Witness Name: Andrew Michael March

Statement No: WITN1369014

Exhibits: WITN1369015-63

Dated: March 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN1369023

Scotland Project

An investigation of events leading up to an announcement by the Scottish Executive of a new support scheme for haemophiliacs and others affected by NHS-supplied contaminated blood products. The announcement was followed by a consultation launched by the Department of Health, detailing their preferred 'Option 2'. This reflects an entirely different mind-set which will result in much-reduced levels of support for the future. We believe this disparity will lead to grave unfairness, resulting in poverty and deprivation in the English group. A legal summary is included which will point to areas where we believe the Westminster response may be in breach of current UK and EU law.

Andrew March & Sue Threakall

June, 2016

Contents

Acknowledgements

We owe a debt of gratitude to the many people who have worked tirelessly for decades, resulting in the wealth of documents, letters, etc. that we have at our disposal today. For their diligence and determination, and in no particular order, we would like to mention these people:

- GRO-A, *Mark Ward, Ade Goodyear, Richard Warwick, Bruce Noval,* GRO-A GRO-A, *Andy Evans, Jason Evans and* GRO-A

Never forgetting the ongoing influence of those who are no longer with us, and whose memory and influence is with us every day:

- ***Gareth Lewis, Haydn Lewis, Mike Dorricott, Charles Loder and Gary Kelly***

Also:

- Su Gorman, for translation work
- Dr Peter Foster, for his invaluable insight into the Penrose Inquiry evidence
- Dan Farthing, for advice regarding the Scottish consultation process & scheme

Introduction

To date, over 2,000 haemophiliacs have died as a result of treatment with contaminated blood products supplied by the NHS. We believe that these deaths have occurred directly as a result of certain decisions made, or failure to be made, by or on behalf of, the British Government, agencies of the State and the United Kingdom Haemophilia Directors Organisation (UKHCDO). The direct consequences of these decisions were that almost 5,000 were infected with blood-borne viruses; namely Hepatitis B, C, and/or HIV, and others. More recently, due to the failure to learn lessons from past actions, over 4,000 haemophiliacs were exposed to vCJD.

This *en masse* infection has, in turn, led to the need for ongoing support systems. Whilst these schemes have historically been recognised as being inadequate and unfit for purpose, they have, nevertheless, been in existence since the late 1980's. The All-Party Parliamentary Group for Haemophilia & Contaminated Blood[1] acknowledged that the present system of support results in: ***'Many trust beneficiaries (living in) poverty.'***

The report recommended that:

> ***'The poverty line alone – even if it is made higher to account for someone's additional costs – is not a sufficient basis on which to set ongoing payments. Payments should be set at a high enough level for beneficiaries to live comfortably, at a level to be set by the public health doctor.'***
>
> **APPG Report**

[1] http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/appg_hcb_fr.pdf

In January 2015, during a parliamentary debate[2] on the issue, Alistair Burt MP stated:

> ***"My hon. Friend is right that many beneficiaries have expressed deep concern about the workings of the trust. The all-party group report that came out yesterday will be addressed by other colleagues. On the MacFarlane Trust in particular he should know that I share his concerns. I do not believe that that trust is salvageable or saveable, and I will speak about that later."***
>
> **Alistair Burt MP**

[2] Commons Hansard, 15 January 2015, Column 1027
http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150115/debtext/150115-0002.htm

Timeline of Events

1968	Cryoprecipitate discovered and used on all UK haemophiliacs
May 1968	DHSS/SHHD intention that Scotland would fractionate plasma for England[3]
1977	Working Group recommended 'complete transfer'[4] in the UK from the use of Cryoprecipitate to fractionated, freeze-dried concentrate.
1970s/1980s	Around 5,000 British haemophiliacs were infected with HIV, Hepatitis C and other viruses, as a result of infected blood products.
1988	The MacFarlane Trust was set up by the British government to support people with haemophilia who were infected with HIV as a result of contaminated NHS blood products, and their spouses, parents, children and dependants.[5]
1990-1991	HIV Haemophilia Litigation in which Scottish and English victims were awarded the same *ex gratia* payments - and were jointly required to sign waivers releasing the Department of Health from future litigation.
1999	The Scottish Parliament was established
2000	Landmark legal case, presided over by Justice Burton, concerning the Consumer Protection Act, Hepatitis C and the right to 'clean blood'.[6]
2003	The Final Report of the Expert Group on "Financial and Other Support", (a.k.a. 'The Ross Report') was published in Scotland[7]
2004	The Skipton Fund was established on 25 March 2004 by ***the Department of Health (England), acting for and on behalf of the Secretary of State for Health, the Scottish Ministers, the National Assembly for Wales and the Department of Health, Social Services and Public Safety (Northern Ireland)*** (together "the UK health administrations"), to administer the scheme and make payments to relevant claimants on behalf of each of the UK health administrations.

[3] Penrose Preliminary, Report, 5.10. http://www.penroseinquiry.org.uk/pdf/SNF0012412.PDF

[4] Self-sufficiency in Blood Products in England and Wales: A Chronology from 1973-1991. DOH (2006) (Dr R.S Lane. Implementation of the working party report on trends in the demand for blood products. July 1979.)

[5] http://www.macfarlane.org.uk/home.php

[6] *A and Others -v- National Blood Authority and Another* QBD 26 Mar 2001 http://www.bailii.org/ew/cases/EWHC/QB/2001/446.html

[7] Report of the Expert Group on Financial and Other Support, March 2003 http://www.gov.scot/Resource/Doc/47034/0024918.pdf

2005 Scottish Ministers have adopted the Skipton Fund as a scheme under Section 28 (Infection with hepatitis C as a result of NHS treatment etc.) of the Smoking, Health and Social Care (Scotland) Act 2005.[8]

2007 On 27th **March** 2007, the Archer Independent Inquiry began. Its 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"***.

2007 In **May** 2007 it was announced that Scottish Ministers had agreed to hold a Judicial Inquiry. A spokesman for the executive said:

"The Scottish government believes in a more accountable health service, and a public inquiry in Scotland to find out why people were infected with hepatitis through NHS treatment is the best way forward.

"Clearly, we will wish to assess the findings of the Archer inquiry before deciding exactly when and how to proceed."

2008 In April 2008, Nicola Sturgeon officially announced the Scottish Public Inquiry, which was to look into where NHS blood and blood products previously came from, whether they were effectively screened and whether heat treatment could have been introduced earlier. It would also probe the practices of the blood transfusion service at the time.

2009 In February 2009 we learned that over 4,000 British haemophiliacs had been exposed to vCJD the human form of ('mad cow disease') following treatment with contaminated blood products. All these haemophiliacs were subsequently placed on the 'At-Risk' register where they remain to this day.

2009 Also in February 2009, Lord Archer delivered the final report of his independent inquiry

2009 In November of this year, TaintedBlood announced that they had filed a claim form for Judicial Review of the Government's response to the Archer Report[9], in particular their reasoning for not implementing Recommendation 6h.

2010 Lord Morris of Manchester's Contaminated Blood (Support for Infected & Bereaved Persons) Bill received its first hearing in the House of Commons. On 5th March 2010, the Bill was blocked for the third time by the government, effectively meaning that it stood little chance of ever becoming law.

---

[8] http://www.skiptonfund.org/

[9] http://taintedblood.info/files/1245509047A5_Booklet_Comparison_Document.pdf

2010 The Judicial Review went to court and Justice Holman decided in our favour on 16th April 2010. The government was ordered to re-make their decision.[10]

2011 The Caxton Foundation started work. The foundation is a registered charity that was set up by the British Government to provide financial and other assistance to individuals who have been infected with the Hepatitis C virus as a consequence of receiving NHS treatment using contaminated blood, blood products or tissue. Caxton is funded solely by the Department of Health but as a charity is run by a board independent of the Department.

2015 Final Report of the Penrose Inquiry was published.[11]

2016 The Scotland Act[12] - making the Scottish Parliament and Government permanent and granting them substantial new powers.

[10] http://www.michelmores.com/what-we-do/client-stories/mr-justice-holmans-judgment-andrew-march-haemophilia-judicial-review

[11] http://www.penroseinquiry.org.uk/

[12] http://www.legislation.gov.uk/ukpga/2016/11/contents/enacted

Historical Context

Haemophilia is an inherited genetic condition whereby a protein in the blood which enables it to clot is either partly or completely missing. Depending on the amount of protein produced, haemophiliacs are generally divided into three groups; severe, moderate and mild. Further details and information can be found on the Haemophilia Society website.[13]

Prior to 1968 the only treatment for haemophilia was very primitive – essentially bed-rest, *hot and cold compresses, and sometimes experimental treatment such as snake venom.* Following the discovery of Cryoprecipitate,[14] things improved, and haemophiliacs were able to go into hospital to receive treatment for a bleed and thereby avoid the worst of the side-effects such as severe pain and swelling, and ultimately arthritis due to ongoing joint damage.

In 1977, a government working group made a decision[15] that was to have catastrophic effects on this small, fragile community. They recommended complete transfer from the use of cryoprecipitate to the new 'miracle' treatment: fractionated freeze-dried concentrate.

[Possible Insert?] What followed was a growth in the prophylactic home-treatment of haemophiliacs from 1976[16], but not everyone was convinced this was heading in the right direction.[17] In the witness testimony of Professor Forbes to the Penrose Inquiry, when asked why he thought some people appeared to have reservations about prophylaxis, he replied[18]:

> ***'I think the concern was that it was the huge amount of exposure to plasma products that it would entail.'***

The results of this decision are well documented, especially on the TaintedBlood Timeline.[19] To date there have been over 2,000 deaths due to contaminated blood products, and out of those co-infected with HIV and Hepatitis C, less than a quarter remain alive.

We believe that this scandal was avoidable to the extent it should never have happened. Warnings were ignored, haemophiliacs were used in trials, no attempt was made to protect

---

[13] http://www.haemophilia.org.uk/
[14] http://www.taintedblood.info/timeline.php#400
[15] http://www.penroseinquiry.org.uk/finalreport/pdf/LIT0013058.PDF
[16] Haemophilia A Home Therapy in the United Kingdom 1975-6, Peter Jones, Maureen Fearns, Charles Forbes, John Stuart. British Medical Journal, 1987, 1, 1447-1450
http://www.penroseinquiry.org.uk/finalreport/pdf/LIT0010258.PDF
[17] Witness Statement of Professor Forbes, Day 17, pgs. 56-57.
http://www.penroseinquiry.org.uk/downloads/transcripts/280411.PDF
[18] Penrose Inquiry, Final Report at [21.115]
http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_21.html
[19] http://www.taintedblood.info/timeline.php

them despite UK infections lagging behind those in the US[20], and at any stage manufacture of the much safer Cryoprecipitate could have resumed and full capacity achieved within days.[21]

For over three decades, since these infections were first acknowledged, all victims from the United Kingdom have been treated as one group. Ex-gratia payments have been made to them through the same trusts and funds, on an equal basis, irrespective of where they live. Now, following consultations in Scotland and from Westminster, it appears that a criterion previously not considered important – i.e. country of residence at the time of infection – is responsible for variations in payment which in many cases can be huge. For example, the English widow of a co-infected haemophiliac has been offered a choice of either continuing in the present scheme, with no guarantees of future top-up payments or grants (presently her income would be 'topped up' to around £19,000 p/a) or exiting from the scheme with a pay-off of only £5,000. By complete contrast the widow of a co-infected man who comes under the Scottish scheme will receive a pension-type payment of around £28,250, index-linked, for life, regardless of any other income. This is a differential of approximately £23,000 P/A. The disparity between payments from the two schemes is made even greater when one bears in mind the fact that the English scheme will result in drastic cuts, so many people will not even be at the level of income they are now. We believe the effect of the English plans, should they go ahead, will result in gross unfairness and discrimination, and this document sets out to explain our reasoning.

It should be noted at this point that, due to holidays, moving house, etc. it has not always been identified and proved categorically when and where individual infections occurred. It has been widely acknowledged that all haemophiliacs were exposed to Hepatitis C when first treated with concentrate, and again at every subsequent treatment, but this is less easy to identify in the case of HIV unless batch numbers and location of administration of product are available. Given that many medical notes have been destroyed over the years, the origin of any particular infection can, for many victims, only be based on an assumption, at best. It is perfectly possible that some co-infected may have been infected with HIV in one country and Hepatitis C in another!

We now find ourselves in a position where Scotland have formulated and agreed a new payments scheme[22] for victims infected whilst resident in Scotland, following a successful consultation period with them. If the proposals become policy, payments to most victims will be greatly enhanced, and, crucially, there is a stated commitment by Scottish officials to re-visit the scheme to improve on certain areas, since they have acknowledged that there is more work to be done. In complete contrast, Westminster has held a completely inadequate consultation resulting in many English victims potentially receiving far less money than their Scottish counterparts.

---

[20] http://www.taintedblood.info/tlfiles/MRC Minutes October 1983.pdf

[21] http://www.penroseinquiry.org.uk/finalreport/pdf/LIT0013058.PDF/
"Blood Transfusion for Clinicians" (1977), Dr John Wallace

[22] http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

Of particular relevance, in terms of historical context, are the following areas:

1. UK-wide Effects of Contaminated Blood

In the announcement made by the Scottish government, the following is stated under background[23]:

> ***"Infected blood products infected thousands of people in hospitals and clinics across the world during the 1970s and 1980s. The whole of the UK's NHS was impacted."***

Since the late 1980s, all haemophiliacs[24] throughout the UK have been treated identically in terms of the support offered to them and the criteria for accessing the varying levels of this support.

The circumstances behind infections were identical across the UK, and took place as a result of decisions made (or the failure to be made) in Westminster. The same ex-gratia payments scheme has been consistently and fairly applied to the entire UK group, regardless of any factor other than being infected by NHS-supplied contaminated blood and blood products.

2. Devolution

The people of Scotland first had an opportunity to vote in a referendum on proposals for devolution in 1979. Following a second referendum opportunity in 1997, this time on a strong proposal, there was an overwhelming 'Yes' victory, leading to the Scotland Act 1988[25] being passed and the Scottish Parliament being established in 1999.

Scottish voters were given the chance to vote 'Yes' on outright independence in a 2014 referendum. In an effort to persuade Scots to remain in the Union, the major UK parties vowed to devolve further powers to Scotland after the referendum. The 'No' vote prevailed (independence was rejected), but the campaign promise of devolution resulted in the formation of the Smith Commission and the eventual passage of the Scotland Act 2016, making the Scottish Parliament and Government permanent and granting them substantial new powers.[26]

---

[23] http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

[24] 'Haemophiliacs' should be taken as including others with a bleeding disorder and those undergoing long-term blood therapy, such as Thalassaemics.

[25] https://en.wikipedia.org/wiki/Scotland_Act_1998

[26] https://en.wikipedia.org/wiki/History_of_Scottish_devolution

It was clear from Scotland's White Paper[27] in 2003, that they were determined to try to improve the Scottish Health system by injections of funds:

> ***'We have already increased Scotland's health budget from £4.6 billion to £6.7 billion over the course of this Parliament. This will continue to rise by over 5% per year in real terms. National Insurance will increase by 1% in April – the Scottish Executive will use this extra money to fund a sustained increase in health spending.'***
>
> **Malcolm Chisholm, Minister for Health & Community Care**

Of particular importance to Scottish haemophiliacs since devolution, has been **The Barnett Formula.** Essentially, this is a system of grants which dictates the level of public spending in Scotland, Wales and Northern Ireland. Under it, extra funding - or cuts - from Westminster are allocated according to the population size of each nation and which powers are devolved to them.[28]

Interestingly, The Barnett formula is said to have "no legal standing or democratic justification" and, being merely a convention, could be changed at will by the Treasury. In recent years, Barnett himself has called it a "terrible mistake". In 2009, the House of Lords Select Committee on the Barnett Formula concluded that ***"the Barnett Formula should no longer be used to determine annual increases in the block grant for the United Kingdom's devolved administrations... A new system which allocates resources to the devolved administrations based on an explicit assessment of their relative needs should be introduced."***

Following the September 2014 Scottish Independence Referendum, the Barnett formula came to widespread attention amid concerns that in a last-minute government bid to sway voters against independence, Scotland had been promised continued high public spending.[29]

The Health System in Scotland

The National Health Service (Scotland) Act 1972 established the Common Services Agency for the Scottish Health Service[30] with effect from 1 April 1974[31]. This was provided for by Section 19 of the Act.[32]

---

[27] Scotland's Health White Paper, Edinburgh, February 2003. www.gov.scot/resource/doc/47032/0013897.pdf
[28] http://www.bbc.co.uk/news/uk-29477233
[29] https://en.wikipedia.org/wiki/Barnett_formula

The SNBTS came under the auspices of the CSA Management Committee.[33] The Scientific Director at the PFC was accountable to the Management Committee of the Common Services Agency (the 'CSA') until 1991.[34]

According to the Witness Statement John G. Davies given to the Penrose Inquiry, the Central Blood Laboratories Authority (CBLA) Central Committee on Research and Development in Blood Transfusion first met on 21 June 1983[35]:

> ***"The committee is described in the papers I have seen as replacing one under the MR6, and was clearly set up and run by the CBLA, an English special health authority, and not by DHSS. It does seem to have been seen by some, including the management of CBLA, as having a UK wide remit (see the minutes of the CBLA/CSA joint meeting of 20/1/1984..."***
>
> **John G. Davies**

3. Skipton Fund and Scotland

A submission[36] by the Skipton Fund to the Scottish Health Committee in March 2005 explained that the company was set up under the auspices of The Macfarlane Trust ("MFT"), a charity, founded in 1987. It is critical to note that the MFT is funded by the Department of Health. During the start of 2004, the Trustees of the MFT worked with officials from the Department of Health and from the devolved administrations to "*design both the operating procedures of the scheme and the administrative vehicle."*

> ***"Following protracted development with the four health administrations of operating procedures, in particular the criteria for determining eligibility for receiving payment and an application form to ascertain for each applicant whether these criteria had been met, Skipton started operations on 5 July 2004."***

---

[30] Penrose Preliminary Report at [5.23]
http://www.penroseinquiry.org.uk/preliminary-report/chapter-5/
[31] The Final Report of the Penrose Inquiry, Chapter 17 at [17.23]
http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_17.html
[32] The Final Report of the Penrose Inquiry, Chapter 17 at [17.23]
http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_17.html
[33] Penrose Inquiry: Witness Statement of John G. Davies
www.penroseinquiry.org.uk/downloads/transcripts/PEN0171020.PDF
[34] Penrose Preliminary Report at [5.8].
http://www.penroseinquiry.org.uk/preliminary-report/chapter-5/
[35] Penrose Inquiry: Witness Statement of John G. Davies
[36] Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence.
http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm

An agency agreement was subsequently drawn up which formalised the contractual arrangements between the Skipton Fund and the DoH (on behalf of the devolved administrations). By March 2005, the Fund had paid out to Scottish registrants, 428 "Stage 1" applications at £8.56m, and 50 "Stage 2" claims costing £1.25m. The total cost in relation to Scotland was £9.81m for 478 claims.

