



DEBATE PACK

Number CDP 2016/0227, 23 November 2016

Reform of the support arrangements for people affected by contaminated blood and blood products

This pack has been prepared ahead of the debate in the Commons Chamber on Thursday 24 November 2016. This debate was scheduled by the Backbench Business Committee following a representation from Diana Johnson, Barbara Keeley and Margaret Ritchie.

The motion for the debate is:

“That this House notes the Government’s recent announcement on the reform of the support schemes for people affected by contaminated blood and blood products; recognises that the contaminated blood scandal was one of the biggest treatment disasters in the history of the NHS; believes that those people affected should have a reasonable standard of living and not just be removed from poverty; is concerned that bereaved partners of people who died with HIV/AIDS and those reliant on regular top-up payments will be worse off; is concerned that the new payments for people infected with Hepatitis C are not commensurate with the pain and suffering caused; notes that people who were infected with other viruses, those who did not reach the chronic stage of Hepatitis C and bereaved parents are not mentioned in this announcement; and calls on the Government to use the funds from the sale of Plasma Resources UK to bring forward revised proposals that are properly funded and which provide appropriate support to all affected people.”

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

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Contents

1.	Reform of the support arrangements for people affected by contaminated blood and blood products	2
2.	News Items	12
3.	Press releases	14
4.	Parliamentary material	27
4.1	Debates	27
4.2	Statements	27
5.	Parliamentary Questions	33
6.	Further reading and useful links	40

1. Reform of the support arrangements for people affected by contaminated blood and blood products

In July 2016, following a public consultation, the Government announced its plans to introduce a new financial support scheme for those affected by infected NHS blood products. In the Ministerial Statement, the then Minister for Public Health reported that the Government recognised the suffering of people that had contracted hepatitis C and HIV as a result of these blood products. She acknowledged criticism of the current schemes, and that the new approach took account of the responses to the consultation.

Key changes in the new scheme include:

- those infected with hepatitis C at stage 1 will receive a new flat rate annual payment of £3,500, rising to £4,500 from 2018/2019. This will not be linked to an individual assessment, as was proposed in the consultation.
- those with hepatitis C at stage 2 or those with HIV, their annual payments will increase to £15,500, rising to £18,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 1 will receive £18,500, rising to £22,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 2, will receive £30,500, rising to £36,500 from 2018/2019
- discretionary support will continue and will be enhanced from 2018/2019
- a new special appeals mechanism for those at hepatitis C stage 1 who consider that the impact of their infection on their health may mean they could qualify for stage 2 payments will be introduced from 2017/2018
- continuation of a £50,000 lump sum payment for those infected with hepatitis C stage 1 who progress to stage 2
- partners/spouses at the time of death of a primary beneficiary will be entitled to a £10,000 one-off lump sum where the HIV/hepatitis C infection contributed to the death of their partner/spouse - this will apply to those already bereaved and newly bereaved.¹

Previously, financial support schemes have applied across the UK. However, the Scottish Government announced a different approach to that proposed in England in March 2016, and the Welsh Government have recent stated that they will remain in line with the scheme in England for the remainder of 2016-17 financial year but will consult on a new scheme from April 2017. The Northern Irish Government have

¹ Department of Health, [News story, Infected blood payment scheme reformed](#), 13 July 2016

not yet made an announcement about plans for future financial support.

This briefing provides further background, information on the current financial support schemes, and the reforms announced in July 2016.

1.1 Background

During the 1970s and early 1980s thousands of UK patients contracted HIV, Hepatitis C, or both, from contaminated blood or blood products. A recent response to a Parliamentary question from the Under-Secretary of State for Health provided some 2011 estimates of how many people had been infected:

The 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, which this Government published in January 2011, included estimates that around 1,300 individuals had been infected with HIV through treatment with National Health Service-supplied blood or blood products, of whom approximately 400 remained alive at the end of 2010. Similarly, it is estimated that around 33,000 individuals may have been infected with hepatitis C, of whom it is estimated that approximately 9,000 remained alive in 2003. The Department does not hold information on the cause of death; however, it is likely that many of those infected with hepatitis C will have died of unrelated causes.²

No-fault Government payment schemes were established to provide support for those affected.

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

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

These concerns eventually led to the establishment of the Independent Public Inquiry into Contaminated Blood and Blood Products (the Archer Inquiry), a non-statutory inquiry which reported in February 2009.³ Amongst the Archer Inquiry recommendations was a call for reform of support for those affected in line with a compensation scheme in place in the Republic of Ireland for those affected by infected blood products which offers higher payments than those in the UK. Successive Governments have rejected comparability with the Irish scheme on the basis that it was established to compensate victims for wrongdoing by a government agency but that no similar wrongdoing occurred in the UK.

² [Blood: Contamination:Written question - 220665 16 January 2015](#)

³ The Archer Inquiry, *Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products*, 23 February 2009

The [Labour Government's response to the Archer Inquiry](#) included:

- increasing annual payments for people infected with HIV to £12,800, replacing the previous variable payments (averaging £6,400)
- the Haemophilia Society to receive £100,000 per year for the next five years
- a review of financial relief for people affected by hepatitis C to be taken in five years.⁴

An April 2010 Judicial review of the previous Labour Government's response to the Archer Inquiry questioned the basis for rejecting comparability with Ireland⁵ and the coalition Government responded with a proposal to review aspects of financial support, while restating its rejection of the Irish model.

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

- reform payments to those infected with Hepatitis C who have developed advanced liver disease, increasing the lump sum from £25,000 to £50,000, introducing an annual payment of £12,800, and establishing a discretionary fund to provide additional hardship payments
- remove a provision preventing payments for Hepatitis C patients deceased before 29 August 2003, allowing new claims in these cases to be made until the end of March 2011
- provide free prescriptions and counselling for those with Hepatitis C and/or HIV.⁶

These measures, introduced in 2011 across the UK, were estimated to represent an additional £100-130m of support over the life of the 2010-2015 Parliament.⁷

They were welcomed as a step in the right direction by some patient and campaign groups, but there has been continuing concern that the level of payments still falls below that in the Republic of Ireland and that a number of those affected by Hepatitis C will not be eligible for the increased payments.

The Penrose Inquiry was set up in Scotland in 2008 to investigate cases of patients with hepatitis C and HIV following the use of infected blood products. The [final report](#) was published in March 2015.

Following the publication of the report, and in response to ongoing concerns about the current financial support system, the Secretary of State for Health announced in March 2015 that the Government would look at a new financial system and a transitional payment of £25 million would be provided.

⁴ Department of Health, [Government response to Lord Archer's Independent report on NHS supplied contaminated blood and blood products](#), 20 May 2009.

⁵ March, R v Secretary of State for Health [\[2010\] EWHC 765 \(Admin\)](#)

⁶ Department of Health, [Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependants](#), 10 January 2011

⁷ [HC Deb 10 January 2011, c1232](#)

1.2 Current financial support system

Support for patients with HIV or Hepatitis C as a result of infected blood products is currently provided by a number of trusts and charities.

