



HIV and Hepatitis C infection from contaminated blood and blood products

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- During the 1970s and early 1980s some blood and blood products supplied by the NHS, mostly to haemophilia sufferers, were contaminated with HIV and Hepatitis C. More than 4500 patients contracted one or both of these diseases as a result, of whom over 2000 are thought to have died.
 - No-fault government payment schemes were established to provide support for those affected. These have been criticised as being insufficient but successive Governments have rejected calls for an independent inquiry and additional compensation. A non-statutory inquiry funded from private donations, the Archer Inquiry, reported in February 2009. Amongst its recommendations was a call for reform of support for those affected, in line with a scheme used in the Republic of Ireland.
 - The Irish scheme offers substantially higher payments than the UK schemes but successive Governments have rejected comparability on the basis that the Irish scheme was established to compensate victims for wrongdoing by a government agency but that no similar wrongdoing occurred in the UK. An April 2010 judicial review of the previous Government's response to the Archer Inquiry questioned that assertion and the current Government responded with a proposal to review aspects of support, while restating a rejection of the Irish model.
 - On 10 January 2011 the Government announced an increase in payments to some of those infected with Hepatitis C, removed a provision preventing payments for Hepatitis C patients deceased before 29 August 2003, and offered additional medical and psychological support for those with Hepatitis C and/or HIV. These new measures currently apply to patients in England and are estimated to be worth £100-130M. While the measures were welcomed as a step in the right direction by some contaminated blood activists and their supporters, remaining concerns include the level of payments relative to the Republic of Ireland, and how entitlement to discretionary payments will be assessed.

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1 Summary and recent events

During the 1970s and early 1980s more than 4500 UK patients contracted HIV, Hepatitis C, or both, from contaminated blood or blood products. It has been estimated that this has resulted in over 2000 deaths to date, the majority from HIV/AIDS but a growing number from the consequences of Hepatitis C infection.¹

Despite two internal Department of Health inquiries, establishment of three bodies to administer payments to those infected, and reassurances that all possible steps were taken to avoid infections, there has been continuing debate over several issues relating to contaminated blood, including:

- the circumstances under which users of blood products became infected, and whether this could have been prevented;
- refusal by successive Governments to hold a public inquiry; and
- financial support for those infected

These concerns eventually resulted in the establishment of the Independent Public Inquiry into Contaminated Blood and Blood Products (the Archer Inquiry), a non-statutory inquiry funded from private donations which reported in February 2009. A Private Member's Bill introduced on 26 May 2010 by Lord Morris, the *Contaminated Blood (Support for Infected and Bereaved Persons) Bill 2010-2011*, seeks to implement the recommendations of the Archer Report and had its Commons first reading on 17 November 2010.²

Amongst the Archer Inquiry recommendations was a call for reform of support for those affected in line with a compensation scheme established in the Republic of Ireland to deal with a similar problem there. The Irish scheme offers substantially higher payments than the UK schemes: typical lump sum payments in the UK are £20,000 to £60,500, whereas the average settled claim in Ireland is approximately €273,000.³

Successive Governments have rejected comparability with this scheme on the basis that it was established to compensate victims for wrongdoing by a government agency but that no similar wrongdoing occurred in the UK.

The previous Government's response to the Archer Inquiry included:

- increasing annual payments for people infected with HIV to £12,800, replacing the previous variable payments (averaging £6,400)
- the Haemophilia Society to receive £100,000 per year for the next five years
- a review of financial relief for people affected by hepatitis C to be taken in five years

An April 2010 judicial review of the previous Government's response to the Archer Inquiry questioned the basis for rejecting comparability with Ireland and the current Government

¹ [HL Deb 10 January 2011 c1234](#)

² For updates on progress see the Bill page on the Parliament website: [Contaminated Blood \(Support for Infected and Bereaved Persons\) Bill \[HL\] 2010-11](#)

³ Hepatitis C and HIV Compensation Tribunal, *Annual Report 2008*, p 96. Note that this figure is an estimate as the format of the data in the report does not allow this to be calculated directly.

responded with a proposal to review aspects of support, while restating its rejection of the Irish model.

On 10 January 2011 the Government announced the results of its review which included proposals to:

- reform payments to those infected with Hepatitis C who have developed advanced liver disease, increasing the lump sum from £25,000 to £50,000, introducing an annual payment of £12,800, and establishing a discretionary fund to provide additional hardship payments
- remove a provision preventing payments for Hepatitis C patients deceased before 29 August 2003, allowing new claims in these cases to be made until the end of March 2011
- provide free prescriptions and counselling for those with Hepatitis C and/or HIV. ⁴

The new measures as announced, estimated to represent an additional £100-130M of support over the life of the current parliament, initially applied only to patients in England. However, all three devolved administrations announced during March 2011 that they would offer similar benefits to patients living within their jurisdictions.⁵

While the measures were welcomed as a step in the right direction by some contaminated blood activists and their supporters, there is continuing concern that the level of payments still falls below that in the Republic of Ireland, that calls for support for access to travel and life insurance for those affected had not been included, and that most of those affected by Hepatitis C will not be eligible for the increased payments. There was also concern about the brief window for new claims for those deceased before 29 August 2003, although the Government has said that the Skipton Fund would have some discretion in applying this deadline. ^{6 7}

In announcing the new proposals, the Government restated its rejection of comparability with Ireland, generating debate both on the basis of this rejection and a previously quoted estimate of £3.5 billion as the cost of such a scheme in the UK. ⁸

The Haemophilia Society commented:

The Haemophilia Society recognises that the Government has addressed some of the obscene injustices of the old system but is disappointed that the Government hasn't gone further and valued the lives of those affected in the UK as highly as the Republic of Ireland valued those affected there.⁹

The campaign group Taintedblood considered the proposals a missed opportunity to deal adequately with the issue and called on the Government to establish a public enquiry:

⁴ Department of Health, *Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants*, 10 January 2011

⁵ See: <http://wales.gov.uk/newsroom/healthandsocialcare/2011/110308blood/?lang=en>, <http://www.scotland.gov.uk/News/Releases/2011/03/04100602>, <http://www.northernireland.gov.uk/news-dhssps-240311-new-financial-support> [at 11 July 2011]

⁶ HC Deb 10 January 2011 cc35-42

⁷ HC Deb 30 March 2011 c399-400W

⁸ HC Deb 10 January 2011 cc40-41

⁹ Haemophilia Society, *New Hep C Support Announced* [at 13 January 2011]

Whilst there are some minor positive points, we are devastated by this announcement. There are a limited number of people that the new financial support will be available to and the level of payment to those who will qualify is hugely disappointing. It will not bring to an end the years of suffering and will mean that the campaign for achieving proper compensation for all will continue with a new vigour.¹⁰

On 28 March 2011 the Caxton Foundation was established as a registered charity responsible for administering the new discretionary payments for Hepatitis C patients.¹¹

2 Background

The following sections outline some of the main background issues.

2.1 Mechanism of infection with Hepatitis C and HIV

Most of those affected by contaminated blood products were haemophilia sufferers, whose genetic makeup leaves them deficient in the chemical compounds needed for normal clotting of the blood. Patients with severe disease had a life expectancy of only 25 years prior to the development of effective treatments in the late 1950s and early 1960s.

During the 1970's and 1980's treatment relied on repeated intravenous infusions of blood clotting factors (mostly Factor VIII) extracted from donor plasma. While early treatments had used concentrated clotting factors from single donors, a manufacturing process was soon developed to produce powdered clotting factor concentrate, ten times more potent than the liquid form. This became widely available from the early 1970s and could be stored conveniently in a refrigerator and reconstituted with sterile water.

However, because large volumes of blood were needed for each dose of clotting factor concentrate, batches were produced from pooled donations of blood, potentially mixing blood products from thousands of donors. This not only placed a heavy demand on blood supplies but also multiplied the risks of contamination and made it difficult to trace sources of any infections.

Because of local shortages of clotting concentrate, the UK began to import supplies derived from paid-for blood donations in the USA, in some cases sourced from groups at high-risk of carrying HIV or Hepatitis C.

By the mid-1980's most haemophilia sufferers who used blood products were infected with Hepatitis C and approximately 20% were also infected with HIV.^{12 13}

It has been argued that far fewer infections would have occurred had the UK not needed to import blood products, and perceived delays in achieving such self-sufficiency have been a focus of concern by those infected and their supporters. It has also been argued that there were delays in implementing improvements in testing and treating blood products to reduce infections. These issues are dealt with in the following two sections.

¹⁰ Taintedblood, *Government Announces another Inadequate Support Scheme for Contaminated Blood Sufferers*, 10 January 2011

¹¹ <http://www.caxtonfoundation.org.uk/>

¹² Department of Health, *Review of Documentation Relating to the Safety of Blood Products 1970 – 1985 (Non A Non B Hepatitis)*, May 2007, p 8

¹³ Sabin C et al, *Twenty five years of HIV infection in haemophilic men in Britain: an observational study*, BMJ 331(7523), 29 October 2005, pp 997–998

2.2 Self-sufficiency in blood products

It has been argued that had the Department of Health stopped imports of contaminated blood products as soon as it became aware of possible risks there would have been significantly fewer infections of UK haemophiliacs and others.

The internal Department of Health review, *Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991*, published in February 2006, was concerned with this issue.¹⁴

A policy of self-sufficiency in blood products was recommended to the Department of Health by an expert group in 1973, and additional funds were committed to developing the capacity of NHS facilities. The initial concerns were both to reduce spending on expensive imported supplies of clotting factor and to prevent the potential undermining of the UK blood donor system if, as predicted, paid for donations began to be solicited by commercial providers.¹⁵ Further arguments for self-sufficiency relating to possible infection risks from imported supplies were raised from 1978.¹⁶

Because of a variety of problems, including delayed development of production infrastructure and increasing demand for clotting factor, self-sufficiency was never fully achieved. Reliance on imported supplies actually increased during the 1970s before decreasing over the following decade: imports accounted for 60% of UK usage in 1980 and 25% in 1993.¹⁷

The Department summarised the review's findings in a press release:

This review focussed on documents from 1973 to 1991 to produce a chronology of events and analysis of the key decisions which were taken at that time. The question of why England and Wales did not achieve a policy of self-sufficiency in blood products and whether this would have avoided infection rates, was given particular attention within the review.