During the formation of the Skipton Fund in 2003, the Department of Health continued to act as agent to the devolved administrations in relation to the ex-gratia payments to Hepatitis C-infected individuals: [37]

> ***"The Skipton Fund was announced on 29 August 2003 to make payments to individuals infected by hepatitis C by NHS-supplied blood transfusions and blood products. It is a company limited by guarantee, acting as an agent of the Department of Health and the Devolved Administrations."***
>
> **DH Support Review – January 2011**

This important reference demonstrates that the Department of Health appeared to regard the Skipton Fund vehicle almost as an opt-in, opt-out arrangement. It is not entirely clear to what extent the devolved administrations could "choose" whether to be part of the Department of Health's arrangements. It does appear that from August 2003 a new "base position" formed whereby the other administrations of the United Kingdom could effectively opt out and do their own thing. To what extent was this ever an option before this time is unknown but can speculate that it may have come about from the devolved administrations gaining more power.

Following the report of the Lord Ross Expert Group[38], Mr Chisholm accepted in principle the recommendation that an exception should be made in the case of Hepatitis C-infected haemophiliacs on the grounds that payments had already been awarded for HIV infection, but then discovered that Scotland did not have the authority to make the payments that he was recommending. He had assumed that the financial bill would be met from the health budget (which had been devolved to Scotland), but was advised that such payments must be met from the Social Security budget (which was not devolved). This caused a mini-constitutional crisis which was eventually resolved by Mr Chisholm meeting with the relevant UK Ministers and he persuaded them to support his position. The outcome was the Skipton Fund.

---

[37] "*Review of the Support Available to Individuals Infected with Hepatitis C and/or HIV by NHS-Supplied Blood Transfusions or Blood Products and their Dependents.*" January 2011, "Ex-gratia payments to hepatitis C infected individuals" at 2.11, page 8.

[38] Report of the Expert Group on Financial and Other Support, March 2003 http://www.gov.scot/Resource/Doc/47034/0024918.pdf

The notion that residency (at time of infection or otherwise) is relevant to payment criteria has never once been suggested to or accepted by the victims themselves. Moreover, reviews to the scheme have always been applied across the board, payments levels have been identical throughout the UK and all payments have been administered by the same payment trusts and vehicles.

The current idea that Scotland can form its own payment scheme is inconsistent with historic practice and current knowledge of the devolved administration's financial arrangements. For example, welfare benefits have still not been formerly devolved. It has been suggested that either additional powers are now being given to the Scottish Government, or that the UK government has decided to shift responsibility for payment from the Social Security budget to the Health Budget.

4. Connectivity between England and Scotland

For many decades, England and Scotland have been treated in a conjoined way, particularly in relation to over-arching concerns, such as blood policy. Much of the UK policy, as dictated by the then DHSS, was propagated out to the equivalent body, the Scottish Home and Health Department (SHHD), who it seems, would generally adopt it. There are countless examples of this historic connectivity, which forms an established past practice of the two countries being treated the same way by Westminster. According to the Final Report of the Penrose Inquiry[39], the Secretary of State for Scotland, Scottish Health Ministers, and Scottish Home and Health Department Civil Servants had control of health care policy. However, it is not clear from this if the SHHD were simply controlling UK (DH) policy or if they had any statutory power to do things differently (prior to devolution).

As far back as May 1968, at a meeting in Edinburgh[40], there was a *very* early indication of the intention that Scotland would fractionate plasma for England. The DHSS (represented by Dr Thomson), the Scottish Home and Health Department (SHHD), Elstree and Edinburgh were present at this meeting:

> ***"Expected that the new Scottish Fractionation centre would be commission in June 1972 with an initial capacity of 1500 litres plasma per week but capable of being increased to 3000 per week."***
>
> ***"Agreed that the Edinburgh centre should be prepared to cope with the requirements of a larger part of England than originally intended."***
>
> **May 1968**

[39] Penrose Inquiry Final Report, Chapter 22 "Haemophilia Therapy - Use of Blood Products 1985-1987" at 17.93

[40] Penrose Preliminary Report, 5.10. http://www.penroseinquiry.org.uk/pdf/SNF0012412.PDF

Then in 1977, there was further mention by the then DHSS of making use of the processing facilities at Liberton, Scotland.[41] A discussion to this effect took place in the January 1977 meeting[42] of the Haemophilia Centre Directors held at the Middlesex Hospital, London. The supply of Factor VIII in England and Scotland was discussed as follows:

> ***"Prof. Blackburn said that it seemed as if the PFC at Liberton had capacity to supply factor VIII for the whole U.K. Dr Waiter said that in planning the supply of factor VIII, England, Scotland and Wales were all considered.***
>
> ***Plans had been made to divert plasma from South of the Border to Liberton and Mr. Watt was ready to receive it. The factor VIII made from this plasma would return to Centres south of the Border. Agreement in principle had already been reached between the DHSS in London and the Scottish Home and Health Department."***

Direct connection between the Treasury, London and the SNBTS and PFC:

In the late 1980s, the connectivity between Scotland and England was no more pronounced that in the direct dialogue between the Treasury, in London, and the SNBTS.

In a letter[43] of 5th February 1987, from the Treasury, Parliament Street, London, to Mr P. A. Brunning Esq., of the DHSS, under the subject heading "Clinical Trials of Factor VIII" we can see that discussions were well underway for the provision of a compensation scheme for haemophiliacs involved in clinical trials in Scotland:

> *"...I do accept, however, that there is a very real problem in Scotland, where the NHS is totally dependent on the new product being made available and that,* ***whether one accepts the principle of compensation arrangements for Factor VIII or not, it is clear that without them the clinical trials on the new product will not be possible..."***
>
> **Treasury Chambers – Parliament Street, London – 5 February 1987**

[41] Haemophiliac HIV Litigation, Advice on Settlement Document, Appendix 1, Chronology, pp 56-58.
[42] Minutes of the meeting of Haemophilia Centre Directors of the United Kingdom. 13th January 1977, Middlesex Victoria Infirmary London. Agenda item 3, point 3, pgs. 12-13 headed: "Activities of Reference Centre Directors and the supply of Factor VIII"
[43] Letter from Treasury Chambers, Parliament Street, London, to Mr P. A. Brunning Esq., DHSS. 5th February 1987. www.penroseinquiry.org.uk/downloads/transcripts/SGH0031871.PDF

In the Minutes[44] of a Meeting of the Blood Transfusion Service Sub-Committee of 25th February 1987, we can see that a compensation scheme in Scotland had been approved with the Treasury in London, in certain exceptional circumstances, but they were clearly also looking at a UK-wide compensation scheme for haemophiliacs involved in trials:

> ***"We were able in fact able to get Treasury approval for such a compensation scheme in time** (though it was a close-run thing). Dr Cash has now written to me asking if we can agree a scheme for compensation to cover all clinical trials of all PFC products. **I shall pursue this with medical colleagues and DHSS as it will need to be a UK scheme. We will need to approach Treasury with some care however, as we got approval to the Factor VIII compensation scheme on a somewhat exceptional basis** (to meet admittedly exceptional circumstances) and we would not wish our Treasury colleagues (who were indeed helpful) to feel that we had conned them into a precedent..."*
>
> **BTS Minutes – 25 February 1987**

5. Scope of the UKHCDO

The Haemophilia Centre Director's Organisation (HCDO, now UKHCDO) was established in 1968 and was composed of members of the medical profession who worked within Haemophilia Centres throughout the United Kingdom.[45] The organisation was not a government advisory committee, rather an *ad hoc* group of professionals working together within the ambit of which the body was comprised. However, we know that DHSS observers regularly sat in on the meetings, as did SHHD observers[46].

With reference to the minutes of the UKHCDO[47] it can be seen that Civil Servants (from across the UK) attended. As the title implies, there was representation from Scotland in the form of haemophilia doctors, Civil Servants and representatives of the SNBTS. Haemophilia Doctors from Scotland (Dr Forbes[48], Professor Ludlam[49]) have chaired UKHCDO.

---

[44] Minutes of a Meeting of the Blood Transfusion Service Sub-Committee on Wednesday, 25th February 1987, under (b.). www.penroseinquiry.org.uk/downloads/transcripts/SGH0031855.PDF

[45] Penrose Preliminary Report, September 2010, at 3.101

[46] Minutes of the HCDO (Haemophilia Reference Centre Directors Organisation), dated 13th May 1983, Dr. Diana Walford present as Departmental (DHSS) Observer.

[47] Minutes of the Tenth Meeting of the U.K. Haemophilia Centre Director, held in Oxford on 20th & 21st November, 1979, Dr Diana Walford (DHSS) was in attendance; also Minutes of the HCDO (Haemophilia Reference Centre Directors Organisation) 13th May 1983, Dr. Walford was DHSS observer.

[48] Minutes of the 19th Meeting of the UK Haemophilia Centre Directors, Royal Free Hospital Medical School, Friday, 25th September,1987. http://www.penroseinquiry.org.uk/pdf/SNB0017768.PDF

[49] Haemophilia (1977), 3, 63-77. http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2516.1997.00073.x/abstract

The national, cross-border influence of the UKHCDO policy can be seen in the following statement made by Professor Ludlam in a witness statement to Penrose of August 2011:[50]

> ***"The policy adopted in Scotland was as set out in the 14th December 1984 UKHCDO circular by Professor Bloom."***

Professor Arthur Bloom was chairman of the UKHCDO until December 1985[51], therefore he was chairman at the time of this December 1984 circular.

Some of the HCDO meetings, for example, in September 1982, would have representatives of a national institute, such as NIBSC (Dr. T. W. Barrowcliffe, Mr. G. Kemball Cook, Mr A. D. Curtis) in attendance with representatives of the Blood Products Laboratory, (Dr T.J. Snape and Dr R. S. Lane) as well as representation from Scotland, (Dr F.E. Boulton, Edinburgh B.T.S., Dr C. D. Forbes, Glasgow Royal Infirmary, and Dr C. A . Ludlam, Royal Infirmary, Edinburgh.)[52]

6. Licensing Arrangements - UK Ambit

According to the Medicines Act of 1968, manufacturers of plasma products were legally required to be licensed to market products in the U.K. Manufacturer's Licenses and Product Licenses were granted for this purposed by the Medicines Division of the DHSS.[53]

The influence of the Department of Health at this time can also be seen clearly when we look at bodies such as the Medicines Control Agency (MCA) (now MHRA) which is a UK-wide regulatory authority with the power to approve or reject drug applications. The licensing of the Protein Fractionation Centre (PFC) and its products came under the auspices of the MCA regulatory body in the past, and continues to today.

For example if we look at the quote below[54], it is clear that the MCA was able to scrutinise regulatory activities in Scotland.

---

[50] Penrose Inquiry Final Report, Chapter 22 "Haemophilia Therapy - Use of Blood Products 1985-1987", "Edinburgh" at 22.23 http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_22.html Witness Statement of Professor Christopher Ludlam to Schedule issued on 23rd August 2011, related to topic C3A: http://www.penroseinquiry.org.uk/finalreport/pdf/PEN0171790.PDF

[51] Minutes of the 16th Meeting of the UKHCDO. 21 October 1985 http://www.taintedblood.info/tlfiles/UKHCD Minutes 21 Oct 1985.pdf

[52] Minutes of the 13th Meeting of UKHCDO, University Hall of Residence, Owens Park, Manchester. Monday 13th September 1982. Pgs. 1-3.

[53] "Licensing of PFC and its Products During the Period 1976-1990: A Briefing Note, dated 20th December, 2005. Page 1.

[54] Ibid.

> ***"The purpose of this briefing note is to identify those aspects of the PFC operation which were approved by the UK regulatory authority and to explain why these activities were subjected to regulatory scrutiny despite there being no legal requirement to do so under Crown Immunity."***

According to the above-referenced Briefing Note on the operation of PFC, we can see that, historically, the MCA, based in England, licenced both unheated Factor VIII and Factor IX concentrates even though they turned out to be "***the PFC products with the greatest risk of HCV transmission***".[55]

A further example of the UK-wide unity over standards can be found in the following statement taken from a bullet point list in a SNBTS letter sent out in May 1991:

> ***"The SNBTS conforms to the high safety standards laid down for all transfusion services in the UK."***

7. Post-Devolution Commonalties

Even post-devolution, there is still a great deal of common policy, such as the provision of blood products, blood safety, licensing, product recalls and notifications. There was certainly no attempt to set up a separate scheme for Scottish victims as part of Scotland's new powers and financial freedom concerning Health.

In a submission made by the Scottish Haemophilia Forum[56], it is clear that the Scottish Haemophiliacs were not at all happy with what took place leading up to the setting up of the Skipton Fund. They believed that the Skipton Fund only came about as a direct result of their campaigning in Scotland and all the work done by the Scottish Parliament, which included a Motion supported by 80 MSPs from all parties, was "hi-jacked" by Westminster.[57] The Ross Report[58] was published in March 2003 and a comprehensive list of recommendations had

---

[55] Ibid. Page 3, at [4.1].
[56] Submission by the Scottish Haemophilia Forum, Philip Dolan, Chairman. Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence.
http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm
[57] Ibid. at Para 2. (Scottish Haemophilia Forum Submission).
[58] Lord Ross, Chair of the Expert Group on Financial and Other Support, March 2003, pgs. 8-10.

been made. Most notably, Recommendation 1C, stipulated that anyone who subsequently suffered a serious deterioration in their physical condition because of their Hepatitis C infection e.g. cirrhosis or liver cancer, should be entitled to full compensation calculated on the same basis as common law damages.[59] It was not surprising, therefore, that Westminster promptly acted in order to stymie the implementation of these proposals. When Malcolm Chisholm made the announcement on the 29th August 2003, that he would be making ex-gratia payment of £20,000, this was soon followed by another announcement as John Reid, Health Minister said that Westminster would be following Scotland's example.

> ***"Regrettably this announcement stated that the dependants of those who had died prior to 29th August 2003 would be excluded."***
>
> **Scottish Haemophilia Forum**

A series of meetings was hastily convened by the Department of Health which were attended by senior Civil Servants from each of the four countries of United Kingdom, the Chief Executive of the Haemophilia Society, the Chairman of the Scottish Forum, the Chief Executive of the MacFarlane Trust and representatives from two other organisations.
It was clear to the Scottish Haemophilia Forum members that right from the outset, there had been some sort of prior discussions between the civil servants from the Department of Health and the Chairman and Chief Executive of the MacFarlane Trust. In the words of the Forum submission, "...the meeting was faced with a *fait accompli* that the MacFarlane Trust take on the responsibility of administering the now to be known as the Skipton Fund."[60]

> ***"At this first meeting despite requests that a minute of the meeting be taken, this was resisted by the Civil Servant from the Department of Health who undemocratically took the role of chairman."***
>
> **Scottish Haemophilia Forum**

By the time of the meeting of 26th March 2004, the Skipton Fund had been registered as a private company, without any consultation and had appointed four directors all whom were trustees of the MacFarlane Trust.[61]

---

[59] Ibid. at page 8, Recommendation 1C.
[60] Submission by the Scottish Haemophilia Forum, Philip Dolan, Chairman. Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence.
http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm
[61] Ibid. at Para 4. (Scottish Haemophilia Forum Submission).

8. vCJD Product Recall and HPA Notification

In 2004, the same year that the Skipton Fund came into operation, the Health Protection Agency at Colindale, (HPA) issued a notification[62] which included a table of batch numbers of vCJD-implicated plasma-derived products and as expected, Scottish PFC product was on the list. In the accompanying table of products where the likelihood of a recipient surpassing the threshold dose for public health purposes is "High", it states that:

> ***"These batches should be traced, the individual recipients considered 'At-Risk' of vCJD for Public Health Purposes, and special Public Health precautions taken."***
>
> **HPA Colindale – September 2004**

The list deals with English-manufactured product from BPL just as it does the Scottish-manufactured product Z8 from July and August 1987, of which there were two batches (#0301-70320 and #0304-70510), which together comprised 250 vials of vCJD-implicated material. This is another clear example of the UK being dealt with in a unified way.

[62] Health Protection Agency Colindale (HPA), "vCJD and Plasma Products - Tables of vCJD implicated batch numbers", 7th September 2004. Note: Products manufactured by the Protein Fractionation Centre, Scotland are designated 'PFC'.

Cross-Border Product Supply

We have long suspected that Scottish-manufactured clotting concentrates moved across the border to meet supply demands in England, Wales and Northern Ireland. We can now confirm that this was the case. We know of examples of Scottish product (PFC Edinburgh's Z8) being used in Oxford[63] and also in Wales. Similarly, products manufactured in England such as BPL's 8Y was shipped to Edinburgh[64].

The following are examples of cross-border product supply:

1. During the 1960's the early FVIII (AHF) prepared in Edinburgh was sometimes sent to Newcastle.

2. In 1983 SNBTS began contract fractionation for N. Ireland. This would have involved BPL, Elstree.

3. In 1984, some SNBTS FVIII concentrate was sent to England as Scotland had a surplus (which would have otherwise outdated), whereas England was importing about half of its FVIII from the USA. This was sent directly to BPL who arranged its distribution.