A table within the Government consultation document on a new financial support scheme provides an overview of the different organisations and the types of support currently available:

Figure 1. Table of current payment schemes⁸

Organisation	Year set up	Status of organisation	Who it supports	Types of support available
MFET Ltd	2010	Non-discretionary company limited by guarantee	People infected with HIV	Variable lump sum on entry Annual payments (£14,749 in 2015/16) Reimbursement for Prescription Pre- payment Certificate
Macfarlane Trust	1988	Discretionary charity	People with bleeding disorders infected with HIV (including those co-infected with hepatitis C) and their families, including bereaved family members and dependents	Means-tested income top-ups One-off grants Means-tested winter payments Other support, including benefits advice
Eileen Trust	1993	Discretionary charity	People infected with HIV (including those co-infected with hepatitis C) through blood transfusion and their families, including bereaved family members and dependents	Means-tested regular payments One-off grants Winter payments Beneficiary events Other support, including benefits advice
Skipton Fund Ltd	2004	Non-discretionary company limited by guarantee	People infected with hepatitis C Stage 1: chronic hepatitis C Stage 2: cirrhosis, primary liver cancer, b-cell non-Hodgkin lymphoma, liver transplant	Lump sum at stage 1 and stage 2 Annual payments for stage 2 (£14,749 in 2015/16) Reimbursement for Prescription Pre- payment Certificate

⁸ Department of Health, [Infected blood: reform of financial and other support](#), 21 January 2016

Caxton Foundation	2011	Discretionary charity	People infected with only hepatitis C and their families, including bereaved family members and dependents	Means-tested income top-ups One-off grants Winter payments Other support including benefits advice
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The 2015 APPG on Haemophilia report, [Inquiry into the current support for those affected by the contaminated blood scandal in the UK](#) provides further information on these schemes and an appraisal of them. The APPG reported a number of concerns regarding the current system, these include a lack of awareness about the support available, a need for an improved structure and appeals process and concerns about the failure of current system to meet the needs of those affected.

The then Under-Secretary of State for Health, acknowledged the APPG report and other concerns in responding to a debate on this subject in January 2015, but said that the Penrose Inquiry report should be taken into account when considering changes to the system.⁹

1.3 The Penrose Inquiry

[The Penrose Inquiry](#) was set up in Scotland under section 28 of the *Inquiries Act 2005*, as a judicially led review into the transmission of Hepatitis C and HIV from NHS blood and blood products.

The [final report](#) was published in March 2015 and consists of five volumes. Lord Penrose reported that whilst some commentators believe that more could have been done to prevent infection in certain groups, the evidence showed that there were few areas where matters could have been handled differently. There was one recommendation within the report: that the Scottish Government takes all reasonable steps to offer a Hepatitis C test to everyone in Scotland who had a blood transfusion prior to 1991 and has not previously been tested.

The Prime Minister, was asked about the Penrose inquiry report in PMQs on the day of its publication. He made an apology to all those affected by infected blood products and confirmed the decision to change the payment support system.¹⁰

Following the publication of the Penrose Inquiry report, a written statement from the Secretary of State for Health was published. It stated that the Government would allocate £25 million as a transitional payment and a new support system for these patients would be developed. The Minister stated that despite improvements to the financial systems in 2011, there had been ongoing criticism of the schemes. The challenge for the Government was to find the most appropriate way to provide financial assistance while ensuring any new

⁹ [HC Deb 15 January 2015 c1072](#)

¹⁰ [HC Deb 25 March 2015 c1423](#)

system is responsive to medical advances and sustainable in financial terms.¹¹

There have been a number of responses to the publication of the Penrose Inquiry report. Campaign groups such as Tainted blood expressed disappointment at the weakness of the recommendations in the report and have called for real compensation to be made available for the group of people affected by infected blood.¹² The Chief executive of the Hepatitis C Trust said the organisation were happy that the report provided some answers about the infections, but was disappointed that it did not make recommendations regarding financial support for those affected.¹³

1.4 A new financial support scheme in England

In an oral statement to Parliament in January 2016, the then Public Health Minister, Jane Ellison announced the launch of a public consultation on infected blood scheme reform.¹⁴ She said that the Department of Health had identified another £100 million, in addition to £25 million that had been announced previously, for the proposals within the consultation and laid out the principles on which the consultation would be based:

Scheme reform is a priority for me and for this government, and for this reason I can announce today that the Department of Health has identified £100 million from its budget for the proposals set out in the consultation. This is in addition to the current spend and the £25 million already announced in March 2015. This will more than double our annual spend on the scheme over the next 5 years. This is significantly more than any previous government has been able to provide for those affected by this tragedy.

I know all too well of the ill health and other impacts on many of those affected by the tragedy of infected blood. I have corresponded with many of those affected, and their MPs; they each have their own story to tell. I have reflected carefully on all of this in developing the principles upon which the consultation is based. These are that:

- we focus on those who are infected
- we are able to respond to new advances in medicine
- we provide choice where possible
- we maintain annual payments to everyone currently receiving them

This [consultation](#) is an opportunity for all those who have been affected to have their say, and it's really important this extends to those quieter voices who we hear from less often.¹⁵

¹¹ [Written statement: Infected Blood](#), 25 March 2015

¹² Tainted Blood, [news: Press release](#), 25 March 2015

¹³ Hepatitis C Trust, [The Hepatitis C Trust's Penrose Inquiry report response](#)

¹⁴ Department of Health, [Infected blood scheme reform](#), 21 January 2016

¹⁵ Department of Health, [Infected blood scheme reform](#), 21 January 2016

Following the consultation, Jane Ellison announced in July 2016 that the Government would introduce a new financial support scheme. She acknowledged criticism of the current schemes, and said that the proposals for the new scheme took account of the responses to the consultation.¹⁶

The changes to the scheme include:

- those infected with hepatitis C at stage 1 will receive a new flat rate annual payment of £3,500, rising to £4,500 from 2018/2019. This will not be linked to an individual assessment, as was proposed in the consultation.
- those with hepatitis C at stage 2 or those with HIV, their annual payments will increase to £15,500, rising to £18,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 1 will receive £18,500, rising to £22,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 2, will receive £30,500, rising to £36,500 from 2018/2019
- discretionary support will continue and will be enhanced from 2018/2019
- a new special appeals mechanism for those at hepatitis C stage 1 who consider that the impact of their infection on their health may mean they could qualify for stage 2 payments will be introduced from 2017/2018
- continuation of a £50,000 lump sum payment for those infected with hepatitis C stage 1 who progress to stage 2
- partners/spouses at the time of death of a primary beneficiary will be entitled to a £10,000 one-off lump sum where the HIV/hepatitis C infection contributed to the death of their partner/spouse - this will apply to those already bereaved and newly bereaved.¹⁷

The Minister reported that the increased annual payments and new annual payments would be introduced in this financial year, and backdated to April 2016, and that the new single scheme administrator would be introduced in 2017/18. These changes would only apply in England, but the Department of Health was consulting with the Devolved Administrations.

Responses to the new scheme proposals

The new financial support scheme has generally been welcomed by charities, and patient organisations.¹⁸ However, concerns have been raised about specific parts of the new scheme.

The Haemophilia Society responded to the proposals for the new scheme. The Chief Executive, Liz Carroll welcomed parts of the new scheme. She said that whilst the proposals were an improvement to

¹⁶ [Infected Blood Payment Scheme: Publication of Consultation Response and decisions for a reformed scheme:Written statement - HCWS88](#)

¹⁷ Department of Health, [News story. Infected blood payment scheme reformed](#), 13 July 2016

¹⁸ The Hepatitis C Trust, [Statement from The Hepatitis C Trust on the Government's infected blood support reforms. July 2016](#)

those in the consultation, they still fell short of the support required and deserved by those affected:

We welcome the increases in the annual payment amounts for people with HIV, Hepatitis C at Stage 2 and those who are co-infected, as well as the restoration of the link to CPI. Although these amounts still fall well short of the payments offered in Scotland.

We also welcome that all those infected with Hepatitis C at Stage 1 will be entitled to annual payments without the need for individual assessment. However, the amount announced does not reflect the impact that Hepatitis C has had on those infected.

We are disappointed that the annual payments announced are not sufficient to remove the need for discretionary support. However, the retention of discretionary support is an improvement from the consultation proposals and we recognise that it will be better funded from 2018/19. We await more details on the support that will be available before we can more fully evaluate it.

However, the new scheme still does not do enough for bereaved partners, parents and children. In particular we regret the replacement of ongoing support for bereaved partners with a one-off lump sum payment. There is also no mention of people who have cleared Hepatitis C or were infected with other viruses.

