] Data provided by Skipton. It does not maintain contact with its stage 1 claimants so it can only estimate how many might still be alive.
[2] Data provided by Skipton. This number changes regularly as new people are diagnosed/others die.

### Financial circumstances of those affected

HIV
People infected with HIV had the following incomes 2012/13:

| **Basic Net Household income*** | **Number of infected beneficiaries** | **MfT Payment pa** | **MFET Payment pa*** | **Total net household income** |
|---|---|---|---|---|
| Under £7,600 | 41 | £5,400 | £14,191 | Up to £26,886 |
| £7,601-£15,200 | 101 | £4,080 | £14,191 | £25,567 - £33,166 |
| £15,201-£22,750 | 67 | £2,760 | £14,191 | £31,847 - £39,396 |
| £22,751-£30,000 | 50 | £1,500 | £14,191 | £38,137 – 45,386 |
| £30,001-£37,900 | 20 | £720 | £14,191 | £44,607 - £52,506 |
| Over £37,901 | 35 | £0 | £14,191 | >£51,787 |
| Incomplete | 37 | - | £14,191 | n/k |
| Not known | 9 | - | £14,191 | n/k |

* includes most benefits and Skipton Fund payments.

In 2012/13 the Macfarlane Trust provided top-up payments to widows, to make their net income up to £19,000 per annum. We have no data about the income of Eileen Trust clients, but we assume it to be broadly similar to that of Macfarlane clients.

Hepatitis C
We have little information about the incomes of those infected with hepatitis C and bereaved spouses. It is likely that the majority of those infected are still able to work.

## ANNEX B
## Preliminary analysis of the options.

### Option 1. – The Current System

All payments for HIV and hepatitis C remain as they are.

| **HIV** | |
|---|---|
| MFET Ltd | infected individuals receive annual payment of £14,191 uprated annually by CPI. |
| Macfarlane Trust/Eileen Trust. | Additional discretionary payments to infected individuals, and the partners, parents, carers, children and dependants of infected individuals. |
| **Hepatitis C** | |
| Skipton Fund | Stage 1 - £20k lump sum<br>Stage 2 - £50k lump sum + £14,191 annual payment, uprated annually by CPI.<br>[Eligibility criteria for stage 2 kept under review and revised in line with changes in the evidence base, where feasible]. |
| Caxton Foundation | Additional discretionary payments to infected individuals, and the partners, parents, carers, children and dependants of infected. |

<u>Costs</u>

- Estimated £342,704,675, over the remaining lifetime of the schemes.

<u>Pros</u>

- Robust and evidence based, in respect of hepatitis C.
- The number of hepatitis C infected people who receive regular payments who are not that ill, relatively small.
- Will not add significantly to existing costs.
- Maintains the HIV system, which would be difficult to unpick.

<u>Cons</u>

- The stage1 – stage 2 issue will not be resolved. The scientific evidence tells us that some people experience extreme fatigue/brain fog, but there is no way that such eligibility criteria could be robustly implemented by Skipton.
- Will not have any effect on the campaign.
- HIV system not evidence based.
- HIV people get much more than Hepatitis C people.

## Option 2 – The current system with annual payment for Skipton Stage 1 clients.

| **HIV** | |
|---|---|
| MFET Ltd | Infected individuals receive annual payment of £14,191 uprated annually by CPI. |
| Macfarlane Trust/Eileen Trust. | Additional discretionary payments to infected individuals and family members. |
| **Hepatitis C** | |
| Skipton Fund | Stage 1 – Lump sum of £20K, plus annual payment of £5,000, uprated annually by CPI<br>Stage 2 – Lump sum of £50k, plus annual payment of £14,191 uprated annually by CPI.<br>Anyone who has previously received a stage 1 lump sum will be automatically eligible for the new annual payment. The payments will not be backdated, but payable from the date that the client applies for the new payment.<br>**[DN: lump sums could be abolished under this option because the rationale for them would disappear with the introduction of an annual payment at stage 1.]** |
| Caxton Foundation | Additional discretionary payments to infected individuals and family members. |

Costs

- Estimated £715,218,907, over the remaining lifetime of the schemes.

Pros

- Will provide some level of on-going support to those to Skipton Fund stage 1 who have severe ill health.
- New stage 1 payment removes justification for lump sums, enabling savings.