4. In Aug 1986, a small quantity of 8Y was obtained for use in Scotland (at the request of Dr Ludlam), pending the introduction of the equivalent SNBTS product.

5. In the early 1990s, high purity FIX was obtained from BPL by Scotland's haemophilia directors, pending completion of the development of the equivalent SNBTS product.

"As previously noted, there appears to have been no use of the English heat-treated Factor VIII product, 8Y, in Glasgow. But it was used in Edinburgh. It is therefore necessary to consider the background to the use of English product to treat patients in Scotland."

"8Y was treated at 80°C for 72 hours. It was issued routinely for the treatment of patients with haemophilia in England with effect from September 1985. The Inquiry was interested to ascertain when clinicians in Scotland became aware of this product, and what view they took of it."

Penrose Inquiry

[63] Memorandum of the Oxford Haemophilia Centre (Oxfordshire Health Authority) to All U.K. Haemophilia Centre Directors, "Trials of 'Hepatitis Reduced' Factor VIII - An Update", dated 29th March 1984.
[64] http://www.penroseinquiry.org.uk/finalreport/pdf/SNB0075982.PDF

In the Final Report of the Penrose Inquiry, under the heading "Emerging information about Safety", we learn that 8Y, an English heat-treated Factor VIII product was being used in Edinburgh.

We acknowledge that there would be an obvious difference between the one-off, limited transfer of clotting concentrates across the border and routinely supplying English-manufactured product to Scotland. However, even with occasional use of this practice there is added uncertainty about which product a person was infected by.

In a letter[65] of July 1986 from BPL to the PFC, it is clear that BPL were involved in the provision of 8Y material for trials involving "Virgin" haemophiliacs in Scotland and Northern Ireland. On page 2, there is a rather serious revelation about the status of the source material: "***There is one point, however, that you need to consider. Current batches of 8Y on issue, are not made from certified anti-HIV screened donations. The first individually screened product will not be released for issue until August...***"[66]

The DHSS were clearly tied -in to this, as the letter mentions them in terms of a written reply and two Parliamentary Questions which had been submitted on this problem in relation to both Elstree and PFC.

Then in a further letter of 24th July[67], we can see BPL confirming the supply of 50 vials of their 8Y Factor VIII product to the Protein Fractionation Centre in Scotland:

> ***"I have now confirmed that BPL are happy to supply 50 vials of 8Y to PFC on the understanding that, in the event that the material is used in suitable virgin patients, appropriate serial samples would be taken to contribute to their overall infectivity study."***

The Final Report of the Penrose Inquiry discusses the relationship between the SNBTS and NBTS in the context of cross-border supply of products[68]:

"The cross-border supply of therapeutic products for routine use for any class or classes of patients raises issues about the general relationships between Scottish fractionators and the SNBTS on the one hand and English fractionators and the NBTS on the other that are materially different from the transfer of materials for specific or limited use. When an official request was made for a limited supply of 8Y, arrangements were made, subject to conditions.

---

[65] Letter from N. Pettet, Product Services Manager, Blood Products Laboratory (BPL) to Dr R. J. Perry, Director, PFC, Edinburgh. 24 July 1986. http://www.penroseinquiry.org.uk/pdf/SNB0075980.PDF

[66] Ibid. at page 2

[67] http://www.penroseinquiry.org.uk/finalreport/pdf/SNB0075982.PDF

[68] The Penrose Inquiry, Final Report, Chapter 22: "Haemophilia Therapy - Use of Blood Products 1985-1987", "Supply of 8Y for Scotland" at 22.102.

***Professor Ludlam was also able to obtain some 8Y from Newcastle**, he thought probably on a personal approach to the haemophilia director there.[69] In one sense these two events show that, in absolute terms, **it was possible to obtain some supplies of 8Y for use in Scotland.**"*

Evidence to the Penrose Inquiry from Professor John Cash[70] illustrates very clearly that in 1983/1984 in particular, surplus Scottish product was routinely sent to England for use on their haemophilia patients:

> *"**We had surpluses of the product in 1983/1984 that we produced, and we sent a lot of that surplus down to England**, but in my view, in discussion with clinical colleagues -- and I was well aware of this when I worked in the Edinburgh centre -- there was the odd patient, haemophilia patient, you put in the NHS stuff and they reacted to it."*
>
> **Professor John Cash**

This evidence is particularly important since it is commonly accepted that this was the period when most haemophilia HIV infections occurred. It is accepted that haemophiliacs almost certainly contracted Hepatitis C with their first exposure to concentrate, and were re-exposed with every subsequent treatment, but the time of infection with HIV is less clearly defined and therefore harder to pin down to any particular treatment. In many cases hospital records have been destroyed, so for those who were treated both North and South of the border it is almost impossible to say whether the infected product originated in Scotland or England. Furthermore, all the efforts being made by certain physicians to keep patients consistently on one batch of product were clearly being undermined by this practice.

NOTE: We find it hard to believe that Westminster would consider sanctioning different payment systems within the UK after so many years. To do so on the basis of where patients lived, as opposed to the products prescribed to them, or the treatment centre they used, is difficult to comprehend. It is more than possible that patients both North and South of the border were infected by the same batch numbers of product, which makes a complete mockery of this method of achieving an eligibility threshold.

---

[69] Ibid. Footnote: Professor Ludlam - Day 55, page 120. The Inquiry subsequently learned that this supply appears to have been arranged via Dr Boulton - see letter of 24 August 1987, [PEN.019.1535]. The letter indicates that Dr Boulton was exploring the possibility of obtaining a regular supply of 8Y from England.

[70] http://www.penroseinquiry.org.uk/downloads/transcripts/130511.PDF

Blood from Scottish Prisons:

We know that up until 1984, Scottish prisoners donated blood for transfusions, despite concerns that the practice was unsafe[71] and Medicines Inspectors had commented adversely on the collection of prison blood as far back as 1982.[72] Blood was also being collected from Borstal Institutions.[73]

Scottish Prison blood used in England

In the early 1980's, prison blood was being used by Scottish Transfusion Centres with at least some English Blood Transfusions Centres also receiving blood sourced from Scottish prisons and Borstal Institutions. On 27th July 1983, the then DHSS issued a circular in which the Medicines Division's Inspection Action Group raised concerns about the collection and use of blood from borstal institutions and prisons, yet the practice continued for at least another year. The involvement of the DHSS and English Transfusion Centres identifies the issue of prison blood not just being a Scottish issue, but one that was shared with England.[74]

---

[71] http://news.bbc.co.uk/1/hi/scotland/4201253.stm

[72] Correspondence to Fergus Ewing, MSP from Andy Kerr MSP, the then Minister for Health & Community Care. Dated 6th March 2005. Also: BBC Frontline Scotland - Blood and Tears (2005).

[73] Scottish National Blood Transfusion Service, Minutes of Directors' Meeting, SNBTS Headquarters Unit. 29 March 1983)

[74] DOH Freedom of Information Documents Released July 2007. Volume 30, page 2.

The Penrose Inquiry

On 28th April 2008, the Scottish Minister for Health & Wellbeing, Nicola Sturgeon, announced that there was to be a Public Inquiry into Hepatitis C/HIV acquired infection from NHS treatment in Scotland with blood and blood products. The inquiry was set up by Scottish Ministers under the Inquiries Act 2005, and its Chairman was the Rt. Hon Lord Penrose.[75] There were twelve terms of reference,[76] all of which involved HIV, Hepatitis C, or both.

Although the inquiry investigated events in Scotland, because of the cross-border nature of what happened, and the events that led to the infections, much of the evidence was naturally relevant to the parallel situation in the rest of the UK. This was acknowledged on several occasions by the Westminster government. Indeed, it was clear that they fully understood the possible implications of the inquiry, even to the extent of using it as a valid reason to delay the consultation on a new support system in England:[77]

> ***"We had hoped to consult during this Parliament on reforming the ex-gratia financial assistance schemes, considering, amongst other options, a system based on some form of individual assessment. However, I felt that it was important to consider fully Lord Penrose's report before any such consultation. Given its publication today, we clearly are not in a position to launch a consultation, on one of the last sitting days of this Parliament."***
>
> **Jeremy Hunt – Written Ministerial Statement – 25 March 2015**

In a press release[78] to mark the conclusion of the Penrose Inquiry public hearings, TaintedBlood stated:

> ***'It is already clear that the Westminster Government's assertion that "there is nothing new to learn" and that "all evidence is now in the public domain" is simply wrong...***
>
> **TaintedBlood – March 2012**

[75] http://www.penroseinquiry.org.uk/
[76] http://www.penroseinquiry.org.uk/terms-of-reference/
[77] Written Ministerial Statement- 25th March 2015
[78] http://www.taintedblood.info/news.php?mode=article&newsid=270

> ***...We wish to stress that although Lord Penrose's Inquiry is concerned primarily with how the disaster unfolded in Scotland, it is impossible to extricate the contributing decisions made by Ministers and government officials in Westminster during that pre-devolution era.'***
>
> **TaintedBlood – March 2012**

The Prime Minister himself reassured the House regarding the seriousness the government was applying to the Penrose Inquiry when, on 25th March 2015, he stated that:

> ***'I commit that, if I am Prime Minister in May, we will respond to the findings of this report as a matter of priority.'***
>
> **David Cameron – 25 March 2015**

Also on 25th March, 2015, Jane Ellison, the Under Secretary of State for Health commented[79]:

> **"The apparent thoroughness of Lord Penrose's report and the fact that it sets the events in Scotland in a wider UK context gives us a sense of the fact that he has looked at these events in the widest possible way, including for England. He has done a thorough job of examining the facts, and we now for the first time ever have that detailed authoritative narrative account of what happened, and that is an important building block on which the next Government can take their policy forward."**
>
> **Jane Ellison – 25 March 2015**

Indeed, she also gave a very clear indication[80] that there was to be a formal response from government early on in the next parliament:

> ***"The Prime Minister also said yesterday that if he was still Prime Minister after the election in May, his Government would respond to the findings of the report as a matter of priority."***
>
> **Jane Ellison – 25 March 2015**

[79] https://hansard.parliament.uk/Commons/2015-03-26/debates/15032622000002/PenroseInquiry
[80] https://hansard.parliament.uk/Commons/2015-03-26/debates/15032622000002/PenroseInquiry

Following these reassurances, and apparent understanding of the far-reaching effects of Lord Penrose's report, there then appears to have been a U-turn in the government's thinking. Having given us every indication that they would be presenting a full report on the findings of the Penrose Inquiry, they then all but dismissed its impact and changed their official line, as illustrated by Jane Ellison's answer to a question by Stephen Kinnock MP on 29th February 2916:

Stephen Kinnock Labour, Aberavon:

To ask the Secretary of State for Health, with reference to the Prime Minister's oral statement of 26 March 2015, Official Report, column 1423, on the Penrose Report on contaminated blood, when the Government plans to respond to the findings of that report.

Jane Ellison The Parliamentary Under-Secretary of State for Health:

Lord Penrose made one recommendation in the Final Report, to 'take all reasonable steps to offer a hepatitis C test to anyone who had a blood transfusion before September 1991 who has not been tested for hepatitis C' through reminding general practitioners, nurses and other clinical staff of this matter, along with the National Health Service guidance to offer a hepatitis C test to those who may be at risk.

The Penrose Inquiry was set up by the Scottish Government and so there is no requirement for the Department in England to provide a formal Government response to the final report published on 25 March 2015. We have, however implemented the recommendation in the Penrose Report by issuing reminders as recorded in the Written Ministerial Statement made on 20 July 2015 (Official Record HCWS146) and **addressed in the Contaminated Blood Products debate (HC Deb, 9 September 2015, c86WH).**

There was no question that between 2013, and 2015, the Department of Health made comments that worked towards building expectation among the haemophiliac community in relation to Penrose, and all eyes were turned to Scotland in expectation of the conclusion of the Inquiry.

As far back as October 2013, Jane Ellison acknowledged in Hansard[81] the possibility of implications in light of the Inquiry considering pre-devolution matters:

> **"Given that Lord Penrose is considering pre-devolution matters, it is hard to imagine that there will not be implications to which I and the Department shall need to respond. We do not know the exact shape of things, but the inquiry is on my radar, and we shall be considering it."**
>
> **Jane Ellison – 29 October 2013**

However, as the culmination to the Penrose Inquiry approached, the Department of Health seemed to vacillate over its importance and the significance of the Final Report. They appear to adopt a "take-it or leave-it" approach to the Inquiry by directing the community to it when it suited them, or playing it down, when this was more convenient for them.

The position, since at least January 2015, appears to be that the Department of Health now believe that the Penrose Inquiry was sufficiently thorough to have somehow negated the need for an inquiry in England[82]:

> ***"Given the thoroughness of Lord Penrose's report, published in March 2015 and the fact that the report sets the events in Scotland in the wider UK context at that time, our view remains that there is no need for a further public inquiry in England. The report, together with over 5,000 documents from the period 1970-85 that have already been published by the Government, provides a comprehensive picture of events and decisions made..."***
>
> **Jane Ellison – Written Answer – 22 January 2016**

---

81 http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm131029/halltext/131029h0001.htm#131029h0001.htm_spnew32

82 Blood: Contamination: Written question – 22352, Answered by Jane Ellison. 22 January 2016. http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-01-13/22352

Similarly, we know from a recent legal challenge, to which TaintedBlood were advisers, that the legal team for the Department of Health made the case that the proceedings of Penrose had discharged their enhanced obligations under Article 2 (Right to Life). They stressed that the Scottish Inquiry had managed to investigate any systemic issues in relation to the UK, and that, by proxy, this had satisfied their obligations under Article 2, and that a judicial inquiry in England was no longer necessary.

We would therefore suggest that the government have deliberately changed their stance on the Penrose Inquiry in order to avoid having to make a full report which would cause them to have to deal with the ramifications of evidence contained within it. This is almost certainly because they are aware it addresses such issues as: non-consensual trials on haemophiliacs, breach of the Nuremburg Code, and complete failure to investigate why self-sufficiency was never achieved in England and only for a brief time in Scotland. This is beyond unacceptable and represents the breach of a promise and the misleading of both our community and Parliament itself.

The Scottish Scheme

On 18th March 2016, the Scottish Government made an announcement[83] about its new scheme. The announcement included:

> ***"Today the Scottish Government also confirmed a new Scottish scheme will be established for people who became infected with HIV and hepatitis C after treatment in Scotland, and their dependents. Current support packages for those affected by infected blood are delivered through UK-wide schemes."***

The Recommendations were as follows, and display a stark contrast to Westminster's preferred 'Option 2', under which the majority of victims will face a future of uncertainty, and, for many, the likelihood of poverty:

Scottish plans	DoH proposals for England	Implications for victims
• Annual payments for those with HIV and advanced hepatitis C will be increased from £15,000 a year to £27,000 a year, to reflect average earnings	Existing support to be raised by approximately £250 to £15,000 per year, but capped at this level, existing link to consumer price index being dropped	After this one-off increase to the annual payment, effectively a big cut in support to sufferers for the future as will be no uprating. Also with the cutbacks to discretionary payments, some victims will lose out thousands of pounds. The contrast in approach from the Scottish and Whitehall governments is immense.
• Those with both HIV and hepatitis C will have annual payments increased from £30,000 to £37,000 to reflect additional health needs	No extra payments planned for those with both HIV and hepatitis C except that those with hepatitis C at stage 1 will have access to annual payments for the first time subject to individual assessments and the possibility of access to new treatments.	Little new recognition of extra support needs is given by Whitehall and again the regular annual payment will be frozen. The individual assessment costs will eat into the extra budget proposals.

[83] http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

• When a recipient dies, their spouse or civil partner will continue to receive 75 per cent of their annual payment	A one-off payment only for partners or spouses for existing bereaved is proposed of only £5,000 or 3 x existing support payment, whichever is the greater and then exit from the scheme. The only alternative is to keep to existing discretionary support, which the Government acknowledges many are dissatisfied with. It appears it will not apply to those who don't receive support payments at present, many have not applied as means-tested. For newly bereaved there will be one off full payment of partner's existing support and then exit from the scheme.	Hundreds of widows in particular rely on regular support and this minimal one off payment will not help them with housing or other needs. Many were left destitute by the loss of their husbands. The kind of sums involved will not provide closure to their loss and suffering. Within the consultation paper there is acknowledgement that many beneficiaries dislike the principle of applying for charitable payments that are means-tested. The Scottish approach avoids this.
• Those infected with chronic hepatitis C will receive a £50,000 lump sum payment (previously £20,000), meaning an additional £30,000 for those who have already received the lower payment	At present those with stage 1 hepatitis C receive £20,000 and there is available an additional £50k for very stringent conditions of advanced stage 2 chronic liver disease/cirrhosis. The consultation queries views on the retention of the latter.	A lot more people will qualify for the Scottish proposals than for the English. It is more generous for a wider group of people. The Scottish Government intends to continue reviewing the need for ongoing payments for this group.
• A new Support and Assistance Grants scheme will be established in Scotland, to administer and provide more flexible grants to cover additional needs. Scottish Government funding for this scheme will be increased from £300,000 to £1 million per year.	Existing failing support organisations likely to be merged into one in England. Other details to follow. The proposal is to remove all discretionary payments except for travel and accommodation grants linked to ill-health.	The Scottish scheme will cater for wider elements of ill-health that on-going payments are unable to meet. It is a more generous supportive scheme than that available through Westminster even at present.