We also know the community will welcome the replacement of the five trusts with a single scheme administrator.¹⁹

In November 2016, the Haemophilia Society reported that they had met with the Parliamentary Under-Secretary of State for Health, Lord Prior of Brampton, to discuss a number of concerns. Issues raised included:

- that the Scottish scheme offers more support to those affected, and to introduce this would not be more expensive to the Department;
- that support should be better for bereaved people;
- The Government should use money from the sale of Plasma Resources UK to provide additional lump sum payments; and
- the need for the establishment of an Independent panel to look into the events which led to the infections through NHS blood products.

The Haemophilia Society report that the Minister agreed to take steps following the meeting:

- The Blood Policy Team will work with the Haemophilia Society to look into their figures on the costs of implementing the Scottish support scheme in England.
- Diana Johnson MP will write to the Minister about the prospects of using the proceeds of the sale of Plasma Resources UK to fund additional support for those affected. He agreed to consider the letter and potentially raise our points with Treasury officials.

¹⁹ Haemophilia Society, [The Haemophilia Society Initial Response to Government Announcement on Contaminated Blood](#), July 2016

- The Infected Blood Reference Group will look into the possibility of passporting access to welfare benefits for those affected by the scandal.
- The Minister could only reiterate the Government's position on an independent panel. This was outlined in a recent [letter from Jeremy Hunt](#). Lord Prior made no commitment to reconsider this policy.²⁰

1.5 Proposals for a new financial support system in Scotland

The current financial support systems apply across the UK, but the Scottish Government have recently announced that they will be introducing a new financial support scheme for those affected by infected blood products.

An independent [Scottish Financial Support Review group](#) was established by the Scottish Health Secretary, Shona Robison, following the publication of the Penrose Inquiry report in 2015. This group, which included patient and family representatives, was asked to make recommendations on how to improve the level of support offered to people who contracted Hepatitis C and HIV through infected blood products. The group published its report in December 2015.

On 18 March 2016, the Scottish Government announced that it had accepted the key recommendations of the group and that financial support would be strengthened with an extra £20 million over the next three years:

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, which will be implemented in full in Scotland, are:

- 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
- Those with both HIV and hepatitis C will have annual payments increased from £30,000 to £37,000 to reflect additional health needs
- When a recipient dies, their spouse or civil partner will continue to receive 75 per cent of their annual payment
- 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
- 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.²¹

²⁰ The Haemophilia Society, [Meeting on Contaminated Blood with Lord Prior](#), 15 November 2016

²¹ Scottish Government, [Extra £20 million for infected blood support](#), 18 March 2016

The Chair of the charity, Haemophilia Scotland welcomed the announcement. He said that it was a watershed moment for those involved in this campaign.²²

1.6 Welsh Government announcement

In October 2016, the Cabinet Secretary for Health, Wellbeing and Sport, Vaughan Gething made a statement about the future plans for financial support for those affected by contaminated blood products in Wales.²³ He said that, as an interim measure, the payments in Wales would stay at the same level as in England for the 2016/17 financial year. He also announced a survey to seek further views on a new scheme in Wales, which would inform plans for a reformed scheme from April 2017 onwards. He stated that reform in Wales must ensure that:

- individuals are not disadvantaged in comparison with current arrangements
- decisions take account of views expressed by those affected and their representative bodies
- any move to a new system is equitable and operates transparently and improvements are affordable and sustainable within the health budget.

²² Scottish Government, [Extra £20 million for infected blood support](#), 18 March 2016

²³ Welsh Government, [Written Statement - Wales reform of financial support for those affected by NHS supplied contaminated blood](#), 6 October 2016

2. News Items

BBC News

Payments to contaminated blood victims to rise in Wales

6 October 2016

<http://www.bbc.co.uk/news/uk-wales-37575153>

Independent

Theresa May considering investigation into historic blood contamination scandal that left thousands with Hepatitis and HIV

14 September 2016

<http://www.independent.co.uk/news/uk/politics/blood-contamination-scandal-investigation-theresa-may-nhs-hiv-hepatitis-inquiry-a7307081.html>

Guardian

NHS infected blood scandal: minister defends new delay in compensation

20 July 2016

<https://www.theguardian.com/politics/2015/jul/20/nhs-infected-blood-scandal-minister-defends-new-delay-in-compensation>

Guardian

NHS patients infected with contaminated blood to get extra payments

13 July 2016

<https://www.theguardian.com/society/2016/jul/13/people-infected-with-contaminated-blood-to-get-extra-payments>

BBC Online

Call for swifter action to identify contaminated blood victims

Eleanor Bradford 21 March 2016

<http://www.bbc.co.uk/news/uk-scotland-35856708>

Independent

NHS blood contamination victims hit out at 'returns' which cost them up to £7000a year.

20 March 2016

<http://www.independent.co.uk/life-style/health-and-families/health-news/nhs-blood-contamination-victims-hit-out-at-reforms-which-cost-them-up-to-7000-a-year-in-compensation-a6943151.html>

The Herald

Contaminated blood scandal financial package for Scots receives extra £20m

18 March 2016

http://www.heraldscotland.com/news/health/14354009.Contaminated_blood_scandal_financial_package_for_Scots_receives_extra_20m/

BBC News

Infected blood scandal: Government proposes more money for victims

21 January 2016

<http://www.bbc.co.uk/news/health-35371248>

3. Press releases

Haemophilia Society

Meeting on Contaminated Blood with Lord Prior

[http://www.haemophilia.org.uk/news/view?id=86&x\[0\]=news/list](http://www.haemophilia.org.uk/news/view?id=86&x[0]=news/list)

15 November 2016

On Tuesday 15th November, the Haemophilia Society and a number of MPs met for the first time with the new Minister responsible for contaminated blood support, Lord Prior of Brampton, to discuss the support arrangements for those affected by the contaminated blood scandal. The meeting attendees are copied below.

We raised a number of concerns with the Minister about problems with the reformed English support scheme. In particular, we highlighted the following points:

- We stressed the huge level of concern there is within the affected community about the plans for the new scheme administrator for discretionary support. We urged the Department of Health to look again at the administration of the scheme as a top priority. We also called for better communication with the affected community.
- We raised the concern that people infected in Wales and Northern Ireland still face uncertainty over the support that will be available to them.
- According to research carried out by the Haemophilia Society, if the Scottish support scheme were implemented in England the cost to the Department of Health beyond the current fiscal year would not be any higher than what is currently budgeted. We asked the Minister and his officials to look into this.
- Bereaved people needed to be provided with better support under the English scheme. We felt that the Scottish model offers a better option for the bereaved.
- Additional lump sum payments, and the additional funding for the first fiscal year as under the Scottish scheme, could be paid for by taking some of the proceeds from the Government's sale of Plasma Resources UK. We contested the claims by Treasury officials that this would not be possible under current rules.
- We underlined the need for a Hillsborough-style independent panel into the scandal, so that those affected could receive truth and reconciliation.
- We stressed the continued need to improve the way those affected can access welfare support, to passport access to Employment Support Allowance and other benefits to those affected by the Contaminated Blood scandal.

- We provided two briefings to the Minister and his policy officials on the potential for the budget to be better spent and a wider consideration of concerns with the new scheme.

The Minister agreed to take the following steps:

- The Blood Policy Team will work with the Haemophilia Society to look into their figures on the costs of implementing the Scottish support scheme in England.
- Diana Johnson MP will write to the Minister about the prospects of using the proceeds of the sale of Plasma Resources UK to fund additional support for those affected. He agreed to consider the letter and potentially raise our points with Treasury officials.
- The Infected Blood Reference Group will look into the possibility of passporting access to welfare benefits for those affected by the scandal.
- The Minister could only reiterate the Government's position on an independent panel. This was outlined in a recent [letter from Jeremy Hunt](#). Lord Prior made no commitment to reconsider this policy.

On Thursday 24th November, there will be a debate in the House of Commons on the new support arrangements for those affected. This will give MPs a further opportunity to raise concerns.