Cons

- Not evidence based - significant amounts of money will be paid to people who are experiencing few/no ill health effects*.
- Does not fully resolve the stage1 – stage 2 issue, because stage 1 people can be experiencing ill health effects as great as those at stage 2, so should logically receive the same payment.
- Costly.
- Builds dependency on these payments.
- The size of the stage 1 annual payment is arbitrary, and therefore difficult to justify. We will have a new campaign focusing on the size of this payment.

* We could test this by using income as a proxy. We can assume that people who have jobs are experiencing only limited impacts on their quality of life.

**Option 3 – A Tariff Based system.**

Under this system, a single body, would make payments to people infected with HIV and/or hepatitis C, and their families, according to four set tariffs.

Tariff 1.

Annual payments of £14,191 uprated annually by CPI, payable to:
- individuals infected with HIV; and
- individuals infected with hepatitis C who meet the current Skipton Fund stage 2 eligibility criteria. [Subject to revision in line with evidence base].

[Co-infected people will receive two such payments, if they also meet the Skipton Fund stage 2 eligibility criteria].

Tariff 2.

Top-up payments to everyone in receipt of a Tariff 1 payment, based on total household income. These payments to be uprated annually by CPI.

| **Net Household income*** | **Payment pa** |
|---|---|
| Under £21,791 | £5,400 |
| £21,791 - £29,391 | £4,080 |
| £22,801 - £36,941 | £2,760 |
| £36,942 - £44,191 | £1,500 |
| £44,192 - £52,091 | £720 |
| Over £52,091 | £0 |

*To include Tariff 1 payments, and all state benefits.

Tariff 3.
Payable to mono-hepatitis C infected individuals with chronic hepatitis C infection, who do not meet the eligibility criteria for Tariffs 1& 2, based on personal income of the infected individual, uprated annually by CPI.

| **Net personal income** | **Payment pa** |
|---|---|
| Up to £16,000 | £14,191 |

Tariff 4.
Payable to all widows.

Fixed rate top-ups of total household income to £19,000 net, per annum. Uprated annually by CPI.

**[DN: MfT also makes payments in respect of dependent children – could abolish these on grounds it replicates child benefit, but means some people will lose out].**

**[DN: How are carers to be accommodated in this system?].**

Costs

- Estimated £807,275,111, over the remaining lifetime of the schemes.

Pros

- Evidence based in respect of hepatitis C: i) clinical evidence base in respect re tariff 1, ii) income used as proxy for ill health in tariff 3.
- Compared to options 2 and 3, minimises payments made to people not in financial need, and most resources targeted at those in greatest need.
- People in stage 1 with low incomes will receive regular payments.
- It will save a large portion of the c£500-600k admin costs of running the existing 5 payment schemes.
- Addresses the dislike of the principle of the discretionary mechanisms that we are hearing from campaigners.
- Gives DH more control, and solves the problem of the poor performance of MfT and Caxton.
- Provides greater and more stable financial support to hepatitis C widows (a particular concern of the Manor House Group).

Cons

- Does not entirely solve the stage 1- stage 2 problem.
  - People on tariff 3 will demand what people on tariffs 1 & 2 get.
  - Co-infected people at Skipton Fund stage 1 will not get anything more.
  - People at stage 1 above a certain income will get nothing. (The logic of this is that these people will have jobs, therefore they cannot be too badly affected by their hep C.)
- Payments for HIV not evidence based.
- Criticism that people who are newly diagnosed in future will miss out on the Skipton Fund lump sums.
- Some campaigners will likely be satisfied with this system, but we can expect the campaign to continue in some form. Most of the prominent members of the Contaminated Blood Campaign should benefit, but they have made clear that they see removal of the stage1 – 2 classification as an interim measure only, leading to full compensation. Virtually all of the prominent campaigners for Tainted Blood will not benefit under this system. It is also unclear how MPs will react.
- Some campaigners might continue to demand a discretionary mechanism. Previous submissions from campaigners have indicated that some like the principle of a discretionary body to provide support for exceptional needs.

- Builds dependency and to a certain extent builds incentives not to work, especially for stage 1 people. Also problems around the cut off in tariff 4, some people may only be just above it.