Following the Scottish announcement, and in an atmosphere of disbelief and despair among haemophiliacs *south* of the border, TaintedBlood issued a press release, which stated:

> ***'Tainted Blood today vowed to fight on to win at least parity with the Scottish plans to support contaminated blood victims announced today, which reveal the present Department of Health consultation proposals to be derisory and shameful.***
>
> ***TB Chairs*** GRO-A ***and Sue Threakall said: "We wish to commend Scottish Health Secretary Shona Robinson on her firm commitment to resolving the contaminated blood scandal, and for the fact that she has stuck to timetable of events and to her word.***
>
> ***"Unlike in England it is clear that victims in Scotland have been listened to, and that evidence has been taken on board before today's announcement.***
>
> ***"What is happening in Scotland is in stark contrast to events South of the border where evidence has been disregarded, the views and circumstances of victims ignored and where a current consultation document means that support payments to most victims will be reduced.***
>
> ***"Under the DoH proposals, some people will face cuts of up to several thousand pounds per year due to the withdrawal of most discretionary payments. Westminster are proposing cuts contrasted with Scotland announcing at least a doubling of regular payments to those most vulnerable HIV and Hepatitis C victims of the contaminated blood scandal.***
>
> ***"At a time when benefit payments to disabled people are also being cut, this is another example of Government failure to support those most in need.***
>
> ***"The contrast between Holyrood and Westminster could not be starker and we can only hope that Westminster takes note of Scotland's humanitarian approach and does what is right. Many MPs have taken up our case and we hope we will finally be listened to after our thirty year struggle for justice and closure.'***

More Subtle Differences:

1. Scotland has drawn up its proposals apparently without severe financial restrictions. In contrast, England's proposals appear to have been largely dictated by Treasury constraints. From the outset, this in turn has restricted the thinking and scope for reform. However, it is important to note that whereas Scots were apparently given some indication of what was affordable, the English were afforded no such courtesy, and when completing the consultation were consequently working in the dark. Only when reading the small print in the consultation guidelines was it possible to see that, unlike in Scotland, there was actually *no* extra money available, and therefore any money awarded to some of the victims would have to be found by reducing payments to others. This was not made clear, and nor was it referred to in the consultation itself.

2. In terms of eligibility criteria under the Scottish proposals, there is at least one other important aspect relating to triggers: In Scotland, HIV co-infection will effectively be deemed to be a trigger for advanced disease with greater impact. There is no such distinction made under current arrangements. We understand that the incidence of HIV cases in Scotland is very few in number when compared to the rest of the UK[84]. We believe that, in Scotland, the balance between stage one Hepatitis C cases and the co-infected is effectively the reverse of that in England. As there are so few HIV cases, Scotland's proposal essentially deals with them by subsuming their group into another. In contrast, England has a very large number of people who are currently deemed to be at Stage 1 for Hepatitis C infection, and we believe that this is forming a barrier to Westminster in terms of cost. This is yet another detrimental consequence of Westminster's ongoing failure to deal effectively and fairly with this issue.

3. It is also clear that, whereas Scotland have looked compassionately at the wider group, including widows, the suggested scheme in England is very much focused on enabling ongoing payments for those still at Skipton Fund stage one. This appears to be irrespective of the Skipton Fund criteria for Stage 2, and more as a result of pressure from campaigners still at stage one who feel they have been unjustly dealt with. Whilst this may be so it represents a downgrading of the accepted status for others, particularly the co-infected, and also takes into account a projected large number of transfusion victims, as opposed to the much smaller and more manageable group of those with a bleeding disorder.

---

[84] Transcript for 30/03/11 (day 14); 57 (16) to 58 (3) (Professor Ludlam):
http://www.penroseinquiry.org.uk/downloads/1350481891-PEN0191171.pdf
"Professor Ludlam gave evidence to the Inquiry on this material and suggested that the total number of infections with HIV of people with bleeding disorders in Scotland was around 59." (We believe this to represent the historic total, not the number remaining alive today)
http://www.penroseinquiry.org.uk/downloads/transcripts/day%2014%20300311%20amended.PDF

How Much Money Has Been Committed?

In Scotland, the announcement was for £20 million[85]. The Barnett Formula means that the way to compare this is not by using the population figure: Although Scotland is about 8.3% of the UK population, geography and post-industrial deprivation means that the Scottish spend is higher than that. The result is that the conversion for converting between Scottish and UK figures is to use 10%. Therefore, the Scottish announcement of £20 million is the equivalent of the UK Government announcing £200 million, as compared to the £125 million actually announced by Westminster for the English scheme, which – as explained above – is not actually new money anyway, but more of a re-allocation of funds.[86]

[85] http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

[86] Infected Blood: Reform of Financial and Other **Support, January** 2016, page 5, Footnote 2: ("*This estimate is based on the payments made by the current schemes. Following scheme reform we expect to continue to have approximately the same budget as for the current schemes.*")

Proposals Made By Westminster

Following decades of pressure from campaigners, victims finally felt that the present government was at last prepared to work with us towards fulfilling our campaign aims.

On 11th March 2015, in the House of Commons[87], the Prime Minister said:

> ***"...I am not sure whether that action will ever fully satisfy those who want this wrong to be righted, but as a wealthy and successful country we should be helping these people more. We will help them more, but we need Penrose first, and if I am standing here after the next election it will be done."***
>
> **David Cameron**

The unfairness between the two schemes can be summed up by the following comment made by Diana Johnson, MP during a Commons debate[88] in April 2016:

> **"Fifthly, there is concern about the fact that beneficiaries in England will be worse off than beneficiaries in Scotland. The Scottish proposals are far more generous to hepatitis C stage 2 and HIV sufferers, who will receive £27,000 per annum or £37,000 if they are co-infected, which is welcome, but are much less generous for hepatitis C stage 1s, who will receive an additional lump sum payment but no ongoing support. The Scottish proposals have been broadly welcomed, partly because of the way in which the consultation was conducted in Scotland, and the clear acknowledgement, for example, that the existing trust structure will be scrapped."**
>
> **Diana Johnson MP**

[87] House of Commons, Oral Answers to Questions, Wednesday 11 March 2015, Column 289. http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150311/debtext/150311-0001.htm

[88] Commons Hansard, "Contaminated Blood", 12 April 2016, Volume 608.

On the 25th March, 2015, Rory Stewart MP asked the Prime Minister[89] if he could **deliver a full apology, transparent publication and proper compensation** for the families "terribly affected by this scandal".' The Prime Minister's response was as follows:

> ***"My honourable friend is absolutely right to raise this with the Penrose Report published today and I can do all of the three things he asked for.***
>
> ***I know that many members on all sides of this house have raised questions of infected blood. I've spoken about how constituents have been to my surgery. While it will be for the next Government to take account of these findings, it is right that we use this moment to recognise the pain and suffering experienced by people as a result of this tragedy.***
>
> ***It is difficult to imagine the feelings of unfairness that people must feel at being infected by something like Hepatitis C or HIV as a result of a totally unrelated treatment within the NHS and to each and every one of those people, I would like to say sorry on behalf of the Government for something that should not have happened.***
>
> ***No amount of money can ever fully make up for what did happen, but it's vital we move as soon as possible to improve the way that payments are made to those infected by this blood. I can confirm today that the Government will provide up to £25m in 2015-16 to support any transitional arrangements to a better payment system and I commit that if I'm Prime Minister in May we will respond to the findings of this report as a matter of priority".***
>
> **David Cameron**

[89] http://www.haemophilia.org.uk/news/view?id=27&x%5B0%5D=news/list

The phrase *'transparent publication'* referred to the government's promised response to the Penrose Inquiry. To date we still await such a response, which is looking to be increasingly unlikely to materialise, as demonstrated recently in parliament:

Q. Asked by Stephen Kinnock (Aberavon) Asked on: 19 February 2016

Department of Health Blood: Contamination 27523

To ask the Secretary of State for Health, with reference to the Prime Minister's oral statement of 26 March 2015, Official Report, column 1423, on the Penrose Report on contaminated blood, when the Government plans to respond to the findings of that report.

A. Answered by: Jane Ellison Answered on: 29 February 2016

Lord Penrose made one recommendation in the Final Report, to 'take all reasonable steps to offer a hepatitis C test to anyone who had a blood transfusion before September 1991 who has not been tested for hepatitis C' through reminding general practitioners, nurses and other clinical staff of this matter, along with the National Health Service guidance to offer a hepatitis C test to those who may be at risk. The Penrose Inquiry was set up by the Scottish Government and so there is no requirement for the Department in England to provide a formal Government response to the final report published on 25 March 2015. We have, however implemented the recommendation in the Penrose Report by issuing reminders as recorded in the Written Ministerial Statement made on 20 July 2015 (Official Record HCWS146) and addressed in the Contaminated Blood Products debate (HC Deb, 9 September 2015, c86WH).

The Consultation Process

Before any new schemes could be formulated, both the Westminster and Scottish administrations were required to hold a consultation process. The law governing such a process is quite clear, and its principals are laid out in government documentation.[90]

Government Consultation Principles 2016:

1. Consultations should be clear and concise
2. Consultations should have a purpose
3. Consultations should be informative
4. Consultations are only part of a process of engagement
5. Consultations should last for a proportionate amount of time
6. Consultations should be targeted
7. Consultations should take account of the groups being consulted
8. Consultations should be agreed before publication
9. Consultation should facilitate scrutiny
10. Government responses to consultations should be published in a timely fashion
11. Consultation exercises should not generally be launched during local or national election periods.

90

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492132/20160111_Consultation_principles_final.pdf

The Scottish Consultation

The Scottish White Paper,[91] of 2003, illustrates very clearly that, following devolution, the Scots were determined to understand and respond to the needs of patients:

> ***'Understanding the wants and needs of patients whether children, adults or older people will lead to more effective and high quality healthcare, and must be a core activity of the health service. It means developing a genuinely responsive health service by seeking input and feedback from patients as a key part of developing services and improving quality....***
>
> ***...Our commitment is to a NHS which is dedicated to serving each patient. We want to see a health service where there is: participation by patients, carers and local communities. This should mean that their views are actively sought, listened to and acted on; and treated with the same priority as clinical standards and financial performance...'***

Furthermore, even at this stage they were laying the foundations for their recent holistic approach to the haemophilia community:

> ***'We believe there is also a need for a more coherent approach within NHS Scotland to meeting the needs of disabled people. In this European Year of Disabled People 14 we will extend the principles set out in Fair for All across the NHS to ensure that our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives...***
>
> ***... A focus on patients must mean a willingness to learn from situations where things have gone wrong or a patient has not received the level of service or care he or she expected. We are therefore developing a new complaints, process for NHS Scotland. This is designed to strengthen the response to complaints, increasing the focus on handling complaints, quickly and ensuring that there is a positive and constructive response to patients and the public. This will be a priority for senior management in all health organisations and needs to be reflected in the attitudes and behaviour of staff at all levels.'***

[91] Scotland's Health White Paper, Edinburgh, February 2003. www.gov.scot/resource/doc/47032/0013897.pdf

The Scottish consultation was held in in two phases:

Phase 1:

- Five meetings were held around Scotland (Glasgow, Edinburgh, Inverness, Dundee and Aberdeen).
- The meetings were open to anyone, but only invited people who were Alliance House beneficiaries, (i.e. registrants of one of the UK-wide support trusts), members of Haemophilia Scotland or the Scottish Infected Blood Forum.
- The venues for meetings were all hotels, selected for their accessibility.
- All five meetings were held in the last two weeks of August 2015. The purpose of this phase was to try and get a sense from people about what sort of scheme they wanted to see.
- The meetings covered the same themes as the questionnaire that was put out at the same time.

Phase 2:

- The second phase of the consultation was to bring the proposals back to people at an all-Scotland meeting in Perth. This meeting was held on 31st October 2015.
- There followed one final meeting of the group, aimed specifically at trying to adapt the proposals to reflect concerns raised at the October meeting By submitting evidence gained at that meeting, it was possible to improve several of the recommendations, although the general shape of the proposals stayed the same. The stated deadline was that they should make recommendations to the Scottish Government in November.

The Westminster Consultation

- Only one meeting was arranged by Westminster. On 22nd September 2015, an e-mail was sent to the Haemophilia Society, TaintedBlood and the Contaminated Blood Campaign.[92]
- The three groups were invited to send along only fifteen people between them, with an aim to represent the following groups:
    - Individuals that are infected (HIV) – with haemophilia
    - Individuals that are infected (HIV) – without haemophilia
    - Individuals that are infected (HCV) – with haemophilia
    - Individuals that are infected (HCV) – without haemophilia
    - Individuals that are co-infected with HIV and HCV
    - Widowed uninfected family members
    - Uninfected family members of living infected individual
- TaintedBlood in turn wrote back with a detailed document that showed the various sub-groups that the department had omitted for inclusion in this meeting.[93]
- The meeting was held on 5th October in London. This meant that we had little over two weeks in which to select representatives, arrange transport and accommodation and advise the community of developments.
- When news of the meeting was released to the community there was, understandably, distress, and understandable anger. Unlike in Scotland the overwhelming majority of people were unable to attend in person and so understandably many felt that their views were not being represented. This was in spite of TaintedBlood asking for thoughts and ideas and taking along written testimonies.

---

[92] http://www.taintedblood.info/files/1465746005Invitation%20to%20Reference%20Group%20(5%20Oct)(2).pdf

[93] http://www.taintedblood.info/files/1465747130Appendix%201%20Suggested%20Widened%20Groups%20for%20Consultation%20141015%20Final.pdf

- The Department of Heath did not attend the meeting, and so we were unable to ask questions regarding the consultation, or put our thoughts to them in person. Instead we had to rely on the facilitator who, with our help, drew up a report.[94]

- TaintedBlood also produced their own notes of the meeting.[95]

- The meeting delegates understood that their role was to highlight areas that should be included in the forthcoming consultation questionnaire. We did so to the best of our ability, and at no time recommended policy.

- On 21st January 2016, Jane Ellison announced the launch of a consultation on support for victims of contaminated blood.[96] She noted that:

> ***'Scheme Reform is a priority for me and the Government'***
>
> ***Jane Ellison***

- On 23rd March 2016, TaintedBlood issued its own guidelines[97] to the consultation document, owing to the feelings of confusion and outrage within the community.

- The consultation was open to anyone to complete, including MPs, doctors, charities, etc. No reassurance as to the weighting of beneficiary responses was given to those directly infected/affected, despite a formal request from TaintedBlood.

- The findings of the reference group were dismissed out-of-hand as being 'too expensive'.[98] Despite the fact that no recommendations had been made, we have since been informed that our so-called "preferred monetary resolution" would exceed what the DH deem to be affordable within a new scheme.

---

94 http://www.taintedblood.info/files/1465747387Appendix%207%20%20Reference%20Group%20on%20Infected%20Blood%20-%20Final%20Report%201%20%20November%202011%20(2).pdf

95 http://www.taintedblood.info/files/1465747680TB%20Consolidated%20Points%20-%20Reference%20Group%20-%20vFINAL%20%20%20%20%20%20edits.doc

96 Oral Statement to Parliament: "Infected blood scheme reform", Jane Ellison. 21 January 2016 https://www.gov.uk/government/speeches/infected-blood-scheme-reform

97 TaintedBlood.info "Completing the Consultation Document – Notes for Guidance", 23rd March 2016.

98 Infected Blood: Reform of Financial and Other Support, January 2016, at 2.10

Our Conclusions on the Consultation Process

1. Compared to the Scottish consultation, the Westminster process was cruelly inadequate and did not reflect the apparent willingness of the government in past months to listen to our community and try to address the issues.

2. We accept that due to population size, we would have needed approximately 55 meetings in order to duplicate the meetings held in Scotland. (Scotland's population is a little over 8% of the UK.)[99] That would mean we would need 60 meetings to be held across the UK, in order to be proportional to the five Scottish ones. However, the fact remains that there is enormous disparity between the initial consultation with haemophiliacs in Scotland and those in the rest of the UK, which meant that the Scottish victims had a far stronger voice and were able to put over their points far more effectively.

3. Whereas the ideas brought to meetings by the Scots were clearly considered and included in the final proposals, every single point made in our Reference Group meeting was completely dismissed.[100]

[99] https://en.wikipedia.org/wiki/List_of_Primary_Urban_Areas_in_England_by_population

[100] http://www.taintedblood.info/files/1466106145Master%20Document%20%20-%20combined%20v1.doc

Criticisms of the DH Consultation

Following the consultation, TaintedBlood produced a document which outlined the flaws in the consultation, as we see them.[101] We used this document to enable us to make our concerns known in writing to the Department of Health.[102]

We believe that the consultation was deeply flawed from the outset, for the following reasons:

I. **Failure to Consult on Scottish Departure**
Despite its obvious importance and impact, the government consultation, which was launched after the Scottish proposals were announced, made NO reference whatsoever to the new Scottish proposals. Nor did it refer to devolution or the Scottish Administration. We were not consulted in any way on the splitting off of the Scottish scheme, following over three decades of unity within the group of victims. We have no doubt that, if challenged, the government would justify this by saying that if Scotland chose to it could stay within the Westminster-led scheme, but based on the fact that their given option is so greatly inferior to Scotland's new scheme, we believe this would be indefensible.

II. **Failure to Involve Victims from the Outset**
As soon as the consultation was mentioned by government, TaintedBlood wrote to Jeremy Hunt,[103]suggesting that we beta-test the consultation before it went live. Our exact words were: *"Recalling the failure of successive initiatives aimed at bringing closure to victims, we would like to suggest that before the consultation goes live, it is 'Beta-Tested' by a small group of campaigners."* We made this offer in order that we could help to refine it and hopefully alleviate some of the mistakes and problems in previous efforts to bring closure. Our requests were initially welcomed, and acknowledged by the Department, but were not progressed.[104] We firmly believe that the department

---

101 http://www.taintedblood.info/files/1465748824Key%20points%20objctions%20to%20consultation%20doc%20%20TB%20FINAL.doc

102 Taintedblood letter to Jane Ellison, Parliamentary Under Secretary of State for Public Health, 19th February 2016.

103 Taintedblood letter to Jeremy Hunt, Secretary of State for Health, 3rd August, 2015.

104 Jane Ellison, Parliamentary Under Secretary of State for Public Health, to TaintedBlood, 3 September 2015.

had a fixed idea of the outcome of the consultation from the start and did not want our input. This feeling was reinforced by 'veiled' explanations such as:

"This estimate is based on the payments made by the current schemes. Following scheme reform we expect to continue to have approximately the same budget as for the current schemes."[105]

III. **The Reference Group.** Leading up to the consultation, the government invited TaintedBlood and two other groups to send representatives to a reference group meeting in London, chaired by an independent facilitator. Despite the fact that the DoH did not send anyone to the meeting, therefore rendering us unable to ask specific questions, we went to great lengths to attend the meeting which was hastily convened at very short notice. We tried very hard to fulfil our role which, as we understood it, was not to make any proposals, but to inform the questionnaire of areas that should be covered. Despite this, when the questionnaire was launched, the meeting was dismissed in a few words. Our 'proposals', it seems, were deemed to be too expensive! None of our suggestions were taken on board, and all our ideas were completely ignored. The consultation preamble[106] states: ***"Those at the event agreed that the current schemes need to change. The financial support the group would like to see differs considerably from what is currently being provided. The attendees at the event identified a preferred monetary resolution, which would exceed what will be affordable within a new scheme."***

We have since asked[107] for the economic or financial modelling use by the Department to be provided in order to show us how they arrived at their conclusions. We believe they should provide us with the modelling done on our meeting recommendations, financial modelling on the government's favoured 'Option 2', and a comparison between the two. Our request was completely ignored.