Meeting Attendees

- Diana Johnson MP, Co-Chair of the All-Party-Parliamentary Group on Haemophilia and Contaminated Blood
- Rt Hon Alistair Burt MP
- Andy Slaughter MP
- Liz Carroll, Chief Executive of the Haemophilia Society
- Lynne Kelly, Chair of Haemophilia Wales
- Tom Stephens, Parliamentary Researcher for Diana Johnson MP
- Jeff Courtney, Policy and Public Affairs Manager, Haemophilia Society

For further information or to get copies of the briefings produced for the DH please email Jeff on jeff@haemophilia.org.uk or call our office on 0207 939 0788.

Written Statement from the Welsh Government: - Wales reform of financial support for those affected by NHS supplied contaminated blood

<http://gov.wales/about/cabinet/cabinetstatements/2016-new/bloodservice/?lang=en>

6 October 2016

Vaughan Gething, Cabinet Secretary for Health, Well-being and Sport

For those affected directly or indirectly by NHS supplied contaminated blood I want to end any uncertainty about the level of financial support they will receive from the Welsh Government in the future.

The scheme to support payment was established on a UK wide basis. However, this has now fragmented through new schemes announced for Scotland and England.

Reform in Wales must ensure that:

- individuals are not disadvantaged in comparison with current arrangements
- decisions take account of views expressed by those affected and their representative bodies
- any move to a new system is equitable and operates transparently and improvements are affordable and sustainable within the health budget.

As a first step to reforming the scheme in Wales, I have taken account of the views expressed by those affected and their representative bodies and the need for administrative efficiency. I have therefore decided that, as an interim measure, payments for the remainder of the 2016-17 financial year will be at the same levels as England.

However those affected may have ideas about how this money can best be used to assist them in everyday living and planning for the future. To inform our future arrangements, I am now seeking further views on a new scheme from April 2017 onwards. I will be issuing a short survey to those who currently receive support which will also be available on the Welsh Government website. Completed surveys will need to be submitted by 20 January 2017. I have agreed to hold 2 workshops with those affected during the consultation period, one in the North and one in the South. Any new arrangements put in place need to be affordable and sustainable within the health budget, so funding is available to operate a scheme at the same level as England.

Welsh Government officials are working closely with those in the Department of Health to shape the transitional arrangements of the new scheme administration to ensure this will be as smooth as possible. The new scheme which we will put in place will be administered to the same high level of service that those affected expect to receive.

Reform in England

The new payments being introduced by the Department of Health are:

- From 2017-18, the existing 5 bodies administering support will be replaced by a single scheme and body.

- All annual payments will include a £500 winter fuel payment (currently a discretionary payment).
- A new annual payment of £3,500 for those with HCV Stage 1 in 2016-17.
- An annual payment of £15,500 for those with HCV Stage 2 in 2016-17 (currently £14,749).
- An annual payment of £15,500 for those with HIV in 2016-17 (currently £14,749).
- A new annual payment of £18,500 for those with HIV/HCV Stage 1 in 2016-17.
- An annual payment of £30,500 for those with HIV/HCV Stage 2 in 2016-17 (currently £30,000).
- Continuation of the £20,000 lump sum payment for new registrants with HCV Stage 1.
- Continuation of the £20,000 lump sum payment for new registrants with HIV.
- Continuation of the £50,000 lump sum payment for those who progress to HCV Stage 2.
- A new one-off lump sum payment of £10,000 to partners/spouses of primary beneficiaries when they passed away and where infection with HIV and/or HCV contributed to the death.
- Continuation of payments on an ex-gratia basis and additional to other income received by the beneficiary (disregarded for taxes/benefits).
- Continuation of annual payments being linked to the consumer price index (CPI).

Haemophilia Society

Update on Contaminated Blood Support: Changes to Arrangements for the Bereaved

8 August 2016

<http://www.haemophilia.org.uk/news/view?id=76&x%5b0%5d=news/list>

The new support arrangements for people affected by contaminated blood announced last month contained two changes that will impact on current and future bereaved partners. The two changes were that there is now a £10,000 one-off payment available to some bereaved partners however there are also going to be substantial changes to the discretionary support provided.

The £10,000 lump sum payment will be available to partners, both currently bereaved and those bereaved in future, provided that the infection from contaminated blood and blood products contributed to their partner's death.

The Department of Health (DH) has announced they will provide more information on how a causal link between infection and death will be evidenced but this is not yet available.

Despite not yet releasing the information on what evidence the schemes will require the DH have announced that for already bereaved partners the payment must be claimed before March 2017. We would

encourage all people who think they may be entitled to contact the Alliance House organisations on 0207 233 0057 as soon as possible to register their details.

For bereaved partners who currently receive discretionary support either through grants or regular payments there is more uncertainty and the likelihood that support will reduce over time.

Nothing will change this year, however from April 2017 a new discretionary support scheme will be created that “applies to infected and affected as consistently and as practicable as possible”. Previously the Government had said that no one would be worse off under the new scheme however now the Government is simply saying that “due consideration will be given to those currently relying on discretionary payments”. We are concerned that many bereaved people will see their support decrease from April 2017.

While the budget for discretionary support will rise from April 2018 this new ‘enhanced’ discretionary support scheme will not be sufficiently well-funded when all infected and affected are treated consistently.

The Society has also continued to raise the unfairness that bereaved parents are not entitled to any of these payments or access to the discretionary support scheme.

If you know of anyone who might be entitled but doesn’t have easy access to the internet or Facebook please pass on this information to them.

The Haemophilia Society is continuing to raise these concerns with DH officials. Also through the APPG on Haemophilia and Contaminated Blood (for which the Society provides the secretariat) as well as individuals’ contact with their MPs pressure is being kept on the relevant ministers. In particular, MPs continue to table questions, write letters to parliament and will be seeking a debate when Parliament returns in September.

Members who need any more information on the new scheme or wish to discuss their individual situations in more detail please email info@haemophilia.org.uk or call us on 0207 939 0780.

Haemophilia Society
Update on Contaminated Blood Support and Eligibility for new
Stage 1 Annual Payments
3 August 2016

<http://www.haemophilia.org.uk/news/view?id=75&x%5b0%5d=news/list>

Since the Government announcement of their response to the consultation on the support arrangements for people affected by contaminated blood, The Haemophilia Society have been in discussions with the Department of Health (DH) to address a number of unanswered questions or unclear statements.

The Government have confirmed that people who have been treated for their Hepatitis C in the past and achieved a sustained viral response (SVR) will be entitled to the new annual payments and continue to be eligible for discretionary support for the lifetime of this scheme (until at least April 2021 but likely to continue pending a review).

People who have more recently been successfully treated with new interferon-free direct acting antivirals (DAAs) or are treated for their infection in future will also be eligible for the new annual payments.

A simple proxy for eligibility is that primary beneficiaries who were able to register with Skipton for the £20,000 lump sum payment in the past will be entitled to the new annual payments. It has also been clarified that people do not need to still be resident in the UK to receive the payments.

However, people who cleared the virus naturally without NHS treatment or reaching the chronic stage of infection will still not be eligible. The eligibility criteria for support under the current and reformed schemes are the same.

We understand that the £3,500 a year (rising to £4,500 in 2018/19) will be paid monthly and the new payments will 'be made as soon as practicable through the usual processes'.

There is as yet no date on which the first payments will be made but they will include a backdated payment to cover the period from April 2016 or the date an individual joined the scheme if that is later.

The Haemophilia Society encourages all people who may be entitled to the support to contact the Skipton Fund on 0207 808 1160 or apply@skiptonfund.org to ensure they have the correct contact details. If you know of anyone who might be entitled but doesn't have easy access to the internet and Facebook please pass on this information to them.

Members who need any more information on the new scheme or wish to discuss their individual situations in more detail please email info@haemophilia.org.uk or call us on 0207 939 0780.

Hepatitis C Trust

Statement from The Hepatitis C Trust on the Government's infected blood support reforms

14 July 2016

<http://www.hepctrust.org.uk/blog/jul-2016/statement-hepatitis-c-trust-governments-infected-blood-support-reforms>

The Hepatitis C Trust welcomes the reforms to the infected blood support scheme, which were announced yesterday by the Prime Minister following a Government consultation on its proposals earlier this year.

