

To: 1.PS(PH)
2. SofS

From: Ben Cole
Cleared:
Date: 2 December 2013

OPTIONS FOR REFORM OF THE SYSTEM OF FINANCIAL SUPPORT FOR PEOPLE AFFECTED BY CONTAMINATED BLOOD

Issue

1. This submission
 - responds to your request at our meeting on 16 October 2013 for advice on a range of options for measures that could be introduced to improve the system of ex-gratia financial support for those affected; and in addition,
 - outlines possible models for an inquiry into the events in the 1970s and 1980s which led to people being infected with HIV and hepatitis C through treatment with NHS supplied blood or blood products, as raised in the Westminster Hall debate on 29 October 2013.
2. At a meeting on 14 November 2013 with Alistair Burt MP and campaigners, the Prime Minister also stated that there were issues regarding the system of financial support for those affected, which should be looked at again.

Timing

3. **Urgent.** Number 10 officials wish to meet you to discuss this issue later in the week commencing 2 December.

Recommendation

4. At this stage, we recommend that you:
 - provide a steer on any options for improving the system of financial support that you would like us to work up in more detail (paras 9-11);
 - do not commit to any of the models for an inquiry until the outcome of the on-going Penrose Inquiry in Scotland is known (para 23).

What the campaign groups want

5. The broad aims of the campaign groups are:
 - A comprehensive and fuller financial settlement;
 - A public inquiry; and
 - A public apology from the Prime Minister, acknowledging liability.
6. It is unlikely that anything short of all these demands will bring a complete end to the campaign, but there are some options, especially around the financial settlement aspects, which might bring closure for many. The campaigners' particular concerns about the existing system include:
 - The need for a comprehensive assessment of the health or other needs of the affected individuals, which has never been conducted;
 - The fact that available financial support does not adequately reflect the ill health experienced by many of those with hepatitis C infection, who do not receive annual payments under the current system, unlike all those affected by HIV.
 - Dislike of the principles behind the three discretionary support systems, including the variable way that they operate. For example, bereaved partners of deceased HIV-

infected individuals receive discretionary income top-ups, but those of deceased hepatitis C-infected individuals do not.

7. Background to the current system, which is complex having evolved over many years, is at **Annex A**. Details of the current payment schemes are at **Annex B**.

Options for improving the financial support available to those affected

8. Any future changes to the system overall should aim to be consistent with the evidence base if they are to have the best chance of being able to withstand judicial review. To aid further decision making, we have commissioned a systematic review of the evidence (Naomi Balabanoff's submission of 28 November 2013 refers to timing of that review).
9. In relation to the systems of payments, we have identified two broad approaches, with options within them:
 - i) Reform of the existing system to ensure that those who most need additional support receive it (options 1-3); or
 - ii) Radically overhaul the entire system (options 4-7), with generally bigger payments being made as either a single lump sum or as equivalent annual sums. Options 5-7 would require considerable individual health and actuarial assessment to provide consistency and fairness.These are set out in **Annex C**.
10. Under i), the three options range from reform of the discretionary element of the existing system only (the main discretionary bodies are anyway developing business cases for an uplift in their allocations for 2014-150, to either amending or abolishing (as previously suggested by SoS) the Skipton Fund stage 1 and 2 distinction so that those currently with stage 1 hepatitis C receive greater support.
11. Under ii), there are four options which would provide larger sums of money for the majority of those affected by HIV and hepatitis C. Option 4 provides a single one-off payment and removes any annual or discretionary elements. Options 5-7 are linked to individual assessment of impact, with payments made either as a lump sum or annually as you requested we explore. Option 7 is the most costly as it is a damages system based on impact and loss – this is the campaigners' preferred outcome.
12. Further detailed assessment of the options in the light of your steer will be necessary, in order to ascertain whether they can be implemented in a robust, fair and administratively straightforward manner.

What might a reasonable financial package look like?

13. As well as detailing likely costs, **Annex C** is colour-coded by both likely acceptability and likely ability of any option to withstand legal challenge.
14. Broadly, to be acceptable to campaigners and their MPs, a package would need to:
 - provide a sufficient level of lifetime financial support for a majority of infected individuals and bereaved partners;
 - demonstrate some degree of correlation between impact of infection and overall level of financial support, so that those worst-affected receive the most; and

- address the variations between a discretionary system operated by three different bodies.