The following comprehensive list reflects the thoroughness and depth of the work of the Reference Group and Independent Facilitator. It should be viewed in stark contrast to the Department of Health's dismissive, inaccurate and insulting sentence (mentioned above):

---

[105] Infected Blood: Reform of Financial and Other Support, January 2016, page 5, Footnote 2.
[106] Infected Blood: Reform of Financial and Other Support, January 2016, at 2.10
[107] Taintedblood letter to Jane Ellison, Parliamentary Under Secretary of State for Public Health, 19th February 2016.

Main Points Raised by the Reference Group

1. **Criticism of Department of Health:**
   a) Lack of information and transparency.
   b) Unhelpful language
   c) Suggestions that they were considering only 'tweaking' the current scheme
   d) Facilitator completely uninformed, arty due to his rejection of a DH briefing
   e) No representation at meeting from actuaries, independent lawyers or health experts

2. **A new scheme should:**
   a) Be sorted as soon as possible
   b) Have simple access
   c) Fairly restore financial independence, financial control and security to victims.
   d) Enable registrants not to rely on DWP payments.
   e) Include an entitlement to housing/child benefit, etc.
   f) Include restitution for lost education/career/ earnings opportunities.
   g) Be flexible enough to accommodate a range of health impacts.
   h) Be future-proof to take into account deterioration of health.
   i) Recognise psychological/emotional/practical impact.
   a) Recognise those who had not yet developed a chronic condition.
   j) Recognise Perinatal Infection.
   k) Address health & social care, insurance and prescription exemption
   b) Address lack of access to life insurance

3. **A New Scheme Must Not:**
   a) Include any charitable elements or means-testing.
   b) Include any staff from present support network

4. **Family Members**
   a) Recognition of dependent children and bereaved dependent children.
   b) Recognition of impact on carers & parents.
   c) Full support for all bereaved partners/families.
   d) Recognition of impact on having a family.

5. **Housing**
   a) People should be able to buy their own home or pay off existing mortgages.
   b) A low-cost mortgage facility should be provided.
   c) Partners should not be required to leave a rental property following bereavement.
   d) Newly-bereaved losing their mortgaged home needs to be addressed.
   e) Improper use of loans (from the Trusts / Alliance House entities) secured on homes.

6. **The Group Further Noted That:**
   a) There should be an apology for three decades of inadequate treatment & support.
   b) People would appreciate a national memorial and remembrance service
   c) That the DH expected less than 6,000 cases would need to be dealt with. [108]

[108] Jane Ellison, letter to Joseph Peaty, dated 2nd March 2015:
"The figure of 30,000 for the total number of people who were infected with hepatitis C as a result of treatment with NHS-supplied

IV. **Scope of Questionnaire.** The questionnaire was open for anyone to complete, regardless of whether they were personally affected. The Department invited a large range of individuals and organisations participate[109] - numbers that could have completely overwhelmed our small group and possibly skew the results. We have had no unequivocal assurance from the Department of Health that some form of weighting will be employed in the analysis of the responses.

V. **Lack of Information.** The consultation provided such sparse information and posed questions where possible outcomes were not considered, that TaintedBlood was forced to provide a comprehensive set of guidelines.[110]

VI. **Failure to Address the Unique Circumstances of Haemophiliacs.** The questionnaire was open to all those infected by NHS-prescribed blood and blood products. This means that everyone infected by the transfusion route were also completing the same consultation. For many years TaintedBlood has maintained that the very specific differences between haemophiliacs and whole blood recipients demand unique consideration.[111] Indeed, there have been regular assertions from within government, that haemophiliacs are a unique group within the UK who warrant special treatment.[112] [113] [114] [115] More recently this was supported in evidence submitted to the Penrose Inquiry.

Until the Skipton Fund was formed in 2004, there were separate organisations for haemophiliacs and whole-blood victims (The MacFarlane Trust and the Eileen Trust). This was because of the stated recognition by the government of the *'unique and special status'* of those with haemophilia. Lord MacKay of Drumadoon recognised the new arrangements[116] on 5th February 2008, when he said:

---

blood and blood products, is the best available estimate. However, the Department recognises that the ex-gratia financial assistance scheme needs to support a much smaller number of people, perhaps fewer than 6,000."

[109] https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support Accessed on 24th February 2016. (The page has since changed.) The Department's intended "audience" included: Voluntary groups, Community groups, Members of the public, Patients, Carers, Charities, Advocacy or Support Organisations, GPs, Nurses, Clinicians, Commissioners, Directors of Public Health, Pharmacists, Healthcare Scientists, Occupational Therapists, Care-Givers, the NHS Commissioning Board, Clinical Commissioning Groups, Academic/ Professional Institutions, the Royal Colleges, Local authority, Social care Providers, and Service Users.

[110] TaintedBlood.info "Completing the Consultation Document – Notes for Guidance", 23rd March 2016.

[111] http://www.taintedblood.info/files/1465662501Differences%20Between%20Haemophiliacs%20&%20Whole%20Blood%20Recipients_FINAL_2.doc

[112] http://hansard.millbanksystems.com/commons/1987/nov/16/haemophiliacs-financial-assistance

[113] http://www.publications.parliament.uk/pa/cm199091/cmhansrd/1990-12-11/Writtens-5.html http://hansard.millbanksystems.com/commons/1991/dec/20/infected-blood-transfusions

[114] http://hansard.millbanksystems.com/commons/1991/dec/20/infected-blood-transfusions

[115] http://eppi.ioe.ac.uk/cms/Portals/0/PDF%20reviews%20and%20summaries/ART%20Therapy%202015%20Llewellyn.pdf?ver=2016-04-23-122500-213

[116] Opinion of Lord Mackay of Drumadoon, Petitions by Rosaleen Kennedy and Jean Black for Judicial Review of Decisions of the Lord Advocate and Scottish Ministers. 5th February, 2008, Summary, at [119].

"The Skipton Fund...is an ex gratia payment scheme, which has been in operation since 25 March 2004. The Skipton Fund makes payments to individuals who were treated anywhere in the United Kingdom under the National Health Service before 1 September 1991 by way of the receipt of blood, tissue or blood product and, as a result of that treatment, became infected with the Hepatitis C virus. A first stage payment of £20,000 is available to those who are eligible and a second stage payment is also payable to those whose infection has led to advanced liver disease. Payments can also be made under the provisions of the scheme into the estates of those who became infected with the Hepatitis C virus before 1 September 1991 and have subsequently died, if they died on or after 29 August 2003.

The scheme was initially established by the Department of Health in England, on behalf of health administrations throughout the United Kingdom, including the second respondent. The scheme in Scotland now falls under the provisions of section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 ("the 2005 Act") and the second respondent, the Scottish Ministers, have appointed the Skipton Fund to manage the scheme on their behalf."

Lord Mackay of Drumadoon

It is important to note that at this point the Scottish Executive could have decided to run the scheme themselves and begin a move towards a Scottish scheme, and in fact this would have been an ideal time to do so. Instead they simply agreed to appoint the Skipton Fund to manage the scheme on their behalf and keep Scottish payments firmly in line with the rest of the UK, as had happened previously.

http://www.scotcourts.gov.uk/search-judgments/judgment?id=7ea286a6-8980-69d2-b500-ff0000d74aa7

Lodging Our Complaint with the Department of Health

TaintedBlood made every effort to lodge their concerns about the consultation with the Department of Health. In a letter to Jane Ellison, sent on 19th February 2016, the following concerns and complaints were made:

- That there has been a series of unsubstantiated and unreasonable delays
- That there was really no new money, only the illusion of it
- That the funding of HCV treatments had been enmeshed with support payments.
- That the "consultation" process was a travesty from start to finish.
- That it was not within the spirit of the Prime Minister's words: "***we will help them more***".
- That most people will be materially disadvantaged or financially worse off
- That many widows would be cut loose from the scheme altogether, and that there would be an unclear future for those choosing publicise it for them.to remain in the current scheme.
- That the way in which the Reference Group meeting was conducted was unacceptable
- That the DH were unable to publish the facilitator's final report, apparently because of problems with a web page, and instead asked us to publicise it for them
- That we vehemently contested the DH's claim that "***attendees at the event identified a preferred monetary resolution***". This was completely disingenuous.
- That the entire product of the meeting was summarily dismissed as though it was a single policy or proposal.
- That the two DH 'options' effectively amount to consultation on a single *preferred* option. The alternative was staying as we are, in a support system which has already been acknowledged by Parliamentarians as being 'unfit for purpose'.[117]
- That the amount of money appeared to be predetermined prior to the consultation.
- That they failed to take into account the true impact of the proposed cuts.
- That there was lack of any evidence of their economic modelling

[117] According to the Case Law, it is not unlawful to consult on a single preferred option when the other option being consulted on represents maintaining the '*status quo*'. However, we believe the 'status quo' option should have been ruled out in light of the many criticisms of the current schemes.

The Current Situation and Delays

A recent article in the Herald Scotland[118] reinforces our claim that Westminster is procrastinating and holding-up the implementation of the scheme in Scotland. Dan Farthing-Sykes, Chief Executive of charity Haemophilia Scotland was quoted saying:

> ***"We are concerned that the UK Government might be trying to drag out negotiations, delaying the new Scottish payments, until they are ready to make changes south of the border. The English review process has consistently lagged behind events in Scotland. There is a long history of Scotland facing unacceptable delays while England tries to keep pace on the contaminated blood issue. In our view it would be totally unacceptable for Scottish payments to be delayed by even a day while the UK Government plays catch up."***

The article makes it clear that the Scottish Government is dependent on the Department of Health, and the HMRC in order to utilise the existing UK support schemes to deliver the planned increased payments "*for those infected in Scotland*"[119]

This situation is reminiscent of the events of 2003 where the *ex gratia* payment scheme for those in Scotland was literally prevented from being established due to a question over whether the Scottish Executive had the appropriate powers under the Scotland Act. A letter[120] of August 2003, from Malcolm Chisholm MSP, to Christine Grahame, MSP, sheds more light on what happened:

"I refer to your letter of 9 July. In your letter you express the understandable concern of the Committee that it is taking so long to resolve the various issues that have so far prevented establishment of our proposed ex gratia payment scheme. You also question whether the Executive has been conducting its discussions with the UK government in the fashion recommended in its Memorandum of Understanding with the devolved administrations."

---

[118] *"Victims of NHS infected blood disaster accuse UK Government over payment delay"*; The Herald Scotland, Judith Duffy, Reporter, 12th June 2016.
http://www.heraldscotland.com/news/14551821.Victims_of_NHS_infected_blood_disaster_accuse_UK_Government_over_payment_delay/

[119] Ibid. Para 10: Quotation of Health Secretary, Shona Robison.

[120] Malcolm Chisholm MSP, Minister for Health & Community Care, Letter to Christine Grahame, MSP, Convener, Health and Community Care Committee. August 2003
http://archive.scottish.parliament.uk/business/committees/historic/health/papers-03/hep03-05a.pdf

"I am very pleased to be able to tell you that the UK Government has agreed that the Scottish Executive does have the necessary powers under the Scotland Act to establish the proposed scheme. In addition, in a parallel announcement today the Department of Health will say that it has decided to provide financial assistance to people in England."

"However the Minister was seeking the agreement of the UK government that it would be competent for the Executive to introduce a payment scheme and that any such scheme would not lead to social security "clawback.""

According to an Agenda Item[121] authored by Peter McGrath, Senior Assistant Clerk, the impasse may have been more serious than it appeared on the surface. We note that the Committee were at the point of seeking a judicial resolution:

> ***"At its 25 June 2003 meeting, the Health Committee agreed to write to the Minister seeking more detail on what action the Executive had taken to attempt to reach agreement with Whitehall, having regard in particular to the memorandum of understanding between the UK government and the devolved administration. The committee also agreed to seek further information on the options for resolving the matter judicially."***

We have to ask ourselves what, if anything, might have changed since 2003 to enable Scotland to act in such a different way now. One possibility is that nothing has changed. It is clear that the Scottish proposals have not yet been implemented and rather disappointingly, it seems that Scotland are waiting for 'permission' from Westminster. We can only hope that they are not planning a UK-system, but with regional rates.

On closer examination, it appears that Scotland are being held up because they want to use the Skipton Fund (and possibly also the MFT) as a temporary payment vehicle until such a time as they are able to set up a satisfactory Scottish mechanism. We suspect that what is really at the heart of this delay is that Scotland requires access to the Skipton/MFT databases in order to actually find out which beneficiaries to pay.

It seems to us that unless England either match Scotland and institute a UK-wide scheme, or come up with something better, they have got themselves into an untenable position. Not helped, of course, by the fact that when they set up the Skipton Fund, they included transfusion victims and thereby muddied the waters completely.

---

[121] Agenda item 4 HC/S2/03/05/3 "*Hepatitis C*", Peter McGrath, Senior Assistant Clerk: Pgs. 7-8
http://archive.scottish.parliament.uk/business/committees/historic/health/papers-03/hep03-05a.pdf

It is our understanding that the Scottish Executive obtained legal advice as to whether they could change the criteria for the new system. The advice, apparently, went against making any change, hence them using the same criteria as in the past.

We would suggest that a possible reason for this is that any criteria that divided the UK haemophiliacs up would be discriminatory, so it was safer to stick to the status quo. Therefore, Scotland are fundamentally not proposing to change the admission criteria.

It could be argued that, in the past, it was justifiable to use the criterion of residency at the point of infection in order to administer payments. However this was done at a time when everyone received the same payment regardless of where they were infected.

This is clearly unjustifiable under the new proposals, since we are talking about residency being used as an eligibility criterion for vastly different levels of payment, for infections contracted under exactly the same circumstances.

Whereas in 2003 it was probably a rational judgement made for accountancy purposes which would only have manifested on the balance sheet, in this instance, it represents a gross unfairness and is discriminatory in the extreme. There appears to be absolutely no justification for it; it is plainly irrational.

In summary, a criterion that was appropriate over a decade ago has been carried over regardless of the consequences of the vastly different payments levels.

Legal Commentary

Introduction

This legal analysis may be somewhat premature, as we do not yet have concrete policies in place. The Scottish scheme has been accepted in principle, but has not yet been implemented, due largely to difficulties between the Scottish and Westminster administrations in dealing with the practicalities of a new payment mechanism. In England, it seems we are much further behind, with the analysis of the Department of Health consultation responses currently underway, and no sign of any solid policy anytime soon. However, we have undertaken this project in order to be as prepared as possible should the government's preferred 'Option 2' become policy and in response to the profound concerns shared by our community.

The situation in which we find ourselves appears to be underpinned by two clear legal grounds. The first ground is that of substantive legitimate expectation in Public Law as created by the established past practice of Westminster treating both Scottish and English haemophiliacs as one group, and the second ground is prohibition of discrimination on at least five protected characteristics, the main one being the status of residency.

First Ground – Substantive Legitimate Expectation

We believe that a legitimate expectation has been created in law for all UK haemophilia victims to be treated the same, as one group, in exactly the same way they have been since the late 1980s. We have behind us over three decades of UK-driven, Department of Health engendered common policy, as well as shared practice and guidance, overarching administration and similar treatment.

This is perhaps most noticeable in the English Department of Health's macroscopic approach to the contaminated blood catastrophe by setting up various ex-gratia support schemes that dealt with the UK as a whole. Notwithstanding the minor deviation of the Scottish devolved administration at the inception of the Skipton Fund, the overarching policy has been one of unity and equal treatment. It has only been this past year where any definite moves have taken place to put Scotland on a genuinely separate footing in relation to how infected haemophiliacs and their families are treated.

Established Past Practice:

The point of law regarding past practice is the stronger feature of the underlying legal scenario for the existing UK-wide ex-gratia support schemes. Those who were treated and infected whilst living in England have developed a legitimate expectation based on the many years – over 30 years – of being regarded as one overall group by Westminster, which has included the original HIV Haemophilia Litigation of 1990, the creation of the Skipton Fund in 2004 (signed-off in Scotland in 2005) – which importantly was 8 years after devolution. There are more general examples of the infected community being treated in a like-for-like manner; this includes the central node, or "hub" of decision-making emanating from the then DHSS and decisions affecting Scotland via the SHHD (the Scottish Home and Health Department). Therefore, infected haemophiliacs in England can rightly expect to be considered part of the whole based on the previous well-established response from Westminster.

In the *Unilever* case[122], granting JR, the Revenue's practice over many years of allowing Unilever to submit informal or late tax relief claims had given rise to a legitimate expectation. In departing from that practice (without clear and general advance notice) it was so unfair as to amount to an abuse of power. "*The Revenue ought, in the exercise of its discretion, to allow the claims and its failure to do so was irrational*"

A Finite Group

We have long contended that the haemophiliac population who received contaminated blood products comprise a finite group of around 5,000. In 2009, the Final Report of the Archer Inquiry gave the number for those infected by hepatitis C as some 4,670 patients with 1,200 infections from HIV. The report stated that at the time the Archer Inquiry started in 2007, the infections had caused at least 1,757 deaths in the haemophilia community.[123] Even if we were to include the estate claims of those who have lost their lives, the total figure of those requiring support would not be much above 7,000.

However, since January 2015, the Department of Health have been making reference to far larger figures, in the region of 33,000[124]. The source they are using for this "estimate" is a Parliamentary Written Answer[125]. The answer states: ***"...it is estimated that around 33,000 individuals may have been infected with hepatitis C, of whom it is estimated that***

---

[122] *Unilever: R v Inland Revenue Commissioners, ex p Unilever Plc* [1996] STC 681 CA.