The plans include the introduction, for the first time, of annual payments of £3,500 (including a £500 winter fuel payment) for people

with 'stage 1' hepatitis C, increasing to £4,500 per year from 2018/19. The Government has chosen not to proceed with its original proposal for people with stage 1 hepatitis C to be individually assessed for annual payments, and has instead introduced a scheme of annual payments without assessment. Other plans include:

- Small increases for those in receipt of 'stage 2' payments for hepatitis C up to £15,000 including winter fuel payments, rising to £18,500 per year from 2018/19, as well as increases for those co-infected with HIV and hepatitis C at stage 1 and stage 2.
- The replacement of the five trusts with a single administrator.
- The maintenance of discretionary support payments.
- The creation of a special appeals mechanism for those at stage 1 who consider that the impact of their infection may mean they could qualify for stage 2 annual payments and the £50k lump sum payment.
- A one-off lump sum payment of £10,000 for the bereaved.

Charles Gore, Chief Executive of The Hepatitis C Trust, commented that "The new plans unveiled by the Government represent an important step forwards in terms of the support provided to those affected by hepatitis C as a result of NHS contaminated blood. Whilst the support arrangements still look likely to fall somewhat short of those being developed in Scotland, these plans are a vast improvement on those initially outlined by the Government. In particular, we welcome the fact that discretionary support payments are being maintained and that unassessed annual payments have been introduced, in recognition of the fact that many people with 'stage 1' hepatitis C (without cirrhosis) may also experience severe symptoms as a result of the virus which can restrict their ability to fully participate in society."

Our response to the Government's consultation document on the reforms, which can be viewed [here](#), also challenged the original proposal that priority access to treatment for hepatitis C should be provided as part of the payment scheme for those affected by contaminated blood. All eligible patients should already be able to exercise their right to NICE-approved drugs on the NHS, rather than having their access restricted by the national cap on treatment imposed by NHS England. We therefore welcome the fact that the Government has today confirmed it will not be using funding available for the scheme to provide enhanced access to the new treatments.

To read more about the Government reforms in full and how they will affect you, view the full response [here](#).

The Haemophilia Society Initial Response to Government Announcement on Contaminated Blood

13 July 2016

<http://www.haemophilia.org.uk/news/view?id=72&x%5B0%5D=news/list>

This afternoon the Government announced their response to the consultation on support for people affected by contaminated blood.

Responding to the announcement Liz Carroll, Chief Executive of The Haemophilia Society said, "The new scheme announced today is an improvement on the proposals in the consultation, however, it still falls short of the support the affected community deserve and require."

We welcome the increases in the annual payment amounts for people with HIV, Hepatitis C at Stage 2 and those who are co-infected, as well as the restoration of the link to CPI. Although these amounts still fall well short of the payments offered in Scotland.

We also welcome that all those infected with Hepatitis C at Stage 1 will be entitled to annual payments without the need for individual assessment. However, the amount announced does not reflect the impact that Hepatitis C has had on those infected.

We are disappointed that the annual payments announced are not sufficient to remove the need for discretionary support. However, the retention of discretionary support is an improvement from the consultation proposals and we recognise that it will be better funded from 2018/19. We await more details on the support that will be available before we can more fully evaluate it.

However, the new scheme still does not do enough for bereaved partners, parents and children. In particular we regret the replacement of ongoing support for bereaved partners with a one-off lump sum payment. There is also no mention of people who have cleared Hepatitis C or were infected with other viruses.

We also know the community will welcome the replacement of the five trusts with a single scheme administrator.

We will be reviewing further the full consultation response (available at <https://www.gov.uk/government/news/infected-blood-payment-scheme-reformed>) and we will issue a more detailed analysis as soon as possible.

For further details please contact Jeff Courtney on jeff@haemophilia.org.uk or 0207 939 0788.

Department of Health

Infected blood payment scheme reformed

13 July 2016

<https://www.gov.uk/government/news/infected-blood-payment-scheme-reformed>

All infected individuals will now receive annual payment including extra £500 winter fuel payment without the need to apply for it.

Reforms to the infected blood payment scheme have been announced today following a public consultation. The payment schemes are for individuals who were infected with HIV and/or hepatitis C following treatment with NHS-supplied blood or blood products before September 1991.

Since 1988, successive governments have set up 5 schemes to provide financial and other support to infected and affected people. However, criticisms about inconsistencies caused by the current system led to calls for reform.

The planned changes include:

- those infected with hepatitis C at stage 1 will receive a new flat rate annual payment of £3,500, rising to £4,500 from 2018/2019. This will not be linked to an individual assessment, as was proposed in the consultation.
- those with hepatitis C at stage 2 or those with HIV, their annual payments will increase to £15,500, rising to £18,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 1 will receive £18,500, rising to £22,500 from 2018/2019
- those co-infected with HIV and hepatitis C at stage 2, will receive £30,500, rising to £36,500 from 2018/2019
- discretionary support will continue and will be enhanced from 2018/2019
- a new special appeals mechanism for those at hepatitis C stage 1 who consider that the impact of their infection on their health may mean they could qualify for stage 2 payments will be introduced from 2017/2018
- continuation of a £50,000 lump sum payment for those infected with hepatitis C stage 1 who progress to stage 2
- partners/spouses at the time of death of a primary beneficiary will be entitled to a £10,000 one-off lump sum where the HIV/hepatitis C infection contributed to the death of their partner/spouse - this will apply to those already bereaved and newly bereaved.

Increased annual payments and new annual payments will take effect this year and be backdated to April 2016.

All payments will continue to be ex-gratia, which means they are funded voluntarily by government. These payments will also continue to be additional to any other income a person may receive, and are disregarded when calculating income tax and eligibility for other state benefits. In addition, all annual payments will continue to be linked to the consumer price index from next year.

[See more information in consultation response.](#)

The consultation particularly sought views from people who are beneficiaries of the current schemes, their families and their clinicians on how best to reform them

Haemophilia Scotland

18 March 2016

The [Scottish Government announced](#) changes to the level of support that it would be providing to those whose infection occurred in Scotland. Part of the package of changes was the establishment of a new scheme based in Scotland to administer the payment.

This new scheme will be administered by [National Service Scotland \(NSS\)](#). It is intended that this new scheme will start at the beginning of the 2017/18 financial year in April.

To give beneficiaries the chance to meet key National Services Scotland (NSS) staff and ask questions about the transition to the new Scottish support scheme, NSS have scheduled a stakeholder event for,

19 December at 2pm – 4pm, Scottish Health Service Centre Edinburgh, Crewe Road South.

Anyone interested can [book a place at the link below](#). The event will also include some background on the key aims and membership of the scheme's Advisory Board.

<https://book.shsc.scot/SG16>

The room can only hold around 30 people so we may have to restrict attendance if there is a lot of interest. There is no announcement being made, this is just a chance to talk about the new NSS role.

Anyone who will benefit from the new scheme can attend. This means the event is open to those who were infected and their immediate families, including bereaved families.

The event organiser is Victoria Delargy, tel. 0131 275 7925, if anyone wants to book via phone.

You may have already seen the update posted on the Skipton Fund website regarding the interim payments: <http://www.skiptonfund.org/>

It makes it clear that until the end of the financial year the Alliance House organisations will be responsible for,

Making the additional lump sum payments to those at Skipton Stage 1

Making the increased annual payment to those with HIV and at Skipton Stage 2

The Skipton Fund and MFET will write to everyone affected by the changes individually, giving further information about payments and timescales, and any further information required. They have asked that if you have any questions regarding the new payments that you wait for your letter before contacting their office.

Because different levels of payments will be in place for the four UK countries, the country in which a person was infected is important information. When they write to you about your new or enhanced payments, they will confirm the country to which you have been allocated, based on the data they hold. Where there is reference to treatment in more than one country of the UK, they have been asked to assign the you to the country of residence at the time of your registration.