The report concludes that:

- Nobody acted wrongly in the light of the facts that were available to them at the time.
- Every effort was made by the Government to pursue self sufficiency in blood products during the 1970s and early 1980s
- The more serious consequences of Hepatitis C, only became apparent in 1989 and the development of reliable tests for its recognition in 1991.
- Tests to devise a procedure to make the Hepatitis C virus inactive were developed and introduced as soon as practicable

¹⁴ Department of Health, [Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991](#), February 2006

¹⁵ Department of Health, [Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991](#), February 2006, p 13

¹⁶ Department of Health, [Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991](#), February 2006, p 15

¹⁷ Department of Health, [Self-Sufficiency in Blood Products in England and Wales: A Chronology from 1973 to 1991](#), February 2006, p 5 and p 17. The emergence of Variant Creutzfeldt-Jacob (vCJD) contamination of UK blood supplies in the late 1990s ended local sourcing of clotting factors and production is now undertaken in the USA.

- Self sufficiency in blood products would not have prevented haemophiliacs from being infected with hepatitis C. Even if the UK had been self sufficient, the prevalence of hepatitis C in the donor population would have been enough to spread the virus throughout the pool.¹⁸

The report was not welcomed by the Haemophilia Society, who felt that it was compromised by missing source documents (see section 4.1) and contained inaccuracies such as misrepresentations of medical opinion from the time about the seriousness of Hepatitis C.¹⁹

2.3 Identifying and removing Hepatitis C and HIV from blood and blood products

Efforts to protect blood product users during the 1970s and 1980s were complicated by the fact that identification of infected donors and blood products was not well developed at that time, and HIV/AIDS and Hepatitis C were new and poorly understood diseases.

An additional problem during the 1970s and early 1980s was that technologies for sterilisation of blood products were not as effective as they are today. It was not until 1985 that the NHS Blood Products Laboratory was able to develop and introduce a heat-treated clotting factor concentrate, BPL Factor 8Y. This effectively ensured that the product contained no active HIV or hepatitis viruses.²⁰ However, it is not possible to sterilise fresh blood in this way and it is thought that transfusions of fresh blood may have been the source of some continuing Hepatitis C infections.

Hepatitis C

The virus responsible for Hepatitis C was not identified until 1989. During the 1970s and early 1980s the disease was known only as “non-A non-B hepatitis” and was widely thought to be an uncommon, self-limiting and relatively mild disorder which could be transmitted via blood or blood products. Screening of blood for the other main hepatitis virus (Hepatitis B) was routine but the tests available at that time for detecting non-A non-B hepatitis were not specific, although these had been introduced in some countries before the Hepatitis C virus was identified. A specific and reliable Hepatitis C test was developed in 1989 and was introduced in the UK in late 1991.

It is now known that Hepatitis C is far more widespread than originally thought and that many of those who contract Hepatitis C develop a low grade persisting infection that can cause liver failure and liver cancer. The disease is now the subject of major public health campaigns in the UK and elsewhere. Treatment of chronic Hepatitis C is expensive and often unpleasant but is effective in approximately 50% of cases.²¹

HIV

HIV/AIDS was only recognised as a new illness in the early 1980s and was identified as a potential risk to blood product users in 1982. By 1983, blood product manufacturers were excluding donors who admitted to being in a group at high risk for the disease.

However, existing stocks of clotting factor continued to be used, partly due to concerns of precipitating a crisis of supply should they be withdrawn. As there was at that time no way of testing either donors or donated blood samples for HIV, much debate ensued within the NHS regarding the magnitude of the risk of its transmission by potentially contaminated blood and

¹⁸ Department of Health, *Review Published on Infected Blood Products*, 27 February 2006

¹⁹ The Haemophilia Society, *Haemophilia Society condemns Department of Health report* 28 February 2006.

²⁰ Department of Health, *Self-sufficiency in blood products in England and Wales: A chronology from 1973 to 1991*, 27 February 2006, p 2

²¹ For further information see <http://www.nhs.uk/Livewell/hepatitisc/Pages/HepatitisHome.aspx>

blood products. The HIV virus was identified in 1984 and reliable HIV tests became available from 1985, being introduced in the UK in October 1985.

Testing for blood-borne viruses continues to be a routine part of the quality assurance of blood supplies. In 1994 genetically-engineered clotting factors were introduced in the UK, removing the risk of transmission from infected donors. These are now the recommended clotting factor treatments in most types of haemophilia.²²

Blood and blood products continue to be widely used and their safety remains a concern as new infectious agents, such as variant Creutzfeldt-Jakob disease (vCJD), are identified.²³

Perceived delays in implementing technological safeguards against HIV and Hepatitis C infection have been a focus of concern amongst contaminated blood activists. In addition, some have felt that the medical profession at the time underestimated the risks of continuing use of potentially infected blood products, did not communicate this risk to patients, and in some cases did not inform patients of the results of HIV and other tests.²⁴

2.4 Calls for compensation and a public inquiry

Successive Governments have argued that everything possible was done to minimise the risk of infection and that nobody acted wrongly given the evolving understanding of HIV and Hepatitis C at the time, and the balance of risks of treatment versus the possible severe complications of untreated haemophilia.²⁵

However, patient groups (such as the Haemophilia Society, the Hepatitis C Trust, Tainted Blood and the Manor House Group) and their supporters have contested this claim and lobbied for many years for both financial compensation and a public inquiry.²⁶

In response, three government-funded organisations were established between 1987 and 2004 to provide financial support for those infected, and there have been two internal Department of Health inquiries to examine aspects of the contaminated blood issue.

Despite ongoing lobbying UK Governments have continued to resist calls for a public enquiry, arguing that there had been no wrongdoing and that existing support for victims is sufficient. Lord Warner outlined the position held by the previous Government during a debate in January 2006:

... it is important to stress that, despite the Department of Health's decision to make ex gratia payments, we do not accept that any wrongful practices were employed in relation to inadvertent infection of blood which led to hepatitis C, and we do not consider that a public inquiry is justified as we do not believe that any new light will be shed on this issue as a result. [...]

As I have made clear repeatedly and repeat again today, the infection of people with hepatitis C was inadvertent. Nothing could have been done at the time with the technology available to assess the blood for that level of infection. The blood service did nothing wrong. We as a Government have put in place a scheme to alleviate the

²² United Kingdom Haemophilia Centre Doctors' Organisation, *Guideline on the selection and use of therapeutic products to treat haemophilia and other hereditary bleeding disorders*, 2008

²³ The Haemophilia society, *Blood Borne Infections*

²⁴ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, pp 60-64

²⁵ Department of Health, *Review Published on Infected Blood Products*, 27 February 2006

²⁶ See <http://www.haemophilia.org.uk>, <http://www.hepctrust.org.uk/>, <http://www.taintedblood.info/index.php>, and <http://www.manorhousegroup.co.uk/>

suffering of people who were alive after the scheme was announced in August 2003 to provide help for them. We have extended that scheme today in the announcement that I have made, so that the dependants of people who died after the scheme came into operation will also be eligible to make a claim.²⁷

This position prompted the establishment of the Independent Public Inquiry into Contaminated Blood and Blood Products (the Archer Inquiry), a non-statutory inquiry funded from private donations which reported in February 2009. This inquiry and its recommendations are dealt with in a later section of this Note.

In January 2009 the Scottish Executive established a public inquiry under the Inquiries Act 2005, known as the Penrose Inquiry, to investigate similar issues within the Scottish NHS. The inquiry has published a preliminary report summarising matters of fact and evidence and commenced public hearings on 8 March 2011.²⁸

2.5 Previous financial support

Between 1987 and 2004 the Department of Health created and funded three organisations to provide financial support for those infected with HIV and Hepatitis C via contaminated blood or blood products.

The previous UK Government had estimated that total ex-gratia payments from the MacFarlane and Eileen Trusts and the Skipton Fund amounted to approximately £150M at the end of March 2009.²⁹

Patient groups continue to be concerned about anomalies in the eligibility criteria and the levels of payment. For example, typical lump sum payments in the UK are £20,000 to £60,500, whereas a compensation scheme established to address a similar contaminated blood problem in Ireland offers lump sum awards which averaged €275,174 in 2008.³⁰

The MacFarlane Trust

Established in 1987 after a lobby of Parliament by the Haemophilia Society, the MacFarlane Trust provides support for haemophilia sufferers who contracted HIV from contaminated blood products prior to September 1991.³¹

Founded with an ex gratia payment of £10 million from the Department of Health, the Trust initially provided support on request from eligible persons (an initial group of 1,246 registrants), who were required to provide evidence of need. After further lobbying, the Government agreed to grant an extra £24 million to the Trust in 1990, enabling it to provide lump sum payments of £20,000 to its beneficiaries (including some dependents of those who had died).

In 1989 a group of 970 HIV-infected patients had also begun proceedings against the Department of Health, alleging negligence in relation to the safety of blood products. The case was settled out of court and an additional £42 million was allocated to the Trust in 1991, which was then able to provide further payments of between £21,500 and £60,500.³²

²⁷ HL Deb 12 January 2006 c300

²⁸ <http://www.penroseinquiry.org.uk/>

²⁹ HC Deb 11 Nov 2009 c448W

³⁰ Hepatitis C and HIV Compensation Tribunal, *Annual Report 2008*, p 96

³¹ The MacFarlane Trust website is accessible by registered users only but contact details for key staff can be found here: <http://www.macfarlane.org.uk/contact.php>.

³² Scottish Parliament Information Centre, *The MacFarlane Trust and No-fault Compensation (RN 01/80)*, 3 September 2001

Claimants are required to sign a waiver renouncing their right to make further claims via litigation in relation to either HIV or hepatitis infection from contaminated blood products.

In 2008 the Trust was supporting 370 surviving original registrants plus 42 others who acquired the disease through contact with those infected. Monthly payments to registrants vary between £225 and £500, with additional sums available to cover certain specific expenses.³³

The Eileen Trust

The Eileen Trust provides support for non-haemophilia sufferers who contracted HIV from contaminated blood or blood products and was established in 1993 after initial moves towards litigation by a group of affected patients. Although much smaller, with only 27 registrants, the Eileen Trust provides essentially the same level of ongoing support and lump sum payments as the MacFarlane Trust.

The Skipton Fund

Established in 2004, the Skipton Fund provides ex gratia payments of £20,000 (“first stage payments”) to those who developed chronic Hepatitis C from blood or blood products prior to September 1991. Additional payments of £25,000 (“second stage payments”) are available to those who develop advanced liver disease as a result.