[123] Archer Inquiry: "Independent Public Inquiry Report On NHS Supplied Contaminated Blood and Blood Products", Final Report, Published: 23 February 2009, Introduction, page 5.

[124] Commons Library, Debate Pack, "*Reform of support arrangements for people infected with contaminated blood*" by Dr Sarah Barber, CBP 2016/0077, 7th April 2016.

[125] Written Question on Blood Contaminated: 220665. Answered by Jane Ellison, 16th January, 2015. http://www.parliament.uk/written-questions-answers-statements/written-question/commons/2015-01-13/220665

approximately 9,000 remained alive in 2003." In terms of HIV infection, we understand the number of survivors registered with the MFT to be more in the region of 304.[126]

We are not quite sure why the Department are stressing these very high figures, perhaps they are nervous about an influx of estate claims? Even if this were the case it is very flimsy, since most of those who have died would have had their death attributed to other causes, and the vast majority would not even have known they had Hepatitis C. Nevertheless, compared to the very large class of 400,000 UK pensioners in *Carson*[127], (discussed later), who are resident abroad yet still entitled to claim a UK pension, the figures, whichever set one takes, are genuinely finite.

Application of *Coughlan*

The applicant lived in a home for the severely disabled, and had been told by the Health Authority that it would be her home for life. As a result, a substantive legitimate expectation arose of a type from which the council could only depart if there was a justification (sufficient overriding interest). She was then informed that the home was to be closed and she would be transferred. The court held that an enforceable legitimate expectation had been created, which no public interest factor could override (or displace).[128]

In *Coughlan*, we can see that an important aspect of the promise relied on by Miss Coughlan was that it had been made to a small group: "***It was made to a small group of severely disabled individuals who had been housed and cared for over a substantial period in the Health Authority's predecessor's premises at Newcourt.***"[129]

The promise in *Coughlan* was limited to "*a few individuals*", and the consequences to the Health Authority of being held to its promise were "*likely to be financial only*" both aided the argument that only an "***overriding public interest***" could justify the promise not being fulfilled.[130]

This case provides extra scope for demonstrating to the Court that the English infected haemophiliacs could override the public interest test in relation to, for example, the protection of public finance or limitations placed on the DH budget by fiscal constraints, particularly in the context of the current climate of austerity. *Coughlan* shows that a financial consequence - in itself - does not necessarily create a public interest factor. The far more onerous

---

[126] The Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2015, page 6. "MFT's community of care included 344 infected beneficiaries, comprising **304 survivors** of those who were originally registered with MFT..."

[127] *Regina v. Secretary of State for Work and Pensions (Respondent) ex parte Carson (Appellant)* at [6] http://www.bailii.org/uk/cases/UKHL/2005/37.html

[128] *R v North and East Devon Health Authority, ex parte Coughlan* [2000] 3 All ER 850 http://www.bailii.org/ew/cases/EWCA/Civ/1999/1871.html

[129] *R v North and East Devon Health Authority, ex parte Coughlan* [2000] 3 All ER 850 at [86]

[130] Ibid. at [60]

justification test of ***fairness*** would more likely be employed. There has been no justification provided by the Department of Health for the inherent unfairness in proposing an inferior scheme to our neighbour, Scotland, with which we share our considerable history not only as part of the United Kingdom, but also as comparable member states within the EEC area.

The nature of the haemophiliac victim group would most qualify as a public interest factor in itself, not least in that the group is comprised of disabled and severely disabled people, and disadvantaged by the *en masse* contamination, with the added consideration of being a finite, contained group.

Our Legitimate Expectations:

There may also be a legitimate expectation which has arisen due to statements made in the House of Commons by various ministers from the Department of Health. Whilst this is by no means our strongest ground, we do feel that the Department have consistently led us to believe that they are seeking a proper settlement for our cause, and in their own words, "a full and final settlement". This has been said in the House at least once in full, and several other times in shorted forms. They have also used phrases like "we are absolutely determined to get it right." We are aware that statements made in the House of Commons attract a special privilege and that we may not be able to rely on them. Michael Fordham, Q.C. in his Judicial Review Handbook discusses promises made in Parliament and whether a legitimate expectation is capable of being based on statements in Parliament.[131]

However, the sheer number of times that the comments have been reiterated will hopefully reinforce our expectation.

Lord Denning in *Schmidt*[132] first recognised that a legitimate expectation arises "where a citizen has been led to believe by a statement or other conduct of the government that he is singled out for some benefit or advantage of which it would be unfair to deprive him."

This assurance can be announced generally (as in *Khan*) such as in a circular[133], or more specifically through an express promise or assurance given to an individual (as in *Preson*).[134]

An express promise given by a decision-maker should be honoured. The decision-maker was the DOH. There may well be more than one promise. They can be found within statements made in the House of Commons by the Under-Secretary of State for Health, the Parliamentary Under-Secretary of State for Quality (Ben Gummer) and by the Prime Minister.

---

[131] *R (Wheeler) v Office of the Prime Minister [2008] EWHC 1409 (Admin)* at [53].
[132] *Schmidt v Secretary of State for Home Affairs* (1969) [1969] CA, 2 WLR 337, [1969] 2 Ch 149, [1968] EWCA Civ 1, (1969) 133 JP 274, [1969] 1 All ER 904.
[133] *R. v. Secretary of State for the Home Department, ex parte Khan* (1984) EWCA Civ 8 [1984] WLR 1337 C.A.
[134] Preson v IRC (1985) STC 2 282.

"My officials hosted a meeting on 24 March with officials from each of the devolved Administrations to discuss scheme reform, and they will continue to work with their counterparts from the DAs on that."

Jane Ellison – Commons Hansard – 12th April 2016

"...I am not sure whether that action will ever fully satisfy those who want this wrong to be righted, but as a wealthy and successful country we should be helping these people more. We will help them more, but we need Penrose first, and if I am standing here after the next election it will be done."

Prime Minister – Commons Hansard - 11th March 2015

"...The hon. Lady will be aware that this is an enormously complex area, and we want to ensure that all the concerns of sufferers and victims are taken into account in the consultation that we are going to lead, so that we can come to a final settlement that is equitable to all."

Ben Gummer (DH) – Commons Hansard - 20th July 2015

A Given Benefit for People in the Same Position:

A legitimate expectation is generated by consistent past practice whereby people in the same position as the applicant have been given a benefit in the past.[135] In "*GCHQ*", the Prime Minister failed to consult the trade union before making a decision banning trade union membership for workers at *GCHQ*. The House of Lords held that the trade union did in fact have a legitimate expectation that they should be consulted, although the case failed as the subject matter was one of National Security and therefore non-justiciable.

The established practice of being treated in largely the same way as Scottish victims has engendered a legitimate expectation over many years, since a related group (or people originally in the same position) were treated similarly in previous years. Our expectation to be treated in the same way has been induced by the past behaviour of the Department of Health, the public authority.

[135] *CCSU v Minister for the Civil Service* (1985) AC 374. (Also known as the *GCHQ* case).

Departure Requires a Good Reason:

The decision-maker can be held in public law to his policy[136], with departure requiring the articulation of a good reason, given...

(i)	...the principle of consistency (and avoidance of arbitrariness);
(ii)	...the duty to have regard to relevancies;
(iii)	...the avoidance of over-rigidity;
(iv)	...the need to give effect to legitimate expectations.

There is a need for rational grounds for the discontinuation of a practice or policy, and for that matter, any departure from the existing policy or practice.

In relation to (iii) above, in ruling out a more favourable scheme on par with Scotland, the department of Health could be said to be fettering their discretion.

There does not appear to be an obvious explanation as to why Scotland have made this departure now, and not at an earlier stage. The Department of Health have not provided us with a clear reason why Scotland has veered off with its own scheme. We can speculate as to possible reasons, but none of them are compelling enough to justify the extreme unfairness that will ensue if Scotland implements a far more generous scheme than England. Possible reasons might include Scotland's desire to become more independent, to have further powers devolved to them, it could be to do with the Penrose Inquiry, but we firmly believe that the newly proposed Scottish scheme is not as a direct result of them having had the judicial inquiry, as at best, it was perhaps a catalyst, and at worst, an poor excuse to hinge the unjustified changes on.

In chapter P55 of Fordham's "Judicial Review Handbook" [137], the problem of 'inconsistency' is discussed. For a Public Authority to depart from "a legally relevant position", it will require "a good reason or cogent justification." A short list of instances of departure then follow, the most relevant of which include: conduct engendering legitimate expectation; action in other like cases; and prior action in the same case.

We are aware that if the Department of Health, after having consulted, decides to change policy and this leads to the consultees suffering the deprivation of an existing benefit, then this is likely to be more difficult to challenge even though the power of the Public Authority to change its policy is constrained by the legal duty to be fair. The fact they have consulted appear to give them far more scope for change.

---

[136] *R v Secretary of State for the Home Department, ex parte Urmaza* [1996] COD 479.
[137] "Judicial Review Handbook" Sixth Edition, Michael Fordham Q.C. at [55.2]

However, we vehemently assert that the DH's "Infected Blood Consultation" is likely to be found unlawful, deeply flawed, and not fit for purpose. This is not least because of the two options being consulted on:

- "Option one" merely equates to "staying the same". This would leave everyone relying on a support system that has been widely acknowledged as hugely underfunded, demeaning, humiliating and unfit for purpose.
- The Government's preferred "Option two" was, therefore, the only real option being consulted on. However, the ramifications of this option, should it be adopted, would be that most people would actually be worse off, either immediately or within a short period of time. These effects have been cleverly disguised in the consultation so that it is not immediately obvious what the true impact would be.

It is unclear whether "Option one" actually counts as a choice at all, since all it does is maintain the status quo. In real terms, therefore, the government is consulting on a single preferred option ('Option two') which we believe is likely to be unlawful:[138]

> **Consultation on a Single Option:** A public body can consult on a single, preferred, option but that is unlikely to be lawful unless other options are identified and the preferred option explained in a way which allows consultees properly to argue in favour of alternatives.

The Second Ground - Prohibition of Discrimination

It is our belief that there is discrimination against haemophiliacs who became infected whilst resident in England. Haemophiliacs may be categorised as both a national minority group and as a group identifiable by the circumstances of their genetic differences at birth, due to the hereditary nature of the condition. There is also the protected characteristic of disability. These differences, as enshrined in the Convention, have been compromised and our life chances have been curtailed. As a direct result of our genetic differences and infected status, our group has been subjected to sub-standard treatment that has resulted in thousands becoming multiply infected and many dying.

---

[138] http://davidwolfe.org.uk/wordpress/archives/268
R (Madden) v Bury Metropolitan Borough Council [2002] EWHC 1882 (Admin); *Vale of Glamorgan v Lord Chancellor* [2011] EWHC 1532 (Admin).

The Law: Article 14 of the European Convention on Human Rights

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, **association with a national minority, property, birth or other status.**

Key Eligibility Criterion

According to a BBC News article[139], "*only those infected in Scotland are eligible for the Scottish scheme.*" It appears that the key eligibility criterion for entry to the Scottish scheme boils down to: "place of residency at the time of infection." We find this difficult to understand, and see this as an indication of how artificial this whole divide is. It may have been more palatable if the criteria had been set around issues such as treatment centre, batch numbers used, etc., but place of residence appears to be the only way the Scots could justify a cut-off point for their victims, regardless of the fact it has absolutely no connection to the reasons people were infected in the first place!

"Status" and Residency

Article 14 has a somewhat restricted list of the matters in respect of which discrimination is forbidden. Tagged on the end of this list is the residuary category "*other status*".

In *Carson*[140], Lord Walker of Gestingthorpe explains that:

> *"The residual group, "or other status" (in the French text, toute autre situation), is far from precise."*

Whilst the list of grounds outlined in Article 14 does not expressly include all the other potential characteristics on which a discrimination challenge can be based, there a many, including: marital status, sexual orientation, illegitimacy, religion, political or other opinion, trade union membership, transsexual status, imprisonment, disability and age.

We believe the status of residency can be made out as a protected characteristic under Article 14. In order to show discrimination, it will be necessary to identify a group in materially similar circumstances, where the main difference between the two groups is the protected ground. In our case, the Scottish beneficiaries are the 'comparator' group. We know from the

[139] BBC News "Payment rise for hepatitis C infected blood victims", Eleanor Bradford, BBC Scotland Health Correspondent. 18th March 2016.
[140] *R (Carson) v Secretary of State for Work and Pensions* [2006] 1 AC 173

words of Lord Nicholls in *Carson*[141] that the comparator group does not need to be an exact match. The discrimination is directed at those who were resident in England at the time of their infection – and this needs to be viewed in light of a period of over three decades when their support needs were given identical recognition and equal treatment regardless of residency or the geography of where they were infected.

We feel that the situations of Scottish and English haemophiliacs infected through contaminated blood products are more than sufficiently analogous (and need only be in a '*relevantly comparable position*'[142]) in order to satisfy the requirements for use of the Scottish beneficiaries as a comparator group. However, should any relevant differences be identified, and as in *Carson*, a different approach will be called for: "...Then the court's scrutiny may best be directed at considering whether the differentiation has a legitimate aim and whether the means chosen to achieve the aim is appropriate and not disproportionate in its adverse impact."[143]

The eligibility criteria of the Scottish scheme completely disregards other more logical and appropriate factors, such as the purchasing history of the product, where the product was fractionated, and, crucially, whether the same batch of product was used in England as well as Scotland. The sole use of the criterion of where an applicant was resident at the time of infection is illogical, as it could be that a person who had been living in Scotland also received treatment in England, and they will not be able to be certain which treatment caused their infection – well not without an arduous look-back exercise to ascertain which infective batches were administered in which locality to residents of either country. Even if one accepts the hypothesis that Hepatitis C was contracted at the time of first exposure to concentrate, the same cannot be said about HIV, so this makes the matter even more complicated. This is analogous to a multitude of persons with haemophilia, living independently on different barges, each travelling the waterways of the United Kingdom in differing directions, whilst receiving clotting factor concentrates at various Haemophilia Centres in both England and Scotland at different times with little or no awareness of the crossing of borders within the UK, resulting in different people being infected at different hospitals with various products at different times; some of them being infected by commercial imported products, whilst some by Scottish or English products.

One possible answer to this complexity would be to take a "market share" approach in order to divide up the responsibility for infection and thus the financial bill for the support packages according to a suitable split (or division). This would be the approach in Tort. However, what would not be a satisfactory answer to this problem is to have a far more beneficial support scheme in one territory and an inferior, much-reduced scheme in another. When we take into account the history of the contamination affecting the UK as a whole, and the very much central role of the decision-maker (the Department of Health), then this

---

[141] Ibid. at [3].

[142] *Purja & Ors, R (on the application of) v Ministry of Defence* [2003] EWCA Civ 1345 [2004] 1 WRL 289 at [60] [65] [85] [87].

[143] *R (Carson) v Secretary of State for Work and Pensions* [2006] 1 AC 173 at [24].

difference in treatment, if it becomes policy, will be manifestly unfair and contrary to the rules of natural justice.

Analysis of *Carson*

This case deals with residency in a foreign country, as opposed to nationality, and for that matter residency of a non-EEC country.[144] It is not the best fit to be used as an authority (or precedent) for our case, but it raises many relevant issues.

Annette Carson, a writer, emigrated to South Africa. She became entitled to a United Kingdom retirement pension. Her connection to the United Kingdom is based in the main, on her having paid all the necessary contributions, including voluntary payments made after emigration. The more specific aspect of the case relates to annual uprating as pensioners ordinarily resident abroad are not entitled to such cost of living increases.

Most notably, Ms Carson was part of a very large class of 400,000 UK pensioners who live abroad. There is an absence of reciprocal treaties (for cost of living increases) with South Africa, and for that matter, many other states. However, there are such treaties with EEC countries.

Lord Hoffmann explains that "*Discrimination means a failure to treat like cases alike*",[145] however, he goes on to say that "there is nothing unfair or irrational about according different treatment to people who live abroad."[146] He offers the following justification for different treatment of those who live abroad: "*The system as a whole is neither adapted nor intended to maintain the standard of living of inhabitants of other countries, even if they have past connections with the United Kingdom.*"

This case is important, however, in that Lord Hoffmann unquestionably accepts residency as a personal characteristic: ***"I am content to assume that being ordinarily resident in South Africa is a personal characteristic."***[147] "*Likewise, I am willing to assume that the reason for the alleged discrimination, Ms Carson's foreign residence, was a Convention ground.*"[148]

Unfortunately, the *Carson* appeal failed, but it should be noted that there were genuine hurdles with the case, not least the somewhat flimsy nature of her past connection, the remoteness of South Africa, the fact that her country of residence was not an EEC country, and the weakness on the issue or requirement of the general public interest which underpins the difference in treatment.[149]

---

[144] *Regina v. Secretary of State for Work and Pensions (Respondent) ex parte Carson (Appellant)*
[145] Ibid. at [14]
[146] *Regina v. Secretary of State for Work and Pensions (Respondent) ex parte Carson (Appellant)* at [8]
[147] Ibid. at [13]
[148] Ibid. at [13]
[149] Ibid. at [16]

Nationality and Difference in Treatment

EU law prohibits discrimination against persons on the ground of "possessing the nationality of one of the member states."[150] The status of nationality may be involved in the formulation of the Scottish Scheme.

The difference in treatment between one EU member group of nationals (English haemophiliacs) and another (Scottish haemophiliacs) will be contrary to Article 14 if the treatment is unjustified. It appears to come down to whether or not the "difference in treatment in the application of the policy can be justified"[151].

In *Luczak v. Poland*[152] the Polish authorities refused to allow a non-national to join a social security system for farmers. Even though he had not made any contributions to the scheme, the ECHR held that property rights were sufficiently engaged. This case confirms property rights in relation to Social Security matters. He submitted that the refusal to admit him to the social security scheme for farmers on the basis of his nationality was discriminatory.