Once you have received your letter, if you believe you have not been allocated to the country in which your infection occurred, you can appeal the decision to the relevant government. The following document provides further information on how to appeal: [Appeals](#)

Scottish Government

Extra £20 million for infected blood support

18 March 2016

Key recommendations of independent group accepted.

Financial support for people affected by infected NHS blood and blood products will be strengthened with an extra £20 million investment over the next three years.

The announcement came as the Scottish Government accepted the key financial recommendations of the independent Financial Review group looking at the issue.

The group, involving patient and family representatives, was set up by Health Secretary Shona Robison following the Penrose Inquiry into infected NHS blood, which reported last year. The group was tasked with recommending how to improve the level of support on offer to people who contracted hepatitis C and HIV through infected NHS blood and blood products in the 1970s and 80s.

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, which will be implemented in full in Scotland, are:

- 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
- Those with both HIV and hepatitis C will have annual payments increased from £30,000 to £37,000 to reflect additional health needs
- When a recipient dies, their spouse or civil partner will continue to receive 75 per cent of their annual payment
- 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
- 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

Ms Robison said:

“Infected blood is one of the most terrible chapters in the history of our NHS. Those affected have suffered dreadful impacts on their health, life expectancy and quality of life, including financial losses. It is quite right that they and their families are given adequate support to help them cope with consequences for which they are entirely blameless.

“We acknowledge that many people affected by this issue believe the financial support packages on offer do not reflect the impact of these infections, not just for them but also their families.

“With this in mind, I established a financial review group so patient groups and others could input into how the new reformed schemes will work. I am pleased today to be able to accept the key financial recommendations in full.

“This will mean a substantial package of additional financial support, recognising the hardships many face.

“I have today accepted the group’s key financial recommendations, and we will move forwards on this basis. I am also clear that this is not the end of the process, and that there will be on-going work with the patient groups on this matter.

“We are now working with the UK Department of Health, and the existing UK-wide support schemes, to provide the additional financial support as soon as possible and manage a smooth transition to our new Scottish scheme.”

Bill Wright, Chair of Haemophilia Scotland, said:

“This announcement is a watershed moment for everyone involved in this long running campaign. There are three key elements of the announcement which are particularly welcome.

“Firstly, the increase in on-going support for those who are most unwell means that we can have some confidence that they will no longer be living in poverty as a result of their infections.

“Secondly, introducing pensions for widows and widowers is an important recognition that they suffered losses in their own right and that they should have a secure future.

“Thirdly, the upfront payment of an additional £30,000 to all those who will not receive on-going support goes some way towards recognising that everyone who has lived with these infections has suffered physically, mentally, or financially.

“No scheme can truly make up for the loss of life, and health, caused by this disaster. The Cabinet Secretary has acknowledged that there is more to be done once these schemes move to Scotland. However, today, we have made historic progress.

“This new, Scottish, approach stands in stark contrast to the deeply concerning proposals currently being consulted on south of the border.”

Background

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.

An estimated £10.5 million will be made available in 2016/17 and 2017/18 and £6.5 million in the years after that. This compares with a

current budget of £2.5 million each year – an additional £20 million over the first three years.

As recommended by the group, the Scottish Government will aim to deliver the new scheme through a single body so those affected no longer need to apply to more than one body for funding. In the interim, the Scottish Government is working with the UK

Department of Health and existing support schemes with the aim of delivering increased financial support through some of the existing schemes during the 2016-17 financial year. A further announcement on the timescales for implementation will be made in due course.

4. Parliamentary material

4.1 Debates

House of Commons Chamber debate:

Contaminated Blood

<https://hansard.parliament.uk/pa/cm201516/cmhansrd/cm160412/debtext/160412-0003.htm%20-%2016041246000185>

12 Apr 2016 | House of Commons chamber | 608 cc240-90

Westminster Hall debate:

Contaminated Blood Products

<http://www.publications.parliament.uk/pa/cm201516/cmhansrd/cm150909/halltext/150909h0001.htm#15090925000002>

HC Deb 09 September 2015 | Vol 599 cc79-88WH

Backbench Debate:

Contaminated Blood

HC Deb 15 January 2015 | Vol 590 cc1025-1075

<http://www.publications.parliament.uk/pa/cm201415/cmhansrd/cm150115/debtext/150115-0001.htm#15011554000001>

4.2 Statements

Infected Blood Payment Scheme: Publication of Consultation Response and decisions for a reformed scheme:

Written statement - HCWS88 Department of Health

14 July 2016

Parliamentary Under-Secretary of State for Health (Jane Ellison)

On 21 January 2016 the Government launched its consultation on reform of the current ex-gratia payment schemes for individuals infected with HIV and/or hepatitis C following treatment with NHS-supplied blood or blood products before September 1991. It sought views particularly from the beneficiaries of the current schemes and their clinicians but the consultation was open to all to respond. The full analysis of the responses, the detail of the final decisions for the new scheme and an overview of the transition arrangements are set out in the Government's formal consultation response published today.

The response is attached and can be found on the Department of Health's website at www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support. The Impact Assessment

and Equalities Impact Assessment will be published on the same website before summer recess.

The Government recognises the suffering experienced by people as a result of this tragedy and the Prime Minister apologised on behalf of the Government in March 2015. Since 1988, successive Governments have set up five schemes to provide financial and other support to those affected. This Government committed further funding of up to £100m (in January 2016) on top of the additional £25m pledged by the Prime Minister in March 2015 and the existing baseline budget. This additional money will more than double the Department of Health's annual spend on the scheme over the Spending Review period. This is significantly more than any previous Government has provided for those affected by this tragedy.

Over the years, there has been criticism from different groups of beneficiaries and their representatives about the way that the current system has been set up and operates. It was clear from this criticism that a more accessible and equitable system of care and support was needed.

In making its decisions for the new scheme, the Government has taken full account of the 1,557 formal responses to the consultation and considered other feedback such as backbench debates on the issue, 21 Parliamentary Questions and 69 individual pieces of correspondence related to the consultation. The detailed description of the reformed scheme is contained in the consultation response document published today.

The key principles for the reformed scheme are that support will be simple, equitable and responsive to individuals' circumstances, and available resource will be focused on those whose health is most affected.

Specifically, the key aspects for the reformed scheme will be:

- All infected individuals will now receive an annual payment. These annual payments will be linked to the consumer price index (CPI) and include the £500 winter fuel payments as a standard payment without the need to apply for it:
 - Those infected with hepatitis C at stage 1 will receive a new flat rate annual payment of £3,500 (rising to £4,500 from 2018/19) that is not linked to an individual assessment, as was proposed in the consultation – this will be the first time ongoing financial support will be provided for approximately 2,500 stage 1 beneficiaries.
 - Those with hepatitis C at stage 2 or those with HIV will see their annual payments increase to £15,500 (rising to £18,500 from 2018/19).
 - Those co-infected with HIV and hepatitis C at stage 1, will receive £18,500 (rising to £22,500 from 2018/19)
 - For those co-infected with HIV and hepatitis C at stage 2, will receive £30,500 (rising to £36,500 from 2018/19)

- Discretionary support will not only continue but will be enhanced from 2018/19
- A new special appeals mechanism for those at hepatitis C stage 1 who consider that the impact of their infection on their health may mean they could qualify for stage 2 payments will be introduced from 2017/18
- Continuation of a £50k lump sum payment for those infected with hepatitis C stage 1 who progress to stage 2
- In addition, partners/spouses at the time of death of a primary beneficiary will be entitled to a £10,000 one-off lump sum where the HIV/hepatitis C infection contributed to the death of their partner/spouse. This will apply to those already bereaved and newly bereaved.

All elements of the published reform package apply to the current spending review period of FY 2016/17 to FY 2020/2021, during which a review of the scheme will be undertaken. This review will particularly take account of the numbers being treated for Hepatitis C and the implications for the future operation of the scheme.