The Fund does not cover those who developed acute Hepatitis C and subsequently cleared the virus from their bodies without treatment, nor does it cover those who died before 29 August 2003.³⁴

The announcement of the creation of the Skipton Fund followed soon after the publication of the Ross Report by the Scottish Executive. This had looked at the general issue of compensation for harms caused by Scottish NHS services, with a specific focus on compensation of those infected with HIV and Hepatitis C. That report had recommended payments of £10,000 to anyone infected, an additional £40,000 for those with chronic Hepatitis C, and full compensation calculated on the same basis as common law damages for those subsequently developing significant liver disease.³⁵

In its response to the announcement of the details of the Skipton Fund, the Haemophilia Society expressed its disappointment that the sums offered were considerably less than this, and that the relatives of those dying before 29 August 2003 or after 5 July 2004 were excluded from compensation. The provisions of the Fund relating to payments to the estates of those who died from Hepatitis C were modified slightly in January 2006 to permit payments to the estates of those dying after 5 July 2004. However, relatives of those who died before 29 August 2003 are still not eligible for payments and this matter continues to be a source of significant concern for contaminated blood activists.³⁶

³³ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 85

³⁴ Department of Health, *Details of hepatitis C ex-gratia payment scheme announced*, 23 January 2004. See also guidance notes on the Skipton Fund website: *The Skipton Fund - What it is and how it works* and *The Skipton Fund - A guide to help you complete an application for the additional payment*

³⁵ Scottish Executive, *Report of the Expert Group on Financial and Other Support*, March 2003, p 8

³⁶ The Haemophilia Society, *2006 January - Skipton Fund announcement*

As of 31 March 2009 the Skipton Fund had made 4,048 Stage 1 payments and 759 Stage 2 payments (equivalent to £99.94 million).³⁷

3 The Archer Inquiry

The Independent Public Inquiry into Contaminated Blood and Blood Products (the Archer Inquiry) was a non-statutory inquiry funded from private donations. The Inquiry held hearings between 27 March 2007 and 12 June 2008 and produced a final report on 23 February 2009. Transcripts of hearings and other relevant documents are available on the Inquiry's website.³⁸

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 suggest further steps to address both their problems and needs and those of bereaved families.³⁹

The Inquiry was chaired by Lord Archer of Sandwell, a former solicitor general. The other members of the inquiry panel were Dr Norman Jones FRCP, Emeritus Consulting Professor to St Thomas' Hospital, London and Ms Judith Willetts, Chief Executive of the British Society for Immunology.⁴⁰

Between 27 March 2007 and 12 June 2008 the Inquiry held 10 days of public hearings in venues within the House of Lords, producing a final report on 23 February 2009.

As a non-statutory body, the Inquiry relied on voluntary provision of documents and attendance by witnesses. Commenting on the consequent relationship of the Inquiry with the Department of Health, the report notes:

The Department of Health maintained its view that the Inquiry was unnecessary, and declined to provide witnesses to give evidence in public, but they supplied documents which we requested, responded to questions from us and sent representatives to three private, informal and unminuted meetings.⁴¹

The Report goes on to clarify the Inquiry's intent with respect to issues of blame:

The past cannot be undone. Nothing can rescue the victims and their families from what they have already suffered. But a review of the events and decisions that led to the tragedy may assist in coming to terms with the consequences, and might suggest ways in which Government may address those aspects which it is not too late to rectify. While hindsight, by definition, operates after damage is done, it may reveal important lessons for the future. We consider that to be more important than apportioning blame.⁴²

³⁷ The Skipton Fund, *Introduction*

³⁸ <http://www.archercbbp.com>

³⁹ The Archer Inquiry, *Opening Public Statement by the Rt Hon The Lord Archer of Sandwell QC*, 27 March 2007, p 4

⁴⁰ Lord Turnberg, past President of the Royal College of Physicians, was also a member of the initial inquiry panel but due to a family tragedy withdrew and was replaced by Dr Jones.

⁴¹ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 9

⁴² The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 9

3.1 Archer Inquiry conclusions

While the recommendations of the Archer Inquiry, chiefly those on compensation, have become widely known, the report also drew conclusions on several aspects of the contaminated blood tragedy. While the report consistently stresses its wish to avoid apportioning blame, the following extracts capture its views on the response to the emerging health risks, issues of informed consent of patients, and deficiencies of the commercially obtained blood products from the USA:

[...] We are dismayed at the time taken by Governmental and scientific agencies to become fully alive to the dangers of Hepatitis C and HIV infections, and also by the lethargic progress towards self-sufficiency in blood products in England and Wales. From the promise of self-sufficiency to its attainment took five years in Ireland, but thirteen years in England and Wales. [...]

A common cause for resentment was the inadequacy of information presented to patients by their doctors. This is understandable given the medical mores of that time (see Chapter 7); nevertheless it highlights the deficiencies of a paternalistic approach when doctors have to operate from an inadequate information base. [...]

The Inquiry considers that a significant burden of responsibility rests on American suppliers of Factor VIII concentrate at the time of this tragedy. Long after alarms had been sounded about the risks of obtaining paid-for blood donations from communities with an increased incidence of relevant infections, such as prison inmates, this practice continued. It is difficult to avoid the conclusion that commercial interests took precedence over public health concerns. [...] ⁴³

The text of the full conclusions of the report is appended to this Note.

3.2 Archer Inquiry recommendations

The Inquiry made wide-ranging recommendations, including:

- establishing a statutory committee to advise on the management of haemophilia
- improving monitoring of donors and users of blood products, particularly for newly identified potential infections such as vCJD
- providing free prescriptions and access to support services for those infected
- substantially increasing financial payments and changing the way they are paid
- redefining payment eligibility criteria to remove anomalies
- actively seeking out those known to have been at risk of infection from contaminated blood but who may remain unaware⁴⁴

The text of the full recommendations is appended to this Note.

⁴³ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, pp 103-105

⁴⁴ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, pp 107-110

3.3 The Labour Government response

The previous Government published its response on 20 May 2009, the key points of which included:

- annual payments of £12,800 for people infected with HIV, replacing the current variable payments (averaging £6,400)
- the Haemophilia Society to receive £100,000 per year for the next five years
- a review of financial relief for people affected by hepatitis C to be taken in five years
- the Haemophilia Alliance (an existing group which includes medical providers and the Haemophilia Society) to meet twice yearly with the Government and to coordinate a look-back exercise to identify patients with bleeding disorders potentially undiagnosed with blood-related infections.⁴⁵

The text of the general and point by point responses are appended to this Note.

3.4 Reactions to Labour Government response

The Labour Government's response was not welcomed by the Haemophilia Society and others who had been active in lobbying for a public inquiry.

Lord Archer was also quoted in several media sources as being disappointed by the modest amounts offered:

An independent inquiry into the scandal, chaired by Lord Archer of Sandwell, in February recommended better payouts for nearly 3,000 affected haemophiliacs, as well as help for widows and dependants. [...]

Archer condemned the response as "deeply disquieting" and a "faltering step that only compounds the anguish of the afflicted and bereaved". He said: "It is difficult to avoid the conclusion that humanitarian impulses have come a bad second to Treasury constraints."

Archer branded the new funding for patients with HIV "paltry", and said the failure to increase help available to victims with hepatitis C and to offer payment to their dependants was "sadly lacking both in understanding and in compassion"...⁴⁶

Chris James, Chief Executive of the Haemophilia Society, commented:

"The Government claims to accept the moral case for action but then, by not implementing the recommendations in full, shows its contempt for the victims of what Lord Winston has described as the "worst treatment disaster in the history of the NHS." While haemophilia patients crossed the country to give evidence to the Inquiry no Heath Minister was prepared to even cross the road. [...]"⁴⁷

⁴⁵ Department of Health, *Government response to Lord Archer's Independent report on NHS supplied contaminated blood and blood products*, 20 May 2009.

⁴⁶ The Guardian, *Anger after government rejects increase in infected blood payouts*, 20 May 2009. See also The Times, *Ministers condemned for 'paltry' help for blood scandal haemophiliacs*, 20 May 2009; The Telegraph, *Hepatitis C patients given contaminated blood refused compensation*, 21 May 2009; BBC Online, *Tainted blood victims left angry*, 20 May 2009

⁴⁷ Haemophilia Society, *Haemophilia Society React To Government Response To The Archer Report*, 20 May 2009

4 Comparisons with support in other countries

Contamination of blood supplies with Hepatitis C and HIV was an international problem during the 1970s and 1980s, with a range of approaches taken to investigation of the problem and compensation of those infected.

Substantial public inquiries were undertaken in Canada (the Krever Commission) and Ireland (the Finlay and Lindsay Tribunals), both resulting in significant reform of the systems for supply of blood and blood products and establishment or modification of compensation schemes.^{48 49}

The Irish Hepatitis C and HIV compensation scheme forms a key part of the ongoing debate around contaminated blood supplies, the scheme's level of payment having been cited by the Archer Report as a minimum standard for its recommended compensation scheme. The Government did not accept this recommendation, rejecting the basis for comparability with Ireland, and this became the focus of a successful request for judicial review. The following sections outline this issue in more detail.

4.1 Contaminated blood compensation in the Republic of Ireland

The Irish Hepatitis C and HIV Compensation Tribunal was established by the Irish Government in 1995 to provide compensation for those infected with Hepatitis C via blood or blood products and its remit was extended in 2002 to include infection with HIV. It has a statutory basis in the *Hepatitis C Compensation Tribunal Act 1997*, the *Hepatitis C Compensation Tribunal Act 2002* and the *Hepatitis C Compensation Tribunal Amendment Act 2002*.⁵⁰

The size of awards is assessed in accordance with the principles of civil claims for damage and Tribunal decisions can be appealed in the High Court. From 1996 to the end of 2008 the Tribunal had made 2803 direct awards totalling €561,524,295, or an average of €200,330 per award (the average in 2008 was €275,174). The Tribunal has also paid €205,703,063 in additional High Court claims and other settlements, and incurred €112,300,202 in legal costs. With the additional costs included, the approximate average cost of a settled claim has been approximately €313,781.⁵¹

As well as being entitled to claim compensation, Irish patients infected with HIV or Hepatitis C via blood or blood products may use a government-subsidised scheme to purchase life insurance, mortgage protection and travel insurance with no disease-related premium. Those with Hepatitis C are also entitled to hold a Health Amendment Act Card which provides free access to a range of health services.^{52 53} Similar insurance and healthcare provisions for UK victims of contaminated blood were recommended by the Archer Report.

It should be noted that in Ireland there was a significant problem with Hepatitis C contamination of Anti-D serum (given to women with certain blood types to prevent

⁴⁸ <http://www.hc-sc.gc.ca/ahc-asc/activit/com/krever-eng.php>

⁴⁹ <http://www.dohc.ie/publications/lindsay.html>

⁵⁰ <http://www.hepccomptrib.com/index.php>

⁵¹ Hepatitis C and HIV Compensation Tribunal, *Annual Report 2008*, p 96. Note that the average total cost per settled claim is an estimate (assuming each additional payment is linked to only one base award) as the format of the report does not allow this to be calculated directly.