The Court explained that for the purposes of Article 14, a difference in treatment between persons in "analogous or relevantly similar positions" is discriminatory if it has "no objective and reasonable justification".[153] For the "different treatment" in question to be justifiable, it would need to "pursue a legitimate aim"[154] and strike a "fair balance between the demands of the general interest of the community and the protection of the rights of the applicant societies." Furthermore, the authority's policy choice should not be "*manifestly without reasonable foundation*".

[150] *"EU Anti-Discrimination Law"*, Second Edition, 2012, by Evelyn Ellis and Philippa Watson. Oxford EU Law Library, at page 22.
[151] *AL (Serbia) v Secretary of State for the Home Department* [2008] UKHL 42 [2008] 1 WRL 1434 at [5].
[152] *Luczak v. Poland* Application no. 77782/01.ECHR 27 November 2007
[153] Ibid. At [47].
[154] *National and Provincial Building Society and Others v. the United Kingdom*, judgment of 23 October 1997, Reports 1997-VII, § 80) at [76].

Objective and Reasonable Justification

A series of 4 questions were formulated by Brooke LJ in the *Michalak* case.[155]

> **I. Do the facts fall within the ambit of one or more of the substantive Convention provisions;**
>
> **II. If so, was there different treatment as respects that right between the complainant on the one hand and other persons put forward for comparison ("the chosen comparators") on the other;**
>
> **III. Were the chosen comparators in an analogous situation to the complainant's situation?**
>
> **IV. If so, did the difference in treatment have an objective and reasonable justification.**

We need to be aware of the threshold for what can be considered 'sufficiently analogous' between our chosen comparators:

> *"If an "analogous situation" means that the two cases are not relevantly different **(no two cases will ever be exactly the same)** then a "relevant difference" may be the justification for the difference in treatment."*[156]

> *"There is a single question: is there enough of a relevant difference between X and Y to justify different treatment? Secondly, the invocation of the **"rational and fair-minded person"** (who is, of course, the judge) suggests that the decision as to whether the differences are sufficient to justify a difference in treatment will always be a matter for the judge. In many cases, however, the decision will be a matter for Parliament or the discretion of the official entrusted with statutory powers."*[157]

---

[155] *Wandsworth London Borough Council v Michalak* [2003] 1 WLR 617, 625 at [20]
[156] *Regina v. Secretary of State for Work and Pensions (Respondent) ex parte Carson (Appellant)* at [30]
[157] Ibid. at [31]

Administrative End Purpose

> ***"It might be more logical to confine question (iv) to justification for different treatment of cases which were not relevantly different, eg to achieve some legitimate teleological or administrative purpose, such as correcting the effect of past discrimination or the administrative convenience of having clear distinctions. That would explain why in such cases the courts insist that the discrimination must be necessary and proportionate for the object to be achieved."***[158]

As we can see from Question IV, formulated by Brooke LJ, in *Michalak*[159]: "*...did the difference in treatment have an objective and reasonable justification?*"

In *AL (Serbia) v Secretary of State for the Home Department*, any difference in treatment must be justified by a 'very weighty reason'.[160]

> **"What does matter is whether this condition falls within the class for which *"very weighty reasons"* are required if a difference in treatment is to be justified."**

The requirement of "very weighty reasons" is more than certainly going to apply to our case, as in *Gaygusuz v Austria*[161]. In this case, Mr Gaygusuz complained of the Austrian authorities' refusal to grant him emergency assistance on the grounds that he did not have Austrian nationality, (one of the conditions laid down by the 1977 Unemployment Insurance Act) and that his case did not come under any of the exemption categories. The case was taken in conjunction the right to enjoyment of possessions under A1P1.

> *"According to the Court's case-law, **a difference of treatment is discriminatory**, for the purposes of Article 14 (art. 14), if it **"has no objective and reasonable justification"**, that is if it does not pursue a **"legitimate aim"** or if there is not a **"reasonable relationship of proportionality between the means employed and the aim sought to be realised"**. Moreover the Contracting States enjoy a certain margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a different treatment. However, **very weighty reasons** would have to be put forward before the Court could regard a difference of treatment **based exclusively on the ground of nationality** as compatible with the Convention."*[162]

---

[158] Ibid. at [32]
[159] *Wandsworth London Borough Council v Michalak* [2003] 1 WLR 617, 625, at [20]
[160] *AL (Serbia) v Secretary of State for the Home Department* [2008] UKHL 42 [2008] 1 WRL 1434 at [29]
[161] *Gaygusuz v Austria (1996)* 23 EHRR 364, at [42].
[162] *Gaygusuz v Austria (1996) 23* EHRR 364, at [42].

We would expect the proportionally test, as employed here for "nationality", to also be applied in our case for the status of "residency", and perhaps for that of being born with a hereditary condition, haemophilia, and also the status of a belonging to a group who have been infected with HIV and Hepatitis C.

Failure to Split the Beneficiary Group at an Earlier, More Logical Point:

In fact, in 2003 Scotland made a proposal following the Lord Ross Report, which, had it been implemented, would have meant substantially increased support for Scottish victims. However, this was circumnavigated by Westminster, who responded rapidly by setting up the Skipton Fund, which had the effect of keeping everyone in the UK at the same (much reduced) and uniform level of payment. The Skipton Fund was not codified or enacted in Scotland until 2005, although it was most certainly backdated.

These events presented a prime opportunity for Westminster to diverge from the UK-wide approach to the support schemes, yet it chose not to. Despite the fact that this was at least 6 years post devolution, when Scotland clearly showed signs of wanting to adopt an alternative and more generous scheme, the Department of Health promptly intervened to impose their own scheme modifications by instigating the Skipton Fund.

Disability and Discrimination

> **Direct Discrimination** occurs when a person treats another less favourably than they would a person from a different group. It is not necessary to prove this discrimination is intentional or motivated by prejudice.[163]
>
> **Indirect Discrimination** is defined in *DH v Czech Republic*[164] as: "a general policy or measure that has **disproportional prejudicial effects on a particular group**... notwithstanding that it is **not specifically aimed at that group**...." Again, it is not necessary to prove that the indirect discrimination is intentional.[165]

The ground of disability forbids discrimination under EU law, and under UK domestic legislation[166]. The Equality Act 2010, Section 6(1), offers some clarification on what is intended to be taken by the term "disability": "*a physical or mental impairment*"... where there is "*a substantial and long-term adverse effect.*"

A strictly medical view of disability was taken in *Chacón Navas*[167] where the CJEU looked at whether "sickness" in itself could be considered as disability. The Court stated: *"In order for the limitation to fall within the concept of 'disability', it must therefore be probable that it will last for a long time."*[168]

Historically, many haemophiliacs were exempted from the need to supply constant doctors' letters by being considered under the Special Rules that related to HIV, when their CD4 counts were under 200.

Many persons with haemophilia, particularly those with severe haemophilia, are registered as disabled with local authorities and are in receipt of Disability Living Allowance, now Personal Independence Payment, (DLA/ PIP). They are normally entitled to both components; help with personal living and mobility, and by default, are then awarded a blue parking badge.

Haemophiliacs infected with HIV would qualify as long-term sick (and thus disabled), as would those with HCV whose symptoms has progressed significantly. Those who are doubly infected by both HIV and HCV will be especially impacted by the adverse effects of the two viruses and their accompanying drug regimes working together. This is in addition to the accepted side-effects of both viruses.

---

[163] Liam Healy & Associates, *"Direct and Indirect Discrimination: A Discussion"* (2010). Accessed: 14th June, 2016. http://www.psychometrics.co.uk/discrimination.html

[164] *DH v Czech Republic* (2008) 47 EHRR 3

[165] Liam Healy & Associates, *"Direct and Indirect Discrimination: A Discussion"* (2010). Accessed: 14th June, 2016. http://www.psychometrics.co.uk/discrimination.html

[166] *"EU Anti-Discrimination Law", Second Edition,* 2012, by Evelyn Ellis and Philippa Watson. Oxford EU Law Library, at page 39.

[167] *Chacón Navas v Eurest Colectividadss SA* (case C-13/05 [2005] ECR I-6467).

[168] Ibid. at para [45].

It is clear that the protected characteristic of disability applies to haemophiliacs in a number of ways. It therefore follows that by being awarded a lower value scheme than the comparable class of haemophiliacs in Scotland, disabled English haemophiliacs are being discriminated against. We assert our right to like-for-like treatment as an analogous group who have both been neighbours to catastrophe for over three decades.

Article 14 Taken in Conjunction with A1P1

According to Fordham's Judicial Review Handbook, ***"Violation of Article 1P arises where there is deprivation of property or control of its use, and public authorities are unable to justify their actions (or relevant inaction)."***[169]

Under Article 1 of Protocol 1, if a certain group is not entitled to something that is likely to be the property of others in a similar position, then Article 14 will become engaged.[170]

It follows, therefore, that as past and current UK beneficiaries of the Department of Health's ex-gratia support schemes, English beneficiaries have a right to "possession" within the meaning of Article 1 of Protocol 1 which protects the right to peaceful enjoyment of possessions.

This is confirmed by reference to A1P1being made in many of the aforementioned cases. In *Gaygusuz*, Article 14 of the Convention is taken in conjunction with Article 1 of Protocol No. 1 "(art. 14+P1-1)". This is relied on by Mr Gaygusuz as he complained of infringements of his right to peaceful enjoyment of his possessions.[171] In *Carson*, Lord Hoffmann states: "*The preferred choice of the Strasbourg court in locating a Convention right in cases of economic discrimination by the state has been 1P1.*"[172]

We know that A1P1 has been successfully relied on in an important Italian case[173] which came before the ECHR in Strasbourg back in January 2016. The case is highly relevant as it concerned the claims of plaintiffs who were infected by different viruses (HIV, Hep B, or Hep C) from treatment due to their underlying pathologies (haemophilia or thalassaemia), or through surgical interventions. The plaintiffs also included family members of those who had already died. The case included a claim for violation of Article 1 of Protocol No. 1 (*Article 1 du Protocole no 1 à la Convention*) "Protection of property" and "Peaceful enjoyment of possessions".

---

[169] "Judicial Review Handbook" Sixth Edition, Michael Fordham Q.C. Page 612, at [P.59.9]
[170] *"The European Convention on Human Rights and the Employment Relation"*, published 2013. Edited by Filip Dorssemont, Klaus Lörcher, Isabelle Schömann.
[171] *Gaygusuz v Austria (1996)* 23 EHRR 364 at [29].
[172] *Regina v. Secretary of State for Work and Pensions (Respondent) ex parte Carson (Appellant)* at [12].
[173] *D.A. and Others v. Italy (Affaire D.A. et Authres c. Italie),* ECHR. 14th January 2016. http://www.bailii.org/eu/cases/ECHR/2016/79.html

In an earlier case, "*Affaire M.C. et autres c. Italie*"[174] of 3rd September 2013, the applicants also alleged a violation of Article 1 of Protocol No. 1 of the Convention , arguing that without "*réévaluation*" (annual uprating), the amount of IIS (*Indennità Integrativa Speciale*) was bound to gradually lose its value due to currency devaluation. Moreover, IIS represented between 90% and 95% of the overall amount of compensation. In the opinion of the Court, the adoption of Legislative Decree No. 78/2010 by the Italian government, placed an "abnormal and excessive charge" (« *charge anormale et exorbitante* ») on the applicants, and the damage to their property was of a disproportionate character, upsetting the fair balance between the demands of the general interest and safeguarding the fundamental rights of individuals.

[174] *Affaire M.C. et autres c. Italie,* ECHR. 03.09.2013. http://www.bailii.org/eu/cases/ECHR/2013/802.html

Miscellaneous Factors

Eligibility and Geographical Anomalies

> *"As the right hon. Member for Orkney and Shetland (Mr Carmichael) and my hon. Friend the Member for Caithness, Sutherland and Easter Ross (Dr Monaghan) have pointed out,* ***the Scottish Infected Blood Forum has identified 25 families resident in Scotland who would be covered under the proposed UK Government scheme,*** *as the original incident took place while they were resident elsewhere in the UK. Therefore, MPs representing constituencies in Scotland may find themselves representing constituents with two distinct offers of compensation. That is not fair—it is completely unjust."*
>
> Chris Stephens (Glasgow South West) (SNP)

It is clear from this Hansard[175], that a number of people who are currently resident in England were actually infected in Scotland. Despite this, they will not benefit from the more generous Scottish scheme. Similarly, ***there is at least one example of someone being infected in England who is now resident in Scotland who also will not benefit from the Scottish scheme.***

Devolution and the Law

> ***"Devolution, as implemented in the UK, is an unusual and messy way of dispersing power."***
>
> **Mark Elliott, 11th September, 2014**

The devolved administrations are funded mainly by block grants made by the UK Parliament.

There are limits to the power of the Scottish Parliament. It cannot override European law nor the binding effect of the rights enshrined within the Human Rights Act 1998.

[175] Commons Hansard, Contaminated Blood Debate, 12 April 2016

The fundamental concerns of a particular community can mean that the specific devolution arrangements with unique background and political situation have to be taken into account.[176] This can be regarded as being of almost constitutional importance[177].

The Privy Council decides on matters involving devolution and on appeal will transfer such cases to the Supreme Court. The Attorney-General (England), or Lord Advocate (Scotland), can refer cases directly to the Privy Council on any devolution issue.[178]

There are conventions which prohibits the Westminster Parliament from interfering unilaterally in relation to devolved matters. It can only do so if the devolved legislature consents.[179]

Reviewability of the Schemes

In *R v Criminal Compensation Board and Another, ex parte P* (1995), the prerogative power of making *ex gratia* payments to the victims of crime was held to be reviewable. Also in the *National Farmers Union,*[180] the NFU was able to challenge *ex gratia* payments made to farmers on the culling of their livestock as a result of the foot and mouth epidemic.

Also, we know that the Skipton Fund, as an emanation of the State is reviewable.[181]

[176] "Constitutional and Administrative Law", 7th Edition. John Adler, "Devolution" at [6.4] page 103.
[177] *Robinson v Secretary of State for Northern Ireland* (2002), Lord Hoffmann, at [33].
[178] "Constitutional and Administrative Law", 7th Edition. John Adler, "Scotland" at [6.4.1] page 107.
[179] Constitutional Law: "1,000 words | Devolution in the United Kingdom", Mark Elliott, 11th September, 2014. https://publiclawforeveryone.com/2014/09/11/1000-words-devolution/
[180] *National Farmers Union v Secretary of State for the Environment, food and Rural Affairs* (2003)
[181] *R (on the application of Sharon Moore) v (1) Skipton Fund Ltd (2) Secretary of State for Health* [2010] EWHC 3070 (Admin).

Conclusions

1. Since before the contaminated blood scandal happened, haemophiliacs throughout the UK have been treated as one group. This is best illustrated by the fact that as treatment developed it was overseen by the United Kingdom Haemophilia Centre Directors Organisation (UKHCDO). Regardless of devolution, this remains so today, and their website[182] states that:

> ***The United Kingdom Haemophilia Centre Doctors' Organisation is an association of medical practitioners who work within the Haemophilia Centres of England, Scotland, Northern Ireland or Wales and have an interest in the care of people with Haemophilia or other inherited bleeding disorders...***

2. Following the acknowledgement that around 5,000 British haemophiliacs had been infected by contaminated blood, the government began to make moves towards setting up support schemes in order to process ex-gratia payments. These schemes were made up of registrants from the whole of the UK, and these arrangements continued post-devolution.

3. There have been (three opportunities where Scotland could have justified a separate payment scheme for its haemophilia community: The first was following devolution itself. It failed to do anything. The Department of Health was also quite content to continue treating everyone the same. The second was following the Ross Report. Here, Scotland attempted to begin moves towards a separate payment scheme, but were railroaded by Westminster into a new arrangement which remained UK-wide. Thirdly, in January 2011, the Department of Health published their "Support Review"[183] where yet another opportunity for Scotland to emancipate was lost. The Department of Health failed to relinquish control over Scotland, leaving the devolved administration to continue to act under dictation.

4. There are no new differences between haemophiliacs in Scotland and those in England which are sufficiently significant to justify the different (and more generous) treatment of Scottish members.

---

[182] http://www.ukhcdo.org/

[183] "*Review of the Support Available to Individuals Infected with Hepatitis C and/or HIV by NHS-Supplied Blood Transfusions or Blood Products and their Dependents.*" Published January, 2011.

5. Even though, when setting up the Skipton Fund, the government decided to merge haemophiliacs with transfusion victims for the purpose of dealing with Hepatitis C infections, the fact remains that haemophiliacs, as a group, were still kept together, and not separated in any way according to nationality or residency.

6. The new Scottish scheme relies on criteria that has nothing whatsoever to do with either the circumstances of individual infection, or the reasons for those infections. It does not take into account cross-border supply of products, nor the fact that many haemophiliacs were treated in both England and Scotland and may be unable to identify exactly where they were infected.

7. The proposed English scheme ('Option 2') will commit many English haemophiliacs to a life of poverty and deprivation. Almost all victims will lose out – if not immediately, then within a short time. In contrast, Scotland's scheme offers an acceptable payment for the co-infected and Skipton stage twos, with a commitment to re-visit other areas such as support for bereaved children and parents. There is also a commitment to try and ensure that those currently at stage one are effectively moved into stage two.

8. Events over the last few months have led us to believe that at best the government has delivered hollow promises, and at worst has misled Parliament on several occasions.

9. We believe that there are clear, justifiable grounds for legal action to be taken, particularly in two areas: discrimination and legitimate expectation.

In light of all our research and findings, we believe the Department is under a duty to provide a support scheme that is at least on a par with the Scottish one. However, it should be noted that this would only represent the beginning of a more complete settlement process; one that fully recognises decades of neglect and financial deprivation. This should not, however, be used as an excuse for yet further lengthy delays. We have co-operated with the government throughout, and believe that a full, fair and substantial settlement is now the only acceptable option.