**Option 4 – All infected individuals receive an annual payment plus access to additional discretionary payments.**

| **Non Discretionary payments** | |
|---|---|
| New Body | All infected individuals receive and annual payment of £14,191 uprated annually by CPI, only. (Skipton Fund lump sums abolished). |
| **Discretionary payments** | **[DN: in longer term could merge the three discretionary bodies].** |
| MfT/ET | Additional discretionary payments to infected individuals and family members. |
| Caxton Foundation | Additional discretionary payments to infected individuals and family members. Budget increased by value of the stage 1 and 2 lump sums that would have been paid. |

Costs

- Estimated £1,502,434,592, over the remaining lifetime of the schemes.

Pros

- Addresses the stage1- stage 2 issue.
- The mix of fixed and discretionary payments has flexibility to target additional resources at those in greatest need.
- Potential to significantly defuse political pressure.

Cons

- Costly.
- Not evidence based - significant amounts of money paid to people with little/no ill health arising from Hep C infection.
- Builds dependency.
- Might take some of the political heat out of the issue, but it will not end the campaign because they want full compensation.
- Will still get complaints about discretionary mechanisms. There is a significant mismatch between the HIV and hepatitis C discretionary schemes.

### Option 5 – An independent Trust to disburse a fixed sum as a final settlement.

An independent Trust given a fixed sum to disburse as a final "settlement", based on individual assessment of the ill health of each infected claimant, and the financial needs of the partners, parents, carers, children and dependants of infected individuals, including those who have died.

The impact of Hepatitis C changes over time, and new stage 1 claims should still continue to cone forward for a number of years, so the Trust would have to operate for perhaps a further 20-30 years.

<u>Cost</u>

- Estimated £1,104,241,517.

<u>Pros</u>

- Settles the issue for majority if the amount is big enough.
- The whole system will be put at arms length from DH.
- Will be evidence based. People in greatest need will receive most money.

<u>Cons</u>

- We can expect to receive complaints about decisions made by the Trust.
- Risk that the Trust will spend all its money and then come back to DH for more.
- Risk that DH might be continually lobbied over that time for more money by the campaigners, including for retrospection, arguing that what has been provided is inadequate.
- Can we rely on the Trust do a good job? – the existing ones have not necessarily delivered what ministers intended.

## Option 6 - The Ireland Model

Establish a Tribunal to assess infected individuals, and as well as the partners, parents, carers, children and dependants of infected individuals, including those who have died, and to make payments proportionate to effect of ill health and losses arising from lost earnings. Infected claimants can come back to the Tribunal for additional payments if their condition worsens.

Background: Between 1977 and 1994, a large number of women in the Irish Republic were infected with hepatitis C from contaminated Anti-D immunoglobulin produced by the Irish national Blood Transfusion Service Board (BTSB). An expert group set up by the Irish Government to look into the circumstances of these infections found that the BTSB had made mistakes. The Irish Government then set up a statutory Tribunal of Inquiry (The Findlay Inquiry). But before the Findlay Tribunal ruled, the Irish Government set up a Hepatitis C Compensation Tribunal to operate on a non-statutory basis to review claims for compensation for the many civil actions pending in the Irish courts as a result of infections through contaminated Anti-D. The report of the Findlay Inquiry, which was published on 6 March 1997, found that "wrongful acts were committed".

Infected individuals receive an average of about £750k (the Haemophilia Society states that the average paid to haemophilia patients is €853,636), while the average across all beneficiaries is approx £220k. Ireland cannot give us an exact figure for the average payment to infected individuals, because it varies on a case by case basis. The largest single payment has been €3.1m.

The legal profession has received a total of €146m in fees over the lifetime of the Tribunal to 31/12/11. In recent years this has been increasing by about €10m per annum. (In Ireland there have been 3,495 infected and non-infected claimants. The significantly higher number of people affected in the UK would mean that this figure would inevitably be higher if applied here).

Cost

- Estimated £1,130,673,699.

**[DN: assuming that we do not offset the cost with what they have received already through the existing bodies, and the Burton Judgement].**

Pros

- Should draw a line under this. Although campaigners are also demanding an apology from the PM and a public inquiry.
- Evidence based - will ensure that payments are proportional to need/loss.

Cons

- Cost.
- Establishes a precedent for other things.

- Will need to re-assess people annually/as often as necessary, in respect of hepatitis C.
- Unless it is made retrospective in respect of those who have died, the campaign may continue in some form. Although it will likely be much more manageable.