⁵² <http://www.hepcinsurance.ie/>

⁵³ Citizens Information Board, *Hepatitis C and Health Amendment Act Cards*

haemolytic disease of the newborn) in addition to problems related to blood transfusions and treatment of haemophilia.

4.2 Debates over comparability with Ireland

Successive UK Governments (including the current Government) have argued that the situation in Ireland is not comparable to that in the UK because the Irish scheme had been established on the basis that an official enquiry there had shown wrongdoing by a government agency. It was thus a compensation scheme based on fault. No such wrongdoing had been shown in the UK and therefore the UK ex gratia payments scheme was appropriate.

On 19 November 2009 Lord Morris presented his *Contaminated Blood (Support for Infected and Bereaved Persons) Bill* in the House of Lords, calling for implementation of the recommendations of the Archer Report, including reform of the ex gratia payments schemes. The Bill passed through its Lords stages but did not progress beyond its first Commons reading before dissolution. During the Lords Second Reading Debate on this Bill (11 December 2009) Lord Morris addressed the issue of comparability with Ireland, quoting previous Government statements and correspondence from Irish officials and a representative of the Irish Haemophilia Society:

Let me first, however, make it absolutely clear that the Government of the Republic did not, as stated in this House by my noble friend Lord Warner, briefed by and speaking for the Department of Health on 25 March 2004,

"set up their hepatitis C compensation scheme following evidence of negligence by the Irish blood transfusion service".-[Official Report, 25/3/04; col. 796].

That is untrue.

Again, it was wrong for the Department of Health to have briefed my honourable friend Gillian Merron MP to tell the House of Commons that,

"a judicial inquiry in Ireland found failures of responsibility by the Irish blood transfusion service", and had, "concluded that wrongful acts had been committed", and that the Government of the Republic, "decided to make significant payments to those infected".-[Official Report, Commons, 1/7/09; col. 130WH.]

Brian O'Mahony, chief executive of the Irish Haemophilia Society, who was personally involved in the negotiations with the Department of Health and Children in Ireland in 1994 and 1995 which led to the establishment of a Hepatitis C Compensation Tribunal on a statutory basis on 16 December 1995, has written to me to say that my honourable friend's statement to the House of Commons was "misleading and erroneous".

He goes on to say that the Compensation Tribunal heard its first cases in early 1996 and that the first award for persons with haemophilia was made in March 1996. He concludes:

"Therefore the establishment of the Hepatitis C Compensation Tribunal, and significant payments by the Tribunal, pre-dated the setting up of both the Finlay Tribunal established in October 1996 and the Lindsay Tribunal of Inquiry set up in September 1999".

I also have a letter from Kay Maher of the Republic's Department of Health and Children confirming Brian O'Mahony's statement, which concludes:

"I hope this will serve to clarify the sequence of events in Ireland for Ms Merron and I trust that her department will now correct the record".

I look forward to hearing the department's response to that extremely important request.⁵⁴

Baroness Thornton, on behalf of the previous Government, restated the reasons for rejecting comparisons with Ireland during that debate, and again in a subsequent answer to a PQ from Lord Morris on 5 January 2010:

Baroness Thornton: The compensation scheme in the Republic of Ireland was set up in the light of evidence of mistakes by the Irish Blood Transfusion Service Board (BTSB).

The sections of the letters from the Irish Haemophilia Society and the Department of Health and Children which were quoted during the Second Reading of the Contaminated Blood (Support for Infected and Bereaved Persons) Bill [HL] on 11 December (HL Deb, cols 1263-4), do not mention the fact that the Irish Government had set up an expert group to look into the issue of contaminated blood products, which reported in January 1995. The expert group found that wrongful acts had been committed by the BTSB, which led the Irish Government to set up the Hepatitis-C Compensation Tribunal to operate on a non-statutory basis to review claims for compensation arising from the many civil actions pending in the courts. The Irish Government subsequently set up the Finlay tribunal of inquiry, which reported in March 1997. This found that wrongful acts were committed. Following the findings of the Finlay tribunal, the Irish Government placed the Hepatitis-C Compensation Tribunal on a statutory footing.

This information has been agreed with officials in the Republic of Ireland's Department of Health and Children.⁵⁵

Lord Morris introduced another Private Member's Bill on 26 May 2010, the *Contaminated Blood (Support for Infected and Bereaved Persons) Bill 2110-2011*, which again seeks to implement the recommendations of the Archer Report and had its Commons first reading on 17 November 2010.⁵⁶

5 Judicial review and responses

On 16 April 2010, Andrew March, a haemophilia sufferer who contracted both HIV and Hepatitis C through contaminated blood was successful in his request for a judicial review quashing the basis for the Government's rejection of a part of the recommendations of the Archer Inquiry.

The High Court hearing considered the claim that the Government had erred in rejecting recommendation 6 h) of the Archer Inquiry regarding a new compensation system:

We suggest that payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland.⁵⁷

⁵⁴ HL Deb 11 Dec 2009 cc1263-4

⁵⁵ HL Deb 5 January 2010 c43WA

⁵⁶ For updates on progress see the Bill page on the Parliament website: [Contaminated Blood \(Support for Infected and Bereaved Persons\) Bill \[HL\] 2010-11](#)

⁵⁷ The Archer Inquiry, *Independent Public Inquiry Report On NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 109

Although the Government's published response to the Archer Inquiry in May 2009 did not specifically mention the issue of comparability with Ireland, the Court held that subsequent answers by the then Minister of State at the Department of Health, Gillian Merron, supported the view that rejection of comparability was a key reason for rejecting 6 h).

During an adjournment debate on 1 July 2009 Dr Brian Iddon had raised the matter of comparability:

Dr. Iddon: I am grateful to my hon. Friend. When I compared the Irish situation with the UK situation in the House the other day, she said:

"I cannot accept the comparison with Ireland, because the Irish blood transfusion service was found to be at fault, and that was not the case here."— [Official Report, 23 June 2009; Vol. 494, c. 656.]

However, will she admit today that the Irish paid out without liability and before any tribunal had met to discuss the position? [...]

Gillian Merron: I stand by the points that I made. Furthermore, a judicial inquiry in Ireland found failures of responsibility by the Irish blood transfusion service and concluded that wrongful acts had been committed. As a result, the Government of the Republic of Ireland decided to make significant payments to those affected. As I will explain, that was not the case with the blood transfusion service here. [...]

I turn to the recommendations on financial relief, our responses to which have come under the closest scrutiny. In the UK, such payments are not compensation but ex gratia payments. That is an important distinction. Lord Archer made recommendations on the payments and made comparisons with Ireland. However, it is important to restate that the position in Ireland is very different. The independent inquiry in Ireland found the transfusion service to be at fault because it had not followed its own official guidelines on protecting the blood supply from contamination. That is not the case in the UK. Comparable levels of payment are therefore not appropriate. [...]⁵⁸

The Court held that this and other Government statements revealed a material error in their reasoning in that the sequence of events in Ireland, the scope of the judicial inquiries there, and the intent of the payment schemes undermined the Government's basis for rejecting comparability. The judgement held that:

45. [...] (a) the Irish government have never been found to be "liable"; (b) "the legal advice to the government was that the State itself was not liable" (see the Brief); and (c) the Irish government have always "paid out" on an ex gratia basis which neither admits nor requires proof of negligence or fault; albeit that (d) findings of error, fault or wrongful acts have been made by both Finlay and Lindsay [*judicial inquiries*].⁵⁹

The Coalition Government did not seek to appeal the judgement after coming to power and in June 2010 the Parliamentary Under Secretary of State at the Department for Health, Earl Howe, again highlighted the issue of compensation in Ireland being based on evidence of mistakes by a government agency:

Earl Howe: My Lords, obviously, I cannot speak on statements made by Ministers of the former Administration. However, I can confirm to the noble and learned Lord that the compensation scheme in the Republic of Ireland was set up in the light of evidence of mistakes made by the Irish Blood Transfusion Service Board. That has been

⁵⁸ [HC Deb 1 July 2009 c131WH](#)

⁵⁹ [March, R v Secretary of State for Health \[2010\] EWHC 765 \(Admin\)](#)

confirmed to us by officials in the Republic of Ireland's Department of Health and Children. It is important to understand that the events that gave rise to the people in Ireland becoming infected through contaminated blood transfusions were quite dissimilar to the sequence of events that occurred here. There were specific circumstances in Ireland, and quite different circumstances in the UK.⁶⁰

On 14 October 2010 the Coalition Government published its response to the judicial review in a written ministerial statement prior to a Backbench Business debate on the issue on the same day. The statement included the following points:

- reiteration of the rejection of comparability with Ireland on the grounds of differing circumstances and affordability
- an estimated cost of £3 billion should a comparable scheme be implemented here
- an undertaking to complete by the end of 2010 a review to include:

the level of ex-gratia payments made to those affected by hepatitis C, including financial support for their spouses and dependants, and taking account of the level of payments made to those infected with HIV in the UK and via schemes in other countries;

the mechanisms by which all ex-gratia payments are made;

access to insurance;

prescription charges;

access to nursing and other care services in the community⁶¹

The full terms of reference of the review have been lodged as a Deposited Paper.⁶²

6 October 2010 Backbench Business debate and compensation costs

A debate on 14 October 2010, allotted via the Backbench Business Committee, considered a motion calling on the government to offer an apology to those affected and to implement the recommendations of the Archer Report:

That this House recalls that the catastrophic problems of infected blood supplied by the NHS date back to the 1970s and 1980s, infecting 4,670 patients and causing what Lord Winston described as the worst treatment disaster in the history of the NHS; notes that successive administrations only very partially responded to this catastrophe by setting up and funding the MacFarlane Trust, the Skipton Fund and the Eileen Trust; regrets the past refusal to accept the principal recommendation of the Independent Public Inquiry into the supply of contaminated NHS blood to haemophilia patients, chaired by Lord Archer and established and financed by private initiative and funds, relating to compensation for the victims and set out in paragraph 6(h) of chapter 12 of the Archer Report; further notes that earlier this year the reasons for rejecting this recommendation were challenged successfully in the High Court, which quashed the decision; believes that this ruling constitutes an appropriate moment for the present Government, which bears no responsibility for the inadequate and misjudged policies of successive previous administrations, to extend an apology to the surviving 2,700

⁶⁰ [HL Deb, 2 June 2010, c248](#)

⁶¹ [HC Deb 14 October 2010 c30WS](#)

⁶² Department of Health, [Review of support for those affected by contaminated blood](#), 14 October 2010

sufferers, their families and the bereaved; and calls on the Government to alleviate their intense hardship and suffering by accepting and implementing the recommendations of the Archer Report despite the intense financial pressure on the public purse at this time.⁶³

The motion was defeated (Ayes 44, Noes 285).