The first two points, which are perhaps the most important to campaigners, could be achieved to varying degrees, and with varying costs and risks, by all options apart from option 1. A fairer, simplified discretionary system could be retained in conjunction with any of the other options.

15. To offer the best chance of being able to withstand legal challenge, any decisions should be reasonable, proportionate, fair and rational. In particular, any option which results in a person receiving less than they do under the existing system, or which is inconsistent with clinical and scientific evidence base, would be vulnerable to legal challenge. The advice of DH Legal Services on this point is at **Annex D**.
16. Overall there is no single option that meets all of these needs apart from the last, which is the most expensive and would mean finding significant sums of money up front. An alternative would be option 6, and although that would also mean finding more money up front, and would incur administrative costs, it would be evidence based and should be broadly acceptable.

Finance issues

17. The existing scheme costs approximately £25m per annum, which is funded from existing DH budgets. A small increase of this amount could potentially be funded within DH budgets but would require reprioritisation of funding away from other existing critical programmes.
18. DH Finance have advised that as requested by SoS they are exploring the potential for making 10-15% savings to DH central programme budgets and ALBs in 2014-15, and for a zero based review in 2015-16, signalling the need to release further savings to the NHS. There is substantial uncertainty regarding the estimated costs of the options presented in this submission, with estimates ranging from £770m over the lifetime of the scheme, to £2.5bn. Expenditure of this level cannot be funded within existing DH budgets without fundamental reprioritisation including the NHS budget, or without additional resources from HMT.
19. Financial support for those affected is currently the same UK-wide, and consultation with the DAs will be required on any potential change to the payment schemes.

Options of models for a Public Inquiry

20. During the Westminster Hall debate on payments for hepatitis C infection on 29 October, you made a commitment to reflect on different approaches to convening an inquiry, or a process or truth and reconciliation, into the events in question. Successive governments have in recent years taken significant and comprehensive steps to be open and transparent. Details of what has been done to date, together with a list of potential models for an inquiry, are at **Annex E**.
21. Campaigners would like further independent scrutiny, ideally with those involved at the time required to give evidence (in which case technically only an Inquiry under the Inquiries Act would suffice).

22. Lord Penrose is expected to report on the broader circumstances which led to the infection of people in Scotland. Since the events in question occurred pre-devolution, it is possible that Lord Penrose's report may criticise some decisions or actions of the UK Government during the period in question. If this is the case, the Department may shortly receive a warning letter from Lord Penrose, whose report is expected in March 2014.
23. We therefore recommend waiting to see what is in Lord Penrose's report before deciding whether to commission a further (potentially costly) inquiry. The reaction of the campaigners themselves to the report will also help to give further pointers to any outstanding issues of concern. However the issue of an inquiry does not appear to be as major a concern to campaigners as review of the payments schemes, since they would see an inquiry as a means of securing enhanced payments; there is thus no reason not to progress review of payments in the interim.

Next Steps

24. After we have received your steer on payments options we will work up those in greater detail, taking account of the systematic evidence review and stakeholder engagement, with a view to providing further advice as soon as practicable in 2014. As part of the stakeholder engagement, we intend to survey as many of those affected as can be reached and will use the outcome to assess whether the options are fair and appropriate for all groups affected. The Haemophilia Society has offered to assist us in this process.

Conclusion

25. You are asked to provide a broad indication of your preferred approach to the options presented for possible review of the payments schemes. Some of the lower cost options could potentially resolve the main issues regarding the existing payments scheme which may give closure to some, but only the more radical options are more likely to bring the campaign to an end. However, more detailed work will need to be carried out in order to ascertain whether some of the options can be implemented in a robust and fair manner.
26. We recommend that you note the models for a public inquiry but do not commit, pending the outcome of the Penrose Inquiry in Scotland.

Blood Policy Team

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Annex A

Background to the Current System

Infection with blood-borne viruses arising following treatment with contaminated blood or blood products was a worldwide problem during the 1970s and 80s, before screening tests or effective methods of viral inactivation were developed. Such infections have had traumatic consequences for many individuals and their families in the UK, although some individuals experience only mild ill-health.