All payments will continue to be ex-gratia, which means they are funded voluntarily by Government. These payments will also continue to be additional to any other income a person may receive, and are disregarded for the purposes of calculating income tax and eligibility for other state benefits.

Increased annual payments and new annual payments will take effect this year and be backdated to April 2016. Lump sum payments for bereaved spouses/partners will also be implemented this year. Arrangements for a single new scheme administrator will be progressed in the current financial year and become operational in 2017/18.

The proposals for scheme reform described in the consultation document are for beneficiaries infected in England. Information gathered through the consultation has been shared with the health departments in the devolved administrations and we will continue to work closely with them.

Consultation Response (PDF Document, 544.58 KB)

Infected Blood

21 January 2016

The Parliamentary Under-Secretary of State for Health (Jane Ellison)

<https://hansard.parliament.uk/commons/2016-01-21/debates/16012124000004/InfectedBlood>

In the urgent question on 16 December, I committed to publishing the consultation on infected blood scheme reform in January. I am pleased, therefore, to announce the launch of that consultation. I recognise that for some this will come too late. I cannot right the pain and distress of 30 years, and the truth is that no amount of money could ever make up

for the impact that this tragedy has had on people's lives. As I have said before, for legal reasons, in the majority of cases, it is not appropriate to talk about compensation payments, but I would like to echo what has been said before in the House and say sorry on behalf of the Government to every person affected by this tragedy.

Scheme reform is a priority for me and the Government, and for that reason I can announce that the Department of Health has identified £100 million from its budget for the proposals in the consultation. This is in addition to the current spend and the £25 million announced in March 2015, and it will more than double our annual spend on the scheme over the next five years. This is significantly more than any previous Government have been able to provide for those affected by this tragedy.

I know all too well of the ill health and other impacts on many of those affected by the tragedy of infected blood. I have corresponded with many of those affected and their MPs—they each have their own story to tell—and I have reflected carefully on all this in developing the principles on which the consultation will be based. These are: that we focus on those infected; that we can respond to new advances in medicine; that we provide choice where possible; and that we maintain annual payments to everyone currently receiving them. The consultation is an opportunity for all those affected to have their say, and it is important that it extends to the quieter voices from whom we hear less often.

It is not appropriate, and I do not have time, to go through the whole consultation document today, but I would like to highlight some of its key components. A large population within the infected blood community currently does not receive any regular financial support. These are the people with hepatitis C. I believe it is important that everybody receives support from the new scheme and that it be linked to the impact infection has on their health. I therefore propose that all those registered with the schemes with hepatitis C at current stage 1 be offered an individual health-based assessment, completion of which would determine the level of annual payment received. This would also apply to anyone who newly joins the scheme.

The consultation document outlines our proposal that those currently receiving annual support should have their payments uplifted to £15,000 a year. Those who are co-infected and currently receive double payments would continue to do so. I often hear that people are unhappy about applying for discretionary charitable payments. I hope that the introduction of new regular annual payments will remove this requirement. I am keen that those who respond to the consultation take the opportunity to answer all the questions about the support proposed so that I can make informed final decisions on the shape of any new scheme once all the responses have been collected and analysed.

During the urgent question, I said I was interested in the opportunities offered by the advent of simpler and more effective treatments that can cure some people of hepatitis C. The NHS is at the start of its

programme to roll out the new hepatitis C treatments previously approved by the National Institute for Health and Care Excellence. As Members will know, the NHS must prioritise treatment on clinical need and not on route of infection, which means that, although some in the infected blood community will be eligible for treatment right away, others might have to wait.

More than anything, I want, if we can, to give the chance to limit the impact of hepatitis C on the infected community by making an offer of treatment. Over recent months, I have received many letters from people expressing a wish to halt the progress of their infection—one of the many letters that particularly struck me asked simply: “Please make me well”—so my intention is that the new scheme will provide an opportunity to enhance access to treatment, especially for those who fall just short of the current NHS criteria. I hope that we can treat more people if finances allow. That is why the consultation is seeking views on offering treatment to those with hepatitis C in the infected blood community not yet receiving treatment on the NHS.

In keeping with the principle of offering choice where possible, I am pleased to announce that we are consulting on a choice of options for the bereaved. Currently, bereaved partners or spouses are eligible to apply for means-tested support from the charities. As I have said, I have heard concerns from many people who do not like having to apply for charity. With that in mind, the consultation offers the choice of continued access to discretionary support or a one-off lump-sum payment for the bereaved based on a multiple of their current discretionary support. There are questions on this in the consultation document, and I am keen to hear from those affected so that I can understand their preference.

Having listened to concerns about the complex nature of the five schemes, the consultation proposes that, following reform, there will be one scheme run by a single body with access to expert advice, including from National Institute for Health and Care Excellence, so that we can keep pace with any new advances in treatment for hepatitis C and HIV that emerge.

On the next steps, the consultation will be published today on gov.uk and will run until 15 April. This is a 12-week consultation to ensure that all those who wish to respond have time to do so. The consultation document contains questions about the proposals on which I would welcome views. I recognise that there has been disappointment that we have not consulted sooner, but the outcome of the consultation will be crucial to informing our final decisions about how to proceed, and I give the House, and those affected, my commitment that we will proceed as rapidly as possible to implementation thereafter.

We need, as a priority, to make progress in rolling out the health assessments as quickly as possible to ensure that people get access to the support and clinical advice they need. I should be clear, however, that my intention is that annual payments for the current stage 1 cohort

should be backdated to April 2016, regardless of when each individual's assessment takes place.

This is the first time that the Government are consulting fully and widely with the entire affected community and all those who might have an interest on the future reform of the scheme. In developing the proposals to include within the consultation, I have taken account of points I have heard in debates here, of correspondence sent to me, of my discussions with the all-party group and of views gathered during pre-consultation engagement. The consultation is now open and it is my hope that all those affected by this tragedy will respond, and that we can move forward from here. I commend the statement to the House.

HC Deb 21 January 2016 | Vol 604 cc1582-1592 HCWS88

5. Parliamentary Questions

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether it is his policy that the new £10,000 lump sum payment for widows and widowers of primary beneficiaries under the new contaminated blood support scheme will also be available to the widows and widowers of people who were not directly infected by contaminated blood but who contracted HIV and hepatitis C from people who were.

Answered by Nicola Blackwood Department of Health

The Department is still working with a reference group of experts and the current schemes on this policy. As soon as the policy is confirmed, the Department will publish it and will give guidance as to who is eligible.

However, we expect that any bereaved partner or spouse of a secondary infectee will also have access to discretionary support, where the primary infectee was infected in England.

17 Nov 2016 | Written questions | House of Commons | 52381

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether it is his policy that widows, partners and others infected with HIV and hepatitis C from people affected by contaminated blood will continue to receive (a) discretionary and (b) non-discretionary support under the reformed support scheme.

Answered by Nicola Blackwood Department of Health

Anyone who is infected with HIV and hepatitis C from people affected by contaminated blood will continue to receive discretionary support on a means tested basis and non-discretionary annual payments.

17 Nov 2016 | Written questions | Answered | House of Commons | 52380

[Blood: Contamination](#)

Asked by Alistair Burt

To ask the Secretary of State for Health, when he plans to announce details of the discretionary support scheme for people affected by contaminated blood.

Answered by Nicola Blackwood Department of Health

As part of the wider reforms of the Infected Blood Payment support schemes in England, a new discretionary scheme is in design and will be

delivered once a new scheme administrator is established in 2017/18. Details of the discretionary support scheme will be provided at that stage. A new discretionary scheme will replace the existing three discretionary schemes.

28 Oct 2016 | Written questions | Answered | House of Commons | 49614

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether the reformed discretionary support scheme for people affected by contaminated blood will consider (a) housing benefit or (b) jobseeker's allowance in calculating eligibility for financial support for (i) widows and widowers of people affected and (ii) other beneficiaries.