Prior to the debate the Government had unsuccessfully sought to substantially amend the motion, highlighting the additional support offered to date, the estimated cost of implementing a compensation scheme comparable with that used in the Republic of Ireland, and highlighting the review proposed in the written ministerial statement:

Line1,leave out from 'House' to end and add 'deeply regrets the fact that many people were infected by contaminated blood and blood products; recognises that the previous Government increased the level of payments to those affected with HIV to a minimum of £12,800 per annum, and increased the discretionary funding available to their dependants; notes that it is estimated that implementing in the UK a scheme similar to that of the Republic of Ireland would cost in excess of £3 billion; recognises that this issue requires urgent attention for those who are living with serious health problems as a result of their infections, as well as their families and the families of those who have already died; and welcomes the Government's commitment to review certain aspects of Lord Archer's recommendations.'⁶⁴

The Government's estimated £3 billion cost of implementing an Irish-style compensation scheme was a recurring new issue of contention during the debate, with the basis for this figure being requested and its size challenged. Particular concern was expressed that the estimate was based in some way on a figure used on page 88 of the Archer Report which may be a mis-transcription from the record of an evidence session (an average payment figure of €353,636 recorded in a transcript having become €853,636 in the Report).⁶⁵

There was no clear resolution of this issue during the debate but the Minister (the Rt Hon Anne Milton MP) undertook to place in the library a copy of the basis for the calculation.

An explanation of the £3 billion cost calculation was received on 19 October 2010 and uses an estimated cost per claim of £750,000, based on informal discussions with colleagues in the Republic of Ireland, and 4700 potential claimants, based on figures in the Archer Report:

Estimating the cost of implementing the Republic of Ireland's Hepatitis C and HIV compensation scheme in the UK

UK estimate of £3.5 billion

- We did not use the figures quoted on page 88 of the report of Lord Archer of Sandwell's Independent Inquiry into NHS Supplied Contaminated Blood and Blood Products when estimating the cost to the UK of implementing in the UK a scheme similar to the one operating in the Republic of Ireland (RoI).
- We do not know how many people in total were infected with HIV and/or hepatitis C by contaminated blood and blood products in the UK, how many of them are still alive, or how many widowed spouses there are. However, we used Lord Archer's estimate that around 4,700 were infected (p.5 of his report).

⁶³ HC Deb 14 October 2010 c521

⁶⁴ <http://www.publications.parliament.uk/pa/cm201011/cmagenda/ob101014.htm>

⁶⁵ Archer Inquiry, *Eighth Day Hearing Transcript - UK and Irish Haemophilia Societies*, 30 August 2007, p 77

- We assumed that infected individuals in RoI received an average payment of £750,000. This was based on informal discussions with colleagues in RoI, which indicated that individual payments to infected individuals in RoI ranged between £500,000 and £1 million. The figure of £750,000 is the average of those two figures.
- Thus, a £750,000 average award to an infected individual in the RoI multiplied by the estimated 4,700 infected individuals here in the UK gave a total UK cost estimate of £3.525 billion for infected individuals only. This figure does not include an element for UK carers and dependants, which would further increase this total.

The previous Government explained this in an answer to a Parliamentary Question published on [29 March 2010 \(Column WA347\)](#).⁶⁶

The average award figure of £750,000 used in this calculation appears to differ from figures published in the 2008 Annual Report of the Irish Hepatitis C and HIV Compensation Tribunal, which provides cumulative records of all payments from this body. For the period 1996-2008, the average base award was €200,330. This award can be supplemented via additional payments subject to either Tribunal decisions or High Court review. Although the figures provided in the Tribunal's Annual Report do not allow simple calculation of an average for these additional payments, they appear to have added approximately €73,387 to the average base award, suggesting an average total payment of €273,717. Legal costs were significant, adding approximately €40,064 per base award.⁶⁷

The figures provided in the Annual Report are summarised in the first three columns of the table below, with the final column showing the derived estimates of average payments:

	Cost (€)	Number of claimants	Average payment per base award (€)
Base awards	561,524,295	2,803	200,330
Additional payments:			
High Court Appeals	79,401,709		
Reparation Fund Payments	126,301,354		
Total payments	767,227,358		273,717
Legal costs	112,300,202		
Total payments and legal costs	879,527,560		313,781

Source: Hepatitis C and HIV Compensation Tribunal, Annual Report 2008, pp 95-6

7 Results of the Government review (January 2011)

On 10 January 2011 the Government announced the results of its review which included proposals to:

- reform payments to those infected with Hepatitis C who have developed advanced liver disease, increasing the lump sum from £25,000 to £50,000, introducing an annual payment of £12,800, and establishing a discretionary fund to provide additional hardship payments

⁶⁶ <http://www.parliament.uk/deposits/depositedpapers/2010/DEP2010-1845.doc>

⁶⁷ Hepatitis C and HIV Compensation Tribunal, *Annual Report 2008*, p 96

- remove a provision preventing payments for Hepatitis C patients deceased before 29 August 2003, allowing new claims in these cases to be made until the end of March 2011
- provide free prescriptions and counselling for those with Hepatitis C and/or HIV.⁶⁸

The new measures as announced, estimated to represent an additional £100-130M of support over the life of the current parliament, initially applied only to patients in England. However, all three devolved administrations announced during March 2011 that they would offer similar benefits to patients living within their jurisdictions.⁶⁹

While the measures were welcomed as a step in the right direction by some contaminated blood activists and their supporters, there is continuing concern that the level of payments still falls below that in the Republic of Ireland, that calls for support for access to travel and life insurance for those affected had not been included, and that most of those affected by Hepatitis C will not be eligible for the increased payments. There was also concern about the brief window for new claims for those deceased before 29 August 2003, although the Government has said that the Skipton Fund would have some discretion in applying this deadline.^{70 71}

In announcing the new proposals, the Government restated its rejection of comparability with Ireland, generating debate both on the basis of this rejection and a previously quoted estimate of £3.5 billion as the cost of such a scheme in the UK.⁷²

The Haemophilia Society commented:

The Haemophilia Society recognises that the Government has addressed some of the obscene injustices of the old system but is disappointed that the Government hasn't gone further and valued the lives of those affected in the UK as highly as the Republic of Ireland valued those affected there.⁷³

The campaign group Taintedblood considered the proposals a missed opportunity to deal adequately with the issue and called on the Government to establish a public enquiry:

Whilst there are some minor positive points, we are devastated by this announcement. There are a limited number of people that the new financial support will be available to and the level of payment to those who will qualify is hugely disappointing. It will not bring to an end the years of suffering and will mean that the campaign for achieving proper compensation for all will continue with a new vigour.⁷⁴

On 28 March 2011 the Caxton Foundation was established as a registered charity responsible for administering the new discretionary payments for Hepatitis C patients.⁷⁵

⁶⁸ Department of Health, [Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants](#), 10 January 2011

⁶⁹ See: <http://wales.gov.uk/newsroom/healthandsocialcare/2011/110308blood/?lang=en>, <http://www.scotland.gov.uk/News/Releases/2011/03/04100602>, <http://www.northernireland.gov.uk/news-dhssps-240311-new-financial-support> [at 11 July 2011]

⁷⁰ HC Deb 10 January 2011 cc35-42

⁷¹ HC Deb 30 March 2011 c399-400W

⁷² HC Deb 10 January 2011 cc40-41

⁷³ Haemophilia Society, [New Hep C Support Announced](#) [at 13 January 2011]

⁷⁴ Taintedblood, [Government Announces another Inadequate Support Scheme for Contaminated Blood Sufferers](#), 10 January 2011

⁷⁵ <http://www.caxtonfoundation.org.uk/>

A copy of the Ministerial Statement announcing the review outcome and proposals is appended to this Note.

8 Other matters dealt with by the Archer Inquiry - missing documents

It became apparent during attempts to access relevant government documents in 2004 that many could not be located by the Department of Health and were presumed to have been destroyed. Although many of the documents were subsequently found, this has led to concerns about the completeness of the evidence available to any earlier or subsequent investigations.

Initial statements suggested that a considerable number of documents had been destroyed in error:

Rt Hon Lord Morris of Manchester: Further to the answer by the Lord Warner on 12 January (Official Report, col. 300) about documents dealing with contaminated National Health Service blood products that were destroyed in error by the Department of Health in the early 1990s, on what date or dates they were destroyed; by whose decision they were destroyed; and whether it is only documents on these products that have been destroyed in error by the department.

Lord Warner: My noble friend is aware that during the HIV litigation many papers were recalled. We understand that papers were not adequately archived and were unfortunately destroyed in the early 1990s. My noble friend is also aware that further documents were destroyed in the 1990s. Officials at the Department of Health have established that these documents related to the minutes and papers of the Advisory Committee on the Virological Safety of Blood between 1989 and 1992. These papers were destroyed between July 1994 and March 1998. A decision, most probably made by an inexperienced member of staff, was responsible for the destruction of these files.⁷⁶

An internal review on this matter disclosed that many of the documents were in fact still held by the department and that photocopies of many of the remaining documents were available from a firm of solicitors who had acted for claimants in previous litigation over HIV infection from contaminated blood products.⁷⁷

In the review the Department stated that some documents, relating to meetings of the Advisory Committee on the Virological Safety of Blood (ACVSB) between May 1989 and February 1992, had been destroyed. However, this was said to have been due to an administrative error and it was also noted that the lost files related to matters post-1985 (after the introduction of heat treated blood products which carried a much lower risk of contamination)⁷⁸

All of the released documents are now available electronically via the DH website.⁷⁹

In December 2008, a PQ from Jenny Willott MP revealed the existence of 35 relevant documents which had been withheld in whole or in part:

⁷⁶ HL Deb 27 February 2006 c26WA

⁷⁷ Department of Health, *Review of documentation relating to the safety of blood products 1970 – 1985 (non-A, non-B hepatitis)*, 22 May 2007

⁷⁸ Department of Health, *Review of documentation relating to the safety of blood products 1970 – 1985 (non-A, non-B hepatitis)*, 22 May 2007, p 5

⁷⁹ Department of Health, *Documents held by the Department of Health on the safety of blood and blood products, 1970-1985*

Jenny Willott: To ask the Secretary of State for Health how many and what proportion of the documents rediscovered by his Department in 2007 relating to the safety of blood products have been (a) publicly released and (b) released to the Archer inquiry; and if he will make a statement.