Legal liability has never been established, although haemophilia patients brought a case in the late 80s, which they chose to settle out of court. All relevant documents that the Department holds from the period up to 1985 have now been published on the Department's website, so the evidence is available for scrutiny.

While the total number of infected individuals can be estimated (approx 4,000-5,000 people), there is no complete record of all individuals affected. Individuals infected with HIV are known, but for hepatitis C some people may have cleared the virus, and others may be unaware of their infection or that it was caused by contaminated blood. We can currently only identify people through their registration with one of the existing support schemes. Affected people continue to come forward, but the rate is now declining (less than a hundred people a year).

Key issues in relation to the current schemes

- There is wide variation in the health impacts of infection on those still living. Some have life-threatening illness or very poor quality of life, while some are only mildly affected. In the case of hepatitis C, some may be cured by new treatments.
- The fact that an individual's health may change over time suggests the need for periodic individual health assessments, which would be time-consuming and costly.
- There is considerable variation in the level of financial support currently provided to individuals, but it does not always appropriately correlate with the impact on their health.
- The decision to make annual payments to all those with HIV was not based on any assessment of the clinical and scientific evidence base. As is the case with hepatitis C, there is variation in the extent of ill health experienced by those infected with HIV. For hepatitis C, the principles underpinning the current system of payments are more consistent with the clinical and scientific evidence.
- Finally, two of the discretionary bodies (Caxton Foundation and the Macfarlane Trust) will be submitting business cases for an uplift in their financial allocations in 2014/15. Decisions on these business cases will need to be considered within the context of this review.

Annex D

Advice from DH Legal Services

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[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Annex E

INQUIRIES

What the campaigners are seeking.

The most recent joint statement from the campaign groups states:

A UK Public Inquiry is still called for that would provide answers to outstanding questions and enable lessons to be learned. However, we acknowledge there are alternative inquiry forums that could lead to comparable depths of scrutiny.

This would require a process which is open and independent, and has the power to compel the production of all available documents and to compel witnesses to give evidence.

This latest public statement is a change from their previously held position. Campaigners have previously also talked about an inquiry that would cover the issue of financial support for those affected, and one which would hold government, and even individuals, accountable. To that end, some campaigners have also wanted an opportunity to put their case before a public inquiry, “to have their day in court”, so to speak.

Campaigners have previously sought an inquiry in the hope that it will find either the NHS or Governmental to have been at fault in some way, which would strengthen their case for compensation. This is what occurred in Ireland where a Government established expert committee concluded that the Irish Blood transfusion Service had made mistakes. Following those findings, the Irish Government established a compensation scheme.

What has been done so far to provide transparency regarding these events.

A considerable amount of information about the events in question is already in the public domain:

- The Department has released all of the relevant documents that it holds from the period from 1970 up to 1985. (We also propose to continue to publish further relevant documents from the period 1986-1991 on the Department’s website, as part of our response to the Penrose Inquiry).
- In 2006, the Department published a 44 page chronology of events called, *Self Sufficiency in Blood Products in England and Wales: A chronology from 1973 to 1991*.
- Between 1988-1991 there was litigation brought by about 1,000 haemophiliacs infected with HIV. This was settled after the disclosure phase, after the litigants own solicitors estimated their chances of success as being about 20%.
- Between 1999-2001 there was litigation under the Consumer Protection Act by just over 100 non-haemophiliacs infected with hepatitis C by whole blood transfusions. Government lost this case.
- Lord Archer’s independent inquiry into Contaminated Blood and Blood Products, reported in 2009. The terms of reference were: “To investigate the circumstances surrounding the supply to patients of contaminated NHS blood and blood products; its consequences for the haemophilia community and others afflicted, and further steps to address both their problems and needs and those of bereaved families”. The campaigners were broadly content with the findings and recommendations, but were frustrated by the inability of Lord Archer to compel witnesses to give evidence and his decision not to apportion blame. The campaigners were content with the recommendations of the Inquiry regarding support for those affected, but they were

also frustrated by the fact that Government was not compelled to implement them in full.

- One of the terms of reference of the Penrose Inquiry in Scotland is to examine the circumstances generally in which patients treated by the NHS in Scotland became infected with hepatitis C and/or HIV, through treatment with NHS supplied blood/ blood products, taking account of the development of scientific and clinical understanding and evidence internationally. Since the events in question occurred pre-devolution, this may inevitably encompass decisions made by the UK governments of the time.