Bibliography

http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/appg_hcb_fr.pdf

http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150115/debtext/150115-0002.htm

Self-sufficiency in Blood Products in England and Wales: A Chronology from 1973-1991. DOH (2006) (Dr R.S Lane. Implementation of the working party report on trends in the demand for blood products. July 1979.)

http://www.macfarlane.org.uk/home.php

A and Others -v- National Blood Authority and Another QBD 26 Mar 2001
http://www.bailii.org/ew/cases/EWHC/QB/2001/446.html

Report of the Expert Group on Financial and Other Support, March 2003
http://www.gov.scot/Resource/Doc/47034/0024918.pdf

http://www.skiptonfund.org/

http://taintedblood.info/files/1245509047A5_Booklet_Comparison_Document.pdf

http://www.michelmores.com/what-we-do/client-stories/mr-justice-holmans-judgment-andrew-march-haemophilia-judicial-review

http://www.penroseinquiry.org.uk/

http://www.haemophilia.org.uk/

http://www.taintedblood.info/timeline.php#400

http://www.penroseinquiry.org.uk/finalreport/pdf/LIT0013058.PDF

http://www.taintedblood.info/timeline.php

http://www.taintedblood.info/tlfiles/MRC Minutes October 1983.pdf

http://www.penroseinquiry.org.uk/finalreport/pdf/LIT0013058.PDF/
"Blood Transfusion for Clinicians" (1977), Dr John Wallace

http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

https://en.wikipedia.org/wiki/Scotland_Act_1998

https://en.wikipedia.org/wiki/History_of_Scottish_devolution

http://www.bbc.co.uk/news/uk-29477233

https://en.wikipedia.org/wiki/Barnett_formula

Letter from Jane Ellison, Parliamentary Under Secretary of State for Public Health to Joseph Peaty (via Geoffrey Robinson MP), Ref. PO00000917511, dated 2nd March 2015.

Minutes of the 19th Meeting of the UK Haemophilia Centre Directors, Royal Free Hospital Medical School, Friday, 25th September, 1987. http://www.penroseinquiry.org.uk/pdf/SNB0017768.PDF

Penrose Preliminary Report at [5.23]
http://www.penroseinquiry.org.uk/preliminary-report/chapter-5/

Transcript for 30/03/11 (day 14); 57 (16) to 58 (3) (Professor Ludlam):
http://www.penroseinquiry.org.uk/downloads/1350481891-PEN0191171.pdf

The Final Report of the Penrose Inquiry, Chapter 17 at [17.23]
http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_17.html

Penrose Inquiry: Witness Statement of John G. Davies
www.penroseinquiry.org.uk/downloads/transcripts/PEN0171020.PDF

Penrose Preliminary Report at [5.8].
http://www.penroseinquiry.org.uk/preliminary-report/chapter-5/

Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence. http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm

"*Review of the Support Available to Individuals Infected with Hepatitis C and/or HIV by NHS-Supplied Blood Transfusions or Blood Products and their Dependents.*" January 2011, "Ex-gratia payments to hepatitis C infected individuals" at 2.11, page 8.

Report of the Expert Group on Financial and Other Support, March 2003
http://www.gov.scot/Resource/Doc/47034/0024918.pdf

Penrose Inquiry Final Report, Chapter 22 "Haemophilia Therapy - Use of Blood Products 1985-1987" at 17.93

Haemophiliac HIV Litigation, Advice on Settlement Document, Appendix 1, Chronology, pp 56-58.

Minutes of the meeting of Haemophilia Centre Directors of the United Kingdom. 13th January 1977, Middlesex Victoria Infirmary London. Agenda item 3, point 3, pgs. 12-13 headed: "Activities of Reference Centre Directors and the supply of Factor VIII"

Penrose Preliminary Report, September 2010, at 3.101

Letter, from Treasury Chambers, Parliament Street, London, to Mr P. A. Brunning Esq., DHSS. 5th February, 1987. www.penroseinquiry.org.uk/downloads/transcripts/SGH0031871.PDF

Minutes of a Meeting of the Blood Transfusion Service Sub-Committee, Wednesday, 25th February 1987, under (b.). www.penroseinquiry.org.uk/downloads/transcripts/SGH0031855.PDF

Minutes of the HCDO (Haemophilia Reference Centre Directors Organisation), dated 13th May 1983, Dr. Diana Walford present as Departmental (DHSS) Observer.

Penrose Preliminary Report, 5.10. http://www.penroseinquiry.org.uk/pdf/SNF0012412.PDF

Minutes of the Tenth Meeting of the U.K. Haemophilia Centre Director, held in Oxford on 20th & 21st November, 1979, Dr Diana Walford (DHSS) was in attendance; also Minutes of the HCDO (Haemophilia Reference Centre Directors Organisation) 13th May 1983, Dr. Walford was DHSS observer.

Penrose Inquiry Final Report, Chapter 22 "Haemophilia Therapy - Use of Blood Products 1985-1987", "Edinburgh" at 22.23 http://www.penroseinquiry.org.uk/finalreport/text/354876_chapter_22.html
Witness Statement of Professor Christopher Ludlam to Schedule issued on 23rd August 2011, related to topic C3A: http://www.penroseinquiry.org.uk/finalreport/pdf/PEN0171790.PDF

Minutes of the 16th Meeting of the UKHCDO. 21 October 1985
http://www.taintedblood.info/tlfiles/UKHCD Minutes 21 Oct 1985.pdf

Minutes of the 13th Meeting of UKHCDO, University Hall of Residence, Owens Park, Manchester. Monday 13th September 1982. Pgs. 1-3.

"Licensing of PFC and its Products During the Period 1976-1990: A Briefing Note, dated 20th December, 2005. Page 1.

Submission by the Scottish Haemophilia Forum, Philip Dolan, Chairman. Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence.
http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm

Lord Ross, Chair of the Expert Group on Financial and Other Support, March 2003, pgs. 8-10. Recommendation 1C.

Submission by the Scottish Haemophilia Forum, Philip Dolan, Chairman. Health Committee 6th Report 2005, 1st March 2005 (6th Meeting, Session 2 (2005)), Written Evidence.
http://archive.scottish.parliament.uk/business/committees/health/reports-05/her05-06-vol02-03.htm

Health Protection Agency Colindale (HPA), "vCJD and Plasma Products - Tables of vCJD implicated batch numbers", 7th September 2004. Note: Products manufactured by the Protein Fractionation Centre, Scotland are designated 'PFC'.

http://www.penroseinquiry.org.uk/

http://www.penroseinquiry.org.uk/terms-of-reference/

Written Ministerial Statement- 25th March 2015

http://www.taintedblood.info/news.php?mode=article&newsid=270

https://hansard.parliament.uk/Commons/2015-03-26/debates/15032622000002/PenroseInquiry

https://hansard.parliament.uk/Commons/2015-03-26/debates/15032622000002/PenroseInquiry

http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm131029/halltext/131029h0001.htm#131029h0001.htm_spnew32

Blood: Contamination: Written question – 22352, Answered by Jane Ellison. 22 January 2016. http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-01-13/22352

Memorandum of the Oxford Haemophilia Centre (Oxfordshire Health Authority) to All U.K. Haemophilia Centre Directors, "Trials of 'Hepatitis Reduced' Factor VIII - An Update", dated 29th March 1984.

http://www.penroseinquiry.org.uk/finalreport/pdf/SNB0075982.PDF

Letter from N. Pettet, Product Services Manager, Blood Products Laboratory (BPL) to Dr R. J. Perry, Director, PFC, Edinburgh. 24 July 1986. http://www.penroseinquiry.org.uk/pdf/SNB0075980.PDF

http://www.penroseinquiry.org.uk/finalreport/pdf/SNB0075982.PDF

The Penrose Inquiry, Final Report, Chapter 22: "Haemophilia Therapy - Use of Blood Products 1985-1987", "Supply of 8Y for Scotland" at 22.102.

Footnote: Professor Ludlam - Day 55, page 120. The Inquiry subsequently learned that this supply appears to have been arranged via Dr Boulton - see letter of 24 August 1987, [PEN.019.1535]. The letter indicates that Dr Boulton was exploring the possibility of obtaining a regular supply of 8Y from England.

http://www.penroseinquiry.org.uk/downloads/transcripts/130511.PDF

http://news.bbc.co.uk/1/hi/scotland/4201253.stm

Correspondence to Fergus Ewing, MSP from Andy Kerr MSP, the then Minister for Health & Community Care. Dated 6th March 2005. Also: BBC Frontline Scotland - Blood and Tears (2005).

Scottish National Blood Transfusion Service, Minutes of Directors' Meeting, SNBTS Headquarters Unit. 29 March 1983)

DOH Freedom of Information Documents Released July 2007. Volume 30, page 2.

http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

http://news.scotland.gov.uk/News/Extra-20-million-for-infected-blood-support-2418.aspx

Infected Blood: Reform of Financial and Other Support, January 2016, page 5, Footnote 2 at [2.10]: ("This estimate is based on the payments made by the current schemes. Following scheme reform we expect to continue to have approximately the same budget as for the current schemes.")

Commons Hansard, "Contaminated Blood", 12 April 2016, Volume 608.

http://www.haemophilia.org.uk/news/view?id=27&x%5B0%5D=news/list

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492132/20160111_Consultation_principles_final.pdf

http://www.taintedblood.info/files/1465746005Invitation%20to%20Reference%20Group%20(5%20Oct)(2).pdf
http://www.taintedblood.info/files/1465747130Appendix%201%20Suggested%20Widened%20Groups%20for%20Consultation%20141015%20Final.pdf

http://www.taintedblood.info/files/1465747387Appendix%207%20%20Reference%20Group%20on%20Infected%20Blood%20-%20Final%20Report%201%20%20November%202011%20(2).pdf

http://www.taintedblood.info/files/1465747680TB%20Consolidated%20Points%20-%20Reference%20Group%20-%20vFINAL%20%20%20%20%20%20edits.doc

Oral Statement to Parliament: "Infected blood scheme reform", Jane Ellison. 21 January 2016
https://www.gov.uk/government/speeches/infected-blood-scheme-reform

TaintedBlood.info "Completing the Consultation Document – Notes for Guidance", 23rd March 2016.

https://en.wikipedia.org/wiki/List_of_Primary_Urban_Areas_in_England_by_population

http://www.taintedblood.info/files/1465748824Key%20points%20objctions%20to%20consultation%20doc%20%20TB%20FINAL.doc

Taintedblood letter to Jane Ellison, Parliamentary Under Secretary of State for Public Health, 19th February 2016.

Taintedblood letter to Jeremy Hunt, Secretary of State for Health, 3rd August, 2015.

Jane Ellison, Parliamentary Under Secretary of State for Public Health, reply letter to Tainted replied, 3rd September 2015.

Taintedblood letter to Jane Ellison, Parliamentary Under Secretary of State for Public Health, 19th February 2016.

https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support Accessed on 24th February 2016. (The page has since changed.) The Department's intended "audience" included: Voluntary groups, Community groups, Members of the public, Patients, Carers, Charities, Advocacy or Support Organisations, GPs, Nurses, Clinicians, Commissioners, Directors of Public Health, Pharmacists, Healthcare Scientists, Occupational Therapists, Care-Givers, the NHS

Commissioning Board, Clinical Commissioning Groups, Academic/ Professional Institutions, the Royal Colleges, Local authority, Social care Providers, and Service Users.

TaintedBlood.info "Completing the Consultation Document – Notes for Guidance", 23rd March 2016.

http://www.taintedblood.info/files/1465662501Differences%20Between%20Haemophiliacs%20&%20Whole%20Blood%20Recipients_FINAL_2.doc

http://hansard.millbanksystems.com/commons/1987/nov/16/haemophiliacs-financial-assistance

http://www.publications.parliament.uk/pa/cm199091/cmhansrd/1990-12-11/Writtens-5.html

http://hansard.millbanksystems.com/commons/1991/dec/20/infected-blood-transfusions

http://hansard.millbanksystems.com/commons/1991/dec/20/infected-blood-transfusions

http://eppi.ioe.ac.uk/cms/Portals/0/PDF%20reviews%20and%20summaries/ART%20Therapy%202015%20Llewellyn.pdf?ver=2016-04-23-122500-213

Opinion of Lord Mackay of Drumadoon, Petitions by Rosaleen Kennedy and Jean Black for Judicial Review of Decisions of the Lord Advocate and Scottish Ministers. 5th February 2008, Summary, at [119]. http://www.scotcourts.gov.uk/search-judgments/judgment?id=7ea286a6-8980-69d2-b500-ff0000d74aa7

Unilever: R v Inland Revenue Commissioners, ex p Unilever Plc [1996] STC 681 CA.

Archer Inquiry: "Independent Public Inquiry Report On NHS Supplied Contaminated Blood and Blood Products", Final Report, Published: 23 February 2009, Introduction, page 5.

Commons Library, Debate Pack, "*Reform of support arrangements for people infected with contaminated blood*" by Dr Sarah Barber, CBP 2016/0077, 7th April 2016.

Written Question on Blood Contaminated: 220665. Answered by Jane Ellison, 16th January, 2015. http://www.parliament.uk/written-questions-answers-statements/written-question/commons/2015-01-13/220665

The Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2015, page 6. "MFT's community of care included 344 infected beneficiaries, comprising **304 survivors** of those who were originally registered with MFT..."

R v North and East Devon Health Authority, ex parte Coughlan [2000] 3 All ER 850 at [53], [60] & [86] http://www.bailii.org/ew/cases/EWCA/Civ/1999/1871.html

Schmidt v Secretary of State for Home Affairs (1969) [1969] CA, 2 WLR 337, [1969] 2 Ch 149, [1968] EWCA Civ 1, (1969) 133 JP 274, [1969] 1 All ER 904.

R. v. Secretary of State for the Home Department, ex parte Khan (1984) EWCA Civ 8 [1984] WLR 1337 C.A.

Preson v IRC (1985) STC 2 282.

CCSU v Minister for the Civil Service (1985) AC 374. (Also known as the *GCHQ* case).

R v Secretary of State for the Home Department, ex parte Urmaza [1996] COD 479.

"Judicial Review Handbook" Sixth Edition, Michael Fordham Q.C. at [55.2], and page 612, at [P.59.9]

BBC News "Payment rise for hepatitis C infected blood victims", Eleanor Bradford, BBC Scotland Health Correspondent. 18th March 2016.

Purja & Ors, R (on the application of) v Ministry of Defence [2003] EWCA Civ 1345 [2004] 1 WRL 289 at [60] [65] [85] [87].

R (Carson) v Secretary of State for Work and Pensions [2006] 1 AC 173 at [3], [6], [8], [12-14], [16], [30-32]
http://www.bailii.org/uk/cases/UKHL/2005/37.html

"EU Anti-Discrimination Law", Second Edition, 2012, by Evelyn Ellis and Philippa Watson. Oxford EU Law Library, at pages 22 and 39.

AL (Serbia) v Secretary of State for the Home Department [2008] UKHL 42 [2008] 1 WRL 1434 at [5], [29]

Luczak v. Poland Application no. 77782/01.ECHR 27 November 2007 at [47].

National and Provincial Building Society and Others v. the United Kingdom, judgment of 23 October 1997, Reports 1997-VII, § 80) at [76].

Wandsworth London Borough Council v Michalak [2003] 1 WLR 617, 625 at [20], [31], [32]

Gaygusuz v Austria (1996) 23 EHRR 364, at [29], [42].

Liam Healy & Associates, *"Direct and Indirect Discrimination: A Discussion"* (2010). Accessed: 14th June, 2016. http://www.psychometrics.co.uk/discrimination.html

DH v Czech Republic (2008) 47 EHRR 3

Chacón Navas v Eurest Colectividadss SA (case C-13/05 [2005] ECR I-6467) at para [45].

"The European Convention on Human Rights and the Employment Relation", published 2013. Edited by Filip Dorssemont, Klaus Lörcher, Isabelle Schömann.

D.A. and Others v. Italy (Affaire D.A. et Authres c. Italie), ECHR. 14th January 2016.
http://www.bailii.org/eu/cases/ECHR/2016/79.html

Affaire M.C. et autres c. Italie, ECHR. 03.09.2013.
http://www.bailii.org/eu/cases/ECHR/2013/802.html

Commons Hansard, Contaminated Blood Debate, 12 April 2016

"Constitutional and Administrative Law", 7th Edition. John Adler, "Devolution" at [6.4] pp. 103 & 107

Robinson v Secretary of State for Northern Ireland (2002), Lord Hoffmann, at [33].

Constitutional Law: "1,000 words | Devolution in the United Kingdom", Mark Elliott, 11th September, 2014.

https://publiclawforeveryone.com/2014/09/11/1000-words-devolution/
National Farmers Union v Secretary of State for the Environment, food and Rural Affairs (2003)

R (on the application of Sharon Moore) v (1) Skipton Fund Ltd (2) Secretary of State for Health [2010] EWHC 3070 (Admin).

http://www.ukhcdo.org/

http://www.legislation.gov.uk/ukpga/2016/11/contents/enacted

http://www.gov.scot/resource/doc/47032/0013897.pdf

Scotland's Health White Paper, Edinburgh, February 2003.
www.gov.scot/resource/doc/47032/0013897.pdf

House of Commons, Oral Answers to Questions, Wednesday 11 March 2015, Column 289.
http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150311/debtext/150311-0001.htm

"*Victims of NHS infected blood disaster accuse UK Government over payment delay*"; The Herald Scotland, Judith Duffy, Reporter, 12th June 2016.(Also at Para [10] Quotation of Health Secretary, Shona Robison.)
http://www.heraldscotland.com/news/14551821.Victims_of_NHS_infected_blood_disaster_accuse_UK_Government_over_payment_delay/

Malcolm Chisholm MSP, Minister for Health & Community Care, Letter to Christine Grahame, MSP, Convener, Health and Community Care Committee. August 2003.
http://archive.scottish.parliament.uk/business/committees/historic/health/papers-03/hep03-05a.pdf

Agenda item 4 HC/S2/03/05/3 "*Hepatitis C*", Peter McGrath, Senior Assistant Clerk: Pgs. 7-8
http://archive.scottish.parliament.uk/business/committees/historic/health/papers-03/hep03-05a.pdf

http://davidwolfe.org.uk/wordpress/archives/268
R (Madden) v Bury Metropolitan Borough Council [2002] EWHC 1882 (Admin); *Vale of Glamorgan v Lord Chancellor* [2011] EWHC 1532 (Admin).