Dawn Primarolo: Some 4,500 documents were discovered in unregistered files. With the exception of a small number withheld under exemptions in the Freedom of Information Act, these documents were issued to Lord Archer's inquiry between June-October 2007 and then placed on the Department's website.

In total 18 documents were withheld entirely, and 17 documents partly withheld, under the following exemptions in the Freedom of Information Act:

Exemption	Document withheld	Part of document withheld	Total documents wholly or partly withheld
Section 38—Health and Safety	1	9	10
Section 40—Personal information	3	6	9
Section 42—Legal professional privilege	8	1	9
Section 43—Commercial interests	6	1	7
Total	18	17	35

The Guardian covered the issue of withheld documents in an article on 26 January 2009, from which the following excerpt is taken:

The government is accused of withholding documents that could be vital to uncovering how thousands of haemophiliacs became infected with hepatitis C and HIV through blood transfusions.

Although the Department of Health has handed over thousands of papers to an independent public inquiry chaired by Lord Archer of Sandwell, the MP Jenny Willott has discovered through a parliamentary question that 35 are being withheld, many on the grounds of commercial interest.

"It is appalling that after 20 years, the government is still withholding information on one of the biggest health disasters this country has ever seen," said Willott. [...] ⁸⁰

On 12 February 2009, the Government agreed to review the status of the seven documents withheld under Commercial interests provisions:

Mr. Meacher: To ask the Secretary of State for Health with reference to the answer to the hon. Member for Cardiff Central of 30 June 2008, Official Report, column 652W, on blood products, if he will disclose the 35 documents wholly or partly withheld by his Department which relate to the infection of haemophiliacs by contaminated blood products. [256830]

⁸⁰ The Guardian, [Government withholding blood scandal evidence](#), 26 January 2009

Dawn Primarolo: These 35 documents were the only papers out of some 4,500 that were, after careful consideration, withheld under an exemption in the Freedom of Information Act 2000. The exemptions that applied are:

Section 38—Health and Safety—10 documents or part documents;

Section 40—Personal information—nine documents or part documents;

Section 42—Legal professional privilege—nine documents or part documents; and

Section 43—Commercial interests—seven documents or part documents.

For the avoidance of any continuing doubt in this matter, and given the time that has now elapsed, I have asked the Department's officials to review the seven documents withheld under Section 43 (Commercial interests), to see if there is another way that this information can be placed in the public domain.

In relation to the other three categories, these documents have been withheld for reasons that are clearly provided for within the FOI Act, and not in any way to withhold relevant information on the subject of contamination of blood and blood products.⁸¹

The Archer Inquiry Report also expressed concern regarding the destruction of the Departmental papers of Lord Owen and Lord Jenkin of Roding relating to their Cabinet roles in the 1970s, during which time concerns over infections from imported blood were first raised:

The destruction of the Departmental papers of Lord Owen and The Rt Hon Lord Jenkin of Roding has precluded us from investigating further the Departmental thinking and the extent to which ministers were made fully aware of the facts.⁸²

⁸¹ HC Deb 12 February 2009 c 2164W

⁸² The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 28

9 Appendices

9.1 Conclusions of the Archer Report

“In this Chapter we attempt to draw conclusions from the mass of evidence presented to us. In this endeavour we have been hindered by the long time that has elapsed from the tragic events with which we are concerned. Many whose experience would have been important were not available to the Inquiry. Had a full investigation taken place nearer the time of these events this difficulty would have been avoided. Nevertheless we looked for lessons to be learned in the hope of reducing the likelihood of a similar catastrophe happening again. The problems surrounding vCJD are a reminder that new infections may yet arise with serious results. In pursuance of our objective the Inquiry did not consider it appropriate to apportion blame, especially given the problems attendant on hindsight.

There is no doubt that the infection of so many patients, often with fatal results, is a horrific human tragedy. It was memorably described by Lord Winston as the worst treatment disaster in the history of the NHS, a view with which we agree. Subsequent events have done little to alleviate the hurt of the victims or their families. The haemophilia community feels that their plight has never been fully acknowledged or addressed. In Chapters 11 and 12 we suggest ways in which this sense of injustice might be eased.

We are dismayed at the time taken by Governmental and scientific agencies to become fully alive to the dangers of Hepatitis C and HIV infections, and also by the lethargic progress towards self-sufficiency in blood products in England and Wales. From the promise of self-sufficiency to its attainment took five years in Ireland, but thirteen years in England and Wales. A prominent factor in this delay was the situation at BPL in Elstree. Not designed for production on the scale that was becoming necessary it also suffered from fragmented management and under-funding. Whether the lack of urgency over much of this period arose from over-hesitant scientific advice or from a sluggish response by Government is now difficult to assess. The availability of extra production resources in Scotland was not pursued and alternative strategies do not seem to have been explored.

The anger and sense of betrayal still present among the haemophilia community was a frequent theme stated by witnesses to the Inquiry. A common cause for resentment was the inadequacy of information presented to patients by their doctors. This is understandable given the medical mores of that time (see Chapter 7); nevertheless it highlights the deficiencies of a paternalistic approach when doctors have to operate from an inadequate information base.

We are satisfied that some patients were subjected to tests without knowledge of their purpose and without their consent, a practice described by some witnesses as being treated as experimental guinea pigs. Such a practice is now condemned by the GMC, except in clearly defined circumstances. But, whether it was done as part of a diagnostic process for a particular patient, or to extend medical knowledge for the benefit of all, we found no indication that the motivation was other than well intentioned. The prescription of products carrying potential risk for patients with mild haemophilia, when safe therapy with DDVAP was available, was ill-advised and sometimes led to serious consequences which were avoidable. We do, however, realise that the potential seriousness of Hepatitis C was not then known, while understanding of AIDS was rudimentary. This may help to explain the regrettable fact that by not informing patients of their infection with Hepatitis C or HIV their partners were thereby placed at risk. The importance of patient involvement in making difficult clinical

decisions is emphasised by these events and is today fully recognised by the medical profession.

The Inquiry considers that a significant burden of responsibility rests on American suppliers of Factor VIII concentrate at the time of this tragedy. Long after alarms had been sounded about the risks of obtaining paid-for blood donations from communities with an increased incidence of relevant infections, such as prison inmates, this practice continued. It is difficult to avoid the conclusion that commercial interests took precedence over public health concerns. We are informed that US regulations in such matters are now much more demanding and we trust that lessons have been learned.

We must now look to the future. We cannot undo the damage done, nor turn back the clock to take a closer view of those past events and decisions. We must address the ongoing needs of those affected and consider how the state can ensure these citizens are recompensed.

A summary of the Inquiry's conclusion follows:

1. A full Public Inquiry into this issue should have been held much earlier to address the concerns of the haemophilia community.
2. The procrastination in achieving national self-sufficiency to avoid the use of high-risk blood products from overseas had disastrous consequences. Had self-sufficiency been achieved earlier the scale of the catastrophe would have been significantly reduced. If in the future concern arises about the safety of blood products this lesson must be remembered.
3. The doctor-patient relationship during the evolution of this tragedy sometimes had unfortunate consequences. The medical profession appears to have made good progress in this area. The importance of patient involvement when making difficult clinical decisions is now appreciated and should not be forgotten.
4. Commercial priorities should never again override the interests of public health."⁸³

⁸³ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, pp 103-106

9.2 Recommendations of the Archer Report

“We believe that the following recommendations would help to meet the unmet needs of patients with haemophilia and their families:-

1. (a) A Committee should be established by Statute to advise Government on the management of haemophilia in the United Kingdom. It should have overarching responsibility for:

- i) the selection, procurement and delivery of the best therapies currently available and recommended by NICE;
- ii) readily available access to any necessary treatment relating to the condition itself or any condition arising from consequent therapy;
- iii) all provisions necessary to address the financial and other needs of haemophilia patients.

(b) We set out on page 96 our recommendations relating to the composition of the Committee. We emphasise the importance of patient representation, through nomination by the Haemophilia Society and other bodies working to support the haemophilia community.

(c) There should be a statutory requirement to consult the Committee prior to the introduction of legislation or substantial changes in policy.

(d) Where the Committee deems it necessary, regional sub-committees should be established to exercise prescribed functions falling to the principal committee.

2. Patients with Haemophilia who have received blood or blood products, and their partners, should be tested for any condition identified by the Committee described in 1 above.

3. Every blood donor should be similarly tested following the donation. We understand that at present donations are tested for Syphilis, Hepatitis B, HIV, Hepatitis C, and HTLV. This list must be kept under review.

4. Those who have been infected should be issued with cards entitling the holder to benefits not freely available under the NHS, including free of charge prescription drugs, general practitioner visits, counselling, physiotherapy, home nursing and support services. The card should facilitate access to an NHS hospital bed and specialist services.

5. We consider it vital that the Government should secure the future of the UK Haemophilia Society by adequate funding. This should be seen as a matter of urgency.

6. Direct financial relief should be provided for those infected, and for carers who have been prevented from working. We propose that the scheme should have the following characteristics:

a) It should be paid through the Department of Work and Pensions in the same way as existing statutory benefits, so that beneficiaries should receive their entitlements from the Government and not through intermediate sources such as the Macfarlane or Eileen Trusts, or the Skipton Fund. The Government would thus have direct responsibility to the individual beneficiary for providing the necessary resources.

b) Entitlements should be payable if infection is established within the appropriate time-frame. An appeal mechanism should be provided against rejection of a claim and the assessment of the amount due.

c) Entitlement should not be means-tested, but should take the form of an initial capital sum, followed by prescribed periodical payments.

d) There should be no distinctions dependent upon the reason for the treatment with blood or blood products.

e) The anomalies which at present apply according to the age when the recipient was first infected, or when the infection took place or, in the case of dependents, the date of death of the original patient should be rectified. In particular, the Government should review the conditions under which the widow of a patient infected by blood products now becomes eligible for benefit from the Eileen Trust and from the Skipton Fund .

f) Payments under the scheme should be disregarded for the purposes of calculating other benefits.

g) There should be a table of amounts payable in the case of double or multiple infections.

h) We suggest that payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland.

7. There is a need for some provision to ensure to patients access to insurance. This could be done either by providing the premiums, or by establishing a separate scheme for the patients in question.

8. In addition, a look back exercise should be undertaken to identify, as far as possible, individuals who may have been unknowingly infected by contaminated blood products and who might still not be aware of this.”⁸⁴

⁸⁴ The Archer Inquiry, *Independent Public Inquiry Report On NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009, p 107-9

9.3 Labour Government response to the Archer Report – introduction

“This document sets out the Government's response to the report of Lord Archer's independent inquiry, published on 23 February 2009. The inquiry examined the events of the 1970s and early 1980s, which resulted in the infection of many patients with HIV and/or hepatitis C through NHS treatment with blood and blood products.