Public Inquiries - General

Public inquiries potentially come in a variety of formats, but broadly they all have the characteristics of:

- Independence;
- Transparency, consistent with the interest of justice and national security;
- Fairness and respect for individuals;
- Power to seek to establish the facts;
- Access to necessary resources and avoidance of unnecessary expenditure.

Cabinet Office guidance on Inquiries states that the default position is to establish an inquiry under the Inquiries Act 2005, although Minister may decide for whatever reason to use other legislation or perhaps proceed on a non-statutory basis.¹

A. The Inquiries Act 2005

- The Act provides for an inquiry to be undertaken either by a Chairman alone, or by a Chairman with one or more others; and imposes a requirement of impartiality
- The Act permits ministers to control inquiry expenditure, suspend or wind up an inquiry; prevent disclosure or publication of any evidence or documents given; and bar the attendance of witnesses. It also provides that an inquiry ‘is not to rule on, and has no power to determine, any person’s civil or criminal liability’.
- However inquiries under the 2005 Act have the power to require the production of evidence and other enforcement powers.

Alternatively if a non-statutory *ad hoc* inquiry is opted for there are a range of possible alternate options. However whilst such inquiries, which may be held in public or in private, are not bound by the procedural rules applied to a 2005 Act inquiry they have no power to compel the attendance of witnesses or the production of documents. Therefore they are reliant on the cooperation of all those involved.

B. The Finucane Inquiry (Documents based review).

- In 2010 the Government appointed Sir Desmond De Silva QC to conduct an independent review to produce a full public account of any state involvement in the murder of the Belfast solicitor Pat Finucane. This was a review of available papers only, and did not involve witness evidence. Any process which does not involve the witnesses giving evidence is unlikely to satisfy campaigners.

C. The Hillsborough Independent Panel

¹ <https://www.gov.uk/national-recovery-guidance-common-issues#inquiries>

- The Hillsborough Independent Panel was chaired by the Bishop of Liverpool. Its remit was to:
 - oversee full public disclosure of relevant government and local information related to the incident;
 - consult with the Hillsborough families to ensure that the views of those most affected by the tragedy are taken into account;
 - manage the process of public disclosure, ensuring that it takes place in an agreed manner and within a reasonable timescale;
 produce a report explaining the work of the panel The panel's report will also illustrate how the information disclosed adds to public understanding of the tragedy and its aftermath.

D. Parliamentary committee

- The Public Administration Committee (PASC) have recommended that inquiries into the conduct and actions of government should “...exercise their authority through the legitimacy of Parliament” by taking the form of a Parliamentary Commission of Inquiry composed of Parliamentarians and others. Parliament has extensive powers to call for documents and witnesses, and has considerable experience through its committee system of analysing complex materials in order to fact find and make recommendations. Additionally, the parliamentary process is favourable to any recommendations being implemented. However, there are two drawbacks compared with a public inquiry: it may be perceived as non-independent; and they require considerable Parliamentary resource and take significant time to hear evidence.

E. Committee of Privy Councillors

- Such a committee (eg. Franks, Butler and Chilcot) is a variation on the non-statutory *ad hoc* form of inquiry although its composition makes it a special and prestigious body It also allows for confidential information to be seen by the Committee that the Government could not otherwise make available. The disadvantage is the proceedings will be viewed as secretive.

F. Royal Commissions

- Royal commissions are *ad hoc* investigatory or advisory committees, established by Government initiative (albeit with greater formality) and without statutory powers to compel the attendance of witnesses or the production of documents.

G. Consultative group or forum

- Occasionally matters of concern thought to be structural and historic have been the subject of proposals for wide ranging commissions. The Eames Bradley Consultative Group of the Past (which looked at the way in which murders during the Northern Ireland troubles should be considered) and the Forum for Preventing Deaths in Custody, are examples However, this type of enquiry is more suited to generic, rather than specific events.

Costs

It is estimated that over £300 million pounds has been spent on inquiries since 2004. Recent Inquiries have ranged in cost from 7m to £195m for the blood Sunday Inquiry