This Government acknowledges and deeply regrets the tragic outcome for many patients and their families, who have suffered as a result of the very treatments which should have transformed their lives for the better.

We welcome this report. Lord Archer and his fellow inquiry members have undertaken a comprehensive and detailed review bearing in mind the difficulty of examining events which took place over 20 years ago.

Our commitment to making information available about past events

Efforts to make properly-informed assessments of the relevant events and decisions taken throughout the period in question, that is the fifteen year period 1970 to 1985, are constrained by the incompleteness of the documentary record, for which this and former governments have apologised. We acknowledge that the loss or misplacement of some official documents has led to suspicion that we have 'something to hide'. We have been very open about these mistakes, and have made every effort to collect and release the relevant papers. Over 5,500 documents have already been placed on the Department of Health website, and we have said that where we identify any further relevant documents, they will also be released, subject to safeguards such as not releasing personal data. Further papers have been identified, which are being released today. We do not believe they add to our knowledge of events in those years. However, we are releasing them in keeping with our commitment to release, in line with the Freedom of Information Act, all relevant documents that we hold on the safety of NHS blood and blood products from 1970 to 1985. We are pleased to see that Lord Archer discovered no evidence of malicious destruction of relevant records.

Assessing the evidence

The introduction in the 1970s of clotting factors made from human plasma as a treatment for haemophilia vastly improved the quality of patients' lives. However, during the late 1970s and early 1980s, the majority of haemophilia patients in regular treatment received clotting factors infected with HIV and/or hepatitis C before it became possible to detect or destroy these viruses. This problem affected many countries.

Internationally, at that time, experts were divided in their views about the infection risk associated with blood, especially clotting factors which were made from pooled donations. There were a few who advised that the risk was worryingly high. However, the prevailing medical opinion did not support this view. Hepatitis C was then thought to be a mild and often asymptomatic infection. We now know that a small proportion of chronically infected people may develop severe liver disease.

There has been criticism of past Governments' management of the objective to achieve self-sufficiency in blood products in England and Wales during the 1970s and much of the 1980s. Funds were allocated in 1975 to increase plasma production, but proved insufficient as demand for clotting factors increased dramatically during the next few years because of the success of the new treatments. It also became clear in 1979 that the Blood Products

Laboratory required significant upgrading and, in light of the greater demand, expansion to meet the goal of self-sufficiency, and it remained necessary to continue to import clotting factor concentrates. The evidence shows that many doctors and patient representatives supported importation, on the basis that assessment of the balance of risks at that time favoured continued availability of treatment. Some of those representing patients with haemophilia felt there were dangers in absolute self-sufficiency, primarily because reliance on a sole supplier might have led to a shortfall, possibly endangering the lives of patients.

The Department of Health reviewed its surviving documentary evidence from the period when the decision to pursue self-sufficiency was made available, and has found no evidence to suggest that the hepatitis C outbreak in the late 1970s and early 1980s in this country could have been avoided if self-sufficiency had been achieved. By the early 1980s there was evidence that commercial (US) and UK plasma concentrates carried a similar risk of transmitting hepatitis. The review was published in 2006, and is available on the Department of Health's website.

In 2006 the Department commissioned a further review of all the documents held between 1970-85 relating to non-A, non-B hepatitis. These mainly refer to the UK's drive to achieve self-sufficiency in blood products, to the reorganisation of the Blood Products Laboratory, and to measures taken to safeguard the blood supply and blood products from contamination by HIV/AIDS and viral hepatitis. A copy of the review report was published in May 2007, together with all the references.

Reducing the viral risks from blood - where are we now?

The introduction of heat treatment in 1985 removed the risk of both HIV and of hepatitis from blood products. Testing of all donations for HIV was introduced in 1985. Testing for hepatitis C was introduced in 1991 when suitable, effective tests became available. An antibody test was developed in 1989, but was not approved for use in the UK because it was both insufficiently specific and sensitive.

Since the mid 1980s the measures in place to assure the safety and quality of human blood and blood components and blood products manufactured from them have developed significantly. All blood donations are now routinely tested for HIV and hepatitis viruses. European Directive 2002/98/EC sets standards of quality and safety for the collection, testing, processing, storage, and distribution of human blood and blood components.

Blood products, such as clotting factors, which are manufactured from pooled plasma donations, are regulated in accordance with the Community code for medicinal products as defined in Directive 2001/83/EC as amended.

Following collection from previously screened donors, individual donations are tested for the presence of viral markers. The donations then contribute to a plasma pool, which is also tested for viral markers.

Upon completion of manufacture, blood products are tested for compliance with specification by the manufacturer. In addition, before final release to the market, all batches of blood products undergo independent testing by EU 'Official Medicines Control Laboratories'

vCJD

Variant CJD remains a threat. It does not behave like a conventional (viral or bacterial) infectious agent, and there is currently no screening test available. We have implemented a

series of measures to protect the blood supply, and continue to monitor the situation closely, together with our expert advisory committees.

To further reduce residual vCJD and viral risk to haemophilia patients from donor-sourced products, we have made synthetic clotting factors available for all patients for whom they are suitable. We are providing £46million to the NHS in 2009/10 to help fund the purchase of clotting factors. The latest versions of synthetic clotting factors contain no human or animal derivatives and are therefore free from the risk of blood borne infection. Since their introduction into clinical practice world wide, there have been no confirmed reports of transmission of infectious agents by these products.

Support and services for those affected - the future

Previous Governments have introduced and funded ex-gratia payment schemes to provide financial relief for those affected. Those schemes have paid out a total of £142 million to patients and their dependents since 1988.

We are committed to ensuring that people with haemophilia, and others who have been infected with hepatitis C and/or HIV from blood and blood products are well cared for, supported in their communities and fully informed about how best to look after their health. We have carefully considered Lord Archer's recommendations, and are responding in as positive a way as possible at the current time, bearing in mind the constraints on public funds.”⁸⁵

⁸⁵ Department of Health, *Government response to Lord Archer's Independent report on NHS supplied contaminated blood and blood products*, 20 May 2009, pp 5-8

9.4 Labour Government response to the Archer Report – point by point response

“Recommendation 1 - A statutory committee to advise the Government on the management of haemophilia

We understand Lord Archer's desire to establish a committee by statute to advise Government on the management of haemophilia in the United Kingdom. Our view is that it is better to build on existing arrangements and expertise, rather than risk disrupting or duplicating those arrangements via legislation. We therefore intend to build on the existing UK-wide partnership of the Haemophilia Alliance, which consists of patients, haemophilia doctors, and others involved in their care. The Alliance is jointly chaired by the Haemophilia Society and the haemophilia doctors' organisation. We will invite the Alliance to meet with Government twice yearly and the Department of Health will host, and fund, these meetings. This will enable the Government to receive advice from the Alliance on matters relating specifically to the care of haemophilia patients. We will also ensure strong links are made between the Alliance and the independent advisory committee on the Safety of Blood Tissues and Organs (SaBTO). Representatives from the Health Departments in Scotland, Wales and Northern Ireland will be invited to participate in this new formal arrangement.

Recommendation 2 - Haemophilia patients and their partners to receive any tests recommended by the statutory committee

Any new relevant tests for transfusion transmitted infections would be offered to haemophilia patients, and their partners, in light of advice from the Haemophilia Alliance.

Recommendation 3 - All blood donors to receive the same tests (recommended by the statutory committee)

The independent advisory committee on the Safety of Blood, Tissues and Organs already advises on tests for blood donors and will continue to do so.

Recommendation 4 - Free prescriptions and free access to other services “not freely available under the NHS including...GP visits, counselling, physiotherapy, home nursing and support services” for those infected

The first part of this recommendation is in line with the Government's policy intentions on prescription charges in England. The Prime Minister announced last year that the Government intends to progressively phase out prescription charges in England for patients with long term conditions. We have asked Professor Ian Gilmore, President of the Royal College of Physicians, to undertake a review of prescription charges in England that will consider how to implement and phase in the Prime Minister's commitment. The review is due to report to Ministers in the Summer. We will consider what, if any, further action is required in England in relation to this recommendation following the Gilmore review.

GP visits, counselling, physiotherapy and home nursing are already available in England under the NHS where needed. The provision of non-residential social care services, such as domiciliary care, in England is a matter for local authorities. They have discretion over whether and how much to charge for services. However, DH statutory guidance to local authorities on charging for non-residential social care services already makes it clear that they should assess and take into account service users' specific needs and costs associated with their condition or disability. This would include any additional costs related to living with HIV or Hepatitis C.

Recommendation 5 - Secure future of Haemophilia Society by adequate funding

We will commit, with immediate effect, £100,000 per annum funding to the Haemophilia Society for the next five years. The Society is also due to receive £80,000 funding from the Department of Health over the next two years, and they will continue to be eligible for project-specific grants, along with other third sector organisations.

Recommendation 6 - Financial assistance should be increased and take the form of prescribed periodic payments.

The Macfarlane Trust and Eileen Trust provide ex gratia lump sum and discretionary payments to, respectively, haemophiliacs and others, who contracted HIV from infected blood and blood products, and their dependents. Over £45m has been paid out to date and there are currently around 600 beneficiaries. The Government recognises Lord Archer's concern about financial relief. We therefore intend to increase the funding available to the Macfarlane and Eileen Trusts to allow them to move to a system of annual payments for infected individuals. The current average annual payment is around £6,400. We intend that, in future, payments of £12,800 per annum would be made to each infected individual, thus eliminating the need for them to make repeated detailed applications. We will also increase the funding available to the Trusts so that the Trustees can make higher payments to dependents. Payment to dependents will continue to be decided on a case-by-case basis - and left to the decision of the Trustees.

The Skipton Fund provides lump sum payments to people infected with hepatitis C from infected blood and blood products. £97m has been paid out to date to over 4000 individuals. The Skipton Fund will continue to make payments to people infected with hepatitis C and I commit to reviewing it in 2014 when the Fund will have been in existence for ten years.

We will begin implementation immediately. We will need to amend the terms of the Trusts to permit these changes, but we will liaise with the Charity Commission and the Trusts themselves to ensure required changes to the Trust Deeds are made as quickly as possible to enable the Trusts to distribute this increased funding.

Recommendation 7 - Access to insurance by providing premiums or setting up separate scheme

The Association of British Insurers (ABI) has assured us that insurers do not treat haemophiliacs or those infected only with HIV or hepatitis C differently from people with other pre-existing conditions. In all cases, a person's insurability and level of premiums are determined through assessment of their individual risk. The increased payments we are making available will help people infected with HIV to meet higher insurance premiums they may face.

Recommendation 8 - A look back exercise to identify any others who may be infected

We commit to funding a look-back exercise this year for patients with bleeding disorders to identify any others who may be infected. The UK haemophilia doctors' organisation has confirmed they will undertake this exercise.”⁸⁶

⁸⁶ Department of Health, *Government response to Lord Archer's Independent report on NHS supplied contaminated blood and blood products*, 20 May 2009, pp 9-12

9.5 Ministerial Statement 10 January 2011 – Contaminated Blood

The Secretary of State for Health (Mr Andrew Lansley): With permission, I would like to make a statement on hepatitis C and HIV-infected blood.

What happened during the 1970s and 1980s, when thousands of patients contracted hepatitis C and HIV from NHS blood and blood products, is one of the great tragedies of modern health care. It is desperately sad to recall that during this period the best efforts of the NHS to restore people to health actually consigned very many to a life of illness and hardship. As the current Health Secretary, and on behalf of Governments extending back to the 1970s, may I begin by saying how sorry I am that this happened and by expressing my deep regret for the pain and misery that many have suffered as a result?

It is now almost two decades since the full extent of the infection was established and two years since the independent inquiry led by Lord Archer of Sandwell reported. The majority of Lord Archer's recommendations are in place, as are programmes of ex gratia payments, which are administered by the Macfarlane Trust and the Eileen Trust for the HIV-infected and by the Skipton Fund for those with hepatitis C. However, significant anomalies remain and I pay tribute to Lord Archer, to other noble Lords and to hon. Members in this place from all parties for highlighting them.

In October, the Under-Secretary of State for Health, my hon. Friend the Member for Guildford (Anne Milton), announced a review into the current support arrangements -to look at reducing the differences between the hepatitis C and HIV financial support schemes and to explore other issues raised by Members during the recent Back-Bench debate, including prescription charges and wider support for those affected. We also asked clinical experts to advise on the impact of hepatitis C infection on a person's health and quality of life and to consider whether an increase in financial support was needed. My hon. Friend the Under-Secretary has met representative groups to understand the impact that these infections were having on people's lives and has also met many Members of both Houses who have been strong advocates on behalf of those affected.

We have now considered the findings of the clinical expert group and we accept that the needs of those with advanced liver disease from hepatitis C merit higher levels of support. At present, the amount of money paid to this group depends on the seriousness of the infection. There are two stages at which the Skipton Fund will make a payment, the first of which is when the person develops chronic hepatitis C infection. At this point, a person is eligible for a stage 1 relief payment-currently a lump sum of £20,000. Some may reach a second stage of developing an advanced liver disease such as cirrhosis or cancer, or of requiring a liver transplant; they then become eligible for a stage 2 payment, which is currently another lump sum of £25,000. Under new arrangements that we will introduce, this second stage payment will increase from £25,000 to £50,000. This will apply retrospectively, so that if a person has already received an initial stage 2 payment of £25,000, they will now get another £25,000 lump sum, bringing the total to £50,000.

In addition, we will also introduce a new, annual payment of £12,800 for those with hepatitis C who reach this second stage. This is the same amount as those who were infected with HIV receive. Those infected with both HIV and hepatitis C from contaminated blood will now receive two annual payments of £12,800 if they meet the stage 2 criteria-one payment for each infection-along with the respective lump sums. All annual payments that are made, both to those so infected with HIV and to those with hepatitis C, will now be uprated annually in line with the consumer prices index to keep pace with living costs.

We know that some of those infected with HIV or hepatitis C from NHS blood and blood products face particular hardship and poverty. Those infected with HIV can already apply for additional discretionary payments from the Eileen Trust and the Macfarlane Trust, but no equivalent arrangements are in place for those infected with hepatitis C, so we will now establish a new charitable trust to make similar payments to those with hepatitis C who are in serious financial need. These payments will be available for those at all stages of their illness, based on individual circumstances. Discretionary payments will also be available to support the dependants of those infected with hepatitis C, including the dependants of those who have since died. Again, this will echo the arrangements in place for those infected with HIV and will enable us to give more to those in the greatest need.

We must also ensure that those infected through NHS blood and blood products get the right medical and psychological support. I can therefore announce two further measures. First, those infected with hepatitis C or HIV will no longer pay for their prescriptions. They will now receive the cost of an annual prescription prepayment certificate if they are currently charged for prescriptions. Secondly, the representative groups raised the issue of counselling support for those infected through blood and blood products. We fully recognise the emotional distress that they have experienced. As a result, we will provide £300,000 over the next three years to allow for around 6,000 hours of counselling to help those groups.

While we focus on those still living with infections, we must also recognise the bereaved families of those who have died. At present, no payment can be made to those infected with hepatitis C who passed away before the Skipton Fund was established. That is a source of understandable distress to those who survive them, and that is something that we now want to put right. I can therefore announce that, until the end of March 2011, there will be a window of opportunity in which a posthumous claim of up to £70,000 can be made on behalf of those infected with hepatitis C who died before 29 August 2003. A single payment of £20,000 will be payable if the individual had reached the first stage of chronic infection. Another single payment of £50,000 will be made if their condition had deteriorated to the second stage, in which they suffered serious liver disease or required a liver transplant. We will work with the Skipton Fund and various patient groups to publicise this new payment to those who may benefit. Those new payments, which will go to the individual's estate, should help more families to get the support that they deserve.

Taken together, these announcements represent a significant rise in the support available to those affected by this tragedy. Putting an exact figure on the package is difficult, as there is some uncertainty about how many people will be eligible, and how their illnesses may progress. However, we believe that the new arrangements could provide £100 million to £130 million-worth of additional support over the course of this Parliament. All payments will be disregarded for calculating income tax and eligibility for other state benefits, including social care. Although the changes apply only to those infected in England, I will be speaking to the devolved Administrations to see whether we can extend the measures across the United Kingdom.

Today's announcements cannot remove the pain and distress that individuals and families have suffered over the years, but I hope that the measures can at least bring some comfort, some consolation, and perhaps even some closure to those affected. I commend the statement to the House.⁸⁷

⁸⁷ [HC Deb 10 January 2011 c33](#)

9.6 Recommendations of the January 2010 Department of Health review

11.1 In deciding on an appropriate package of measures, the representations made by those affected have been considered together with the expert scientific evidence on the spectrum and impact of disease associated with hepatitis C infection, as well as the cost of the various options under consideration, and the affordability in the financial context of the current spending review, given the current fiscal context.

11.2 Based on these considerations, and the principles underpinning the review identified at paragraph 3.6, the following package of measures has been developed:

- i. Introduce a recurrent flat-rate annual payment of £12,800 for all living Skipton Fund stage 2 payment recipients.

Set up access to additional discretionary payments for those infected with hepatitis C by NHS-supplied blood transfusions and blood products, and for the dependants of infected individuals, including of those who have died, targeted at those in greatest need.

These measures will reduce anomalies with HIV payments. Those who have already received a stage 2 payment will start to receive recurrent payments as soon as the necessary arrangements can be put in place, backdated to the date of the announcement of this review report. New individuals who meet the Skipton Fund stage 2 eligibility criteria in future will receive the lump sum stage 2 payment and the first of the recurrent payments prospectively from the date of that payment.

Individuals who have been infected with HIV, and who have severe liver disease as a result of their hepatitis C infection, will receive two flat-rate annual payments of £12,800, one in respect of each infection.

- ii. Uprate levels of this new flat-rate recurrent payment for hepatitis C, as described in (i), and the existing payment for HIV, in line with the CPI annually, to keep pace with living costs.

Officials in HMRC and DWP have confirmed that continued exemption of all payments from tax and benefit calculations can be secured. It may take a little time to set up the necessary payment arrangements but all flat-rate recurrent payments will be backdated to the date of the announcement of this review report or the date of the making of a Stage 2 payment as appropriate.

- iii. Extend eligibility for stage 1, or both stage 1 and stage 2, payments, based on the eligibility criteria of the Skipton Fund, in respect of an individual who was infected with hepatitis C through NHS-supplied blood transfusions or blood products, but who died prior to 29 August 2003. Claims are to be registered by the end of March 2011.

- iv. Make a further payment of £25,000 to those who receive a Stage 2 payment from the Skipton Fund.

Patients who have developed hepatitis C-related B cell non-hodgkins lymphoma, will become eligible for a Skipton Fund stage 2 payment, as well as the additional lump sum of £25,000 for Skipton Fund stage 2 recipients.

This payment should also be applied in respect of individuals infected with hepatitis C through NHS-supplied blood or blood products who died before 29 August 2003.

v. Introduce application for a payment to cover the cost of an annual prescription season ticket for individuals infected with HIV and/or hepatitis C by NHS-supplied blood transfusions and blood products, so that those who are not otherwise exempt from charges will not have to pay for their prescriptions.

vi. Update the Social Care guidance to reflect regulations which exempt ex-gratia payments from means-testing for social care.

vii. Provide £100,000 per annum to selected third sector organisations over the next three years to provide additional access to counselling for individuals infected with HIV and/or hepatitis C by NHS-supplied blood transfusions and blood products.

11.3 There are no changes proposed to the mechanisms by which the ex-gratia payments are made. It is appropriate that the ex-gratia payment schemes should continue to be administered by the Department of Health, as the Department that works most closely with the NHS.

11.4 There is not a systemic issue with respect to access to dentistry for this patient group, so no changes are proposed.

11.5 The DWP has confirmed that those infected with HIV and hepatitis C by NHS-supplied blood transfusions and blood products are not exempt from the Work Capability Assessment.

11.6 Whilst it is recognised that some infected individuals might be uninsurable for some risks, a state run insurance scheme is not considered to represent value for money. Individuals for whom insurance is available have freedom to use the ex-gratia payments that they receive to help pay for the premiums.

11.7 The increased provision in the ex-gratia schemes could go some way to giving infected individuals and their families choice about how to tailor any nursing and social care needs over and above those freely available.

Conclusion

11.8 This package of measures, coupled with the support that is currently available to these infected individuals and DWP benefits that they are eligible for, is consistent with the evidence for greater support for those with hepatitis C, and their dependants. Importantly, it also removes the anomaly that prevents payments in respect of hepatitis C infection being unavailable in respect of those who died before 29 August 2003. Overall it is considered a balanced package of support, is within the range of the representations made by those affected during the course of the review, and given the current fiscal context, meets the principles set out for conduct of the review.⁸⁸

⁸⁸ Department of Health, *Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants*, 10 January 2011, pp 36-38