Answered by Nicola Blackwood Department of Health

In 2017/18, as part of the wider reform of the Infected Blood Payments Scheme in England, a new discretionary scheme will replace the current three discretionary schemes. The new discretionary scheme is in design and the relationship between receipt of welfare support and eligibility for discretionary support from the new scheme has yet to be decided.

27 Oct 2016 | Written questions | Answered | House of Commons | 49348

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, what the tendering process is for the private company that will run the trust which provides support for people affected by contaminated blood; which companies have expressed an interest in that tender; what the size of the initial bids made by those companies has been; and what the timetable is for that tendering process.

Answered by Nicola Blackwood Department of Health

Departmental resource in the tendering process represents input across policy, legal and procurement which divisions cannot be easily quantified.

The Department has not made an estimate of the cost to the private companies that will take part in the tendering process for providing support to people affected by National Health Service supplied infected blood. It will be for each company to make a judgement on the resources that they wish to devote to this process.

The Department is using the 'Open Procedure' as set out by the Public Contract regulations 2015 at:

<http://www.legislation.gov.uk/uksi/2015/102/regulation/27/made>

We intend to issue the invitation to tender on 1 November 2016 and the deadline for bids will be 9 December 2016. The evaluation of tenders is likely to run into January 2017. The new administrator will become operational in the financial year 2017/18 and the current bodies will operate until then.

Further information on the tendering process is already in the public domain, including information from pre-market engagement, and can be found at:

<https://www.contractsfinder.service.gov.uk/Notice/580180d0-5cf3-4eb1-b7c7-07241fc95e84>

24 Oct 2016 | Written questions | House of Commons | 48802-3

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, what the total budget in each year of the Spending Review Period will be for the new support package for people affected by contaminated blood.

Answered by Nicola Blackwood | Department of Health

The annual budget for the new support scheme will range between £46.2 million and £46.6 million for each year of the Spending Review period.

16 Sep 2016 | Written questions | House of Commons | 45717

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether the special appeals process for people infected with Stage 1 Hepatitis C as a result of receiving contaminated blood will be managed by (a) his Department or (b) the new single trust which will be established from 2017-18.

Answered by Nicola Blackwood | Department of Health

In 2017/18, we will introduce a special appeals mechanism for people currently at stage 1 of their hepatitis C infection, to apply for a higher level of payment, equivalent to the stage 2 annual payments of £15,500, details of which are still being considered. We envisage that the new single scheme administrator will administer and manage such a process.

16 Sep 2016 | Written questions | House of Commons | 45716

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether enhanced payments for people infected with Stage 1 Hepatitis C as a result of receiving

contaminated blood will be backdated to April 2016 if their appeal through the special appeals mechanism after 2017-18 is successful.

Answered by Nicola Blackwood | Department of Health

In 2017/18, we will introduce a special appeals mechanism for people currently at stage 1 of their hepatitis C infection, to apply for a higher level of payment, equivalent to the stage 2 annual payments of £15,500. Details of the appeals mechanism are still being developed. Any individual successful in their appeal when operational, will not have these backdated to April 2016, but will be backdated from the point they submitted their application.

16 Sep 2016 | Written questions | House of Commons | 45713

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, whether he plans that the new, single trust for people affected by contaminated blood will be a registered charity; whether he plans that that trust will have trustees representing (a) his Department, (b) the Haemophilia Society and (c) the infected community; and whether he plans that the registered beneficiaries of that trust will be contacted from the (i) wider beneficiary community registered with the MFET and Skipton Fund or (ii) narrower list of people registered with the Caxton Foundation, Eileen Trust or MacFarlane Trust.

Answered by Nicola Blackwood | Department of Health

There will be a new scheme administrator combining the discretionary and annual payment functions of the existing five schemes into a single scheme going forward.

The new scheme administrator will become operational in the financial year 2017/18 and the current bodies will operate until the new scheme is operational.

The Department has initiated the pre-market engagement phase of the procurement process for identifying a new scheme administrator. At this stage, it is too early to comment on who will be successful in the procurement process and what their internal governance arrangements will be.

16 Sep 2016 | Written questions | House of Commons | 45711

[Engagements](#)

Asked by Diana Johnson

Following the successful Hillsborough independent panel, will the Prime Minister consider setting up a similar review of the biggest treatment disaster in the history of the NHS, namely the contaminated blood scandal? Victims are still waiting for answers and justice 35 years on.

Answered by The Prime Minister

The hon. Lady obviously raises a very important point in relation to contaminated blood. I will take it away and consider it. Obviously, she will know the reasons and background that led to the Hillsborough independent panel, but I recognise people's concerns about contaminated blood and will consider the point that she has made.

14 Sep 2016 | Prime Minister's questions - 1st Supplementary | House of Commons chamber | 614 cc898-1012

[Blood: Contamination](#)

Asked by Diana Johnson

To ask the Secretary of State for Health, if he will set a date for the introduction of (a) the 2016-17 and (b) 2017-18 additional support packages for people who were infected with contaminated blood.

Answered by Nicola Blackwood | Department of Health

The Department continues to work closely with the current scheme administrators to fulfil this Government's commitment to make all such payments before the end of March 2017. We have committed to payment, back dated to April 2016 of:

- a) the new annual payments of £3,500 for those infected with hepatitis C stage 1 (rising to £4,500 in 2018/19); and
- b) the continuation of annual payments for those infected with severe hepatitis C (stage 2) or HIV of £15,500 from this year (an increase from the current £14,749), and rising to £18,500 in 2018/19.

In addition, payment of a one-off lump sum payment of £10,000 to all those who were the partner or spouse of a primary beneficiary when they died and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse will apply to those already bereaved (and newly bereaved from April 2016 and beyond).

As well as these payments, the schemes continue to provide their existing support payments to registrants of the schemes, and will do so until the new, single scheme administrator is operational during 2017/18.

Taken together, the Government's action in this area is the most comprehensive ever to those infected with contaminated blood.

13 Sep 2016 | Written questions | House of Commons | 45773

[Blood: Contamination](#)

Asked by: Baroness Randerson

To ask Her Majesty's Government whether they provide a lower level of support for the surviving partners of those infected by hepatitis C

through contaminated blood, compared to the surviving partners of those infected by HIV or co-infected, and if so, why.

Answered by: Lord Prior of Brampton | Department of Health

Under the reformed ex-gratia payment scheme for infected blood announced on 13 July 2016, the partner/spouse at the time of death of a primary beneficiary will be entitled to a £10,000 one-off lump sum where HIV or hepatitis C infection contributed to the death of their partner/spouse. This will apply to those already bereaved, provided they register before the end of this financial year. Anyone newly bereaved from this year will automatically receive the lump sum. Discretionary support, in an enhanced form from financial year 2018/19, will continue to be available to all bereaved partners/spouses.

26 Jul 2016 | Written questions | House of Lords | HL1424

[Blood: Contamination](#)

Asked by Christian Matheson

To ask the Secretary of State for Health, what legal or other agreements the Government has with suppliers of contaminated blood products to provide for liability and compensatory efforts to support people who contracted illnesses as a result of the use of such products.

Answered by Nicola Blackwood | Department of Health

There are no legal or other agreements in place between the Government and suppliers of contaminated blood products to provide support for those who contracted illnesses as a result of the use of such products. No money has been received by the Government from suppliers of such products to fund ex-gratia support.

25 Jul 2016 | Written questions | House of Commons | 43389-90

[Blood: Contamination](#)

Asked by: Luciana Berger

To ask the Secretary of State for Health, pursuant to the oral contribution of the previous Prime Minister on 13 July 2016, Official Report, column 291, on contaminated blood and compensation, when he expects the details of that scheme to be published.

Answered by Nicola Blackwood | Department of Health

Reforming the infected blood ex-gratia support schemes remain a priority for this Government and, at his last Prime Minister's Questions on 13 July 2016, the then Prime Minister announced the publication of the Government's plans for reforming the current payment support schemes for individuals affected by HIV and/or hepatitis C through National Health Service-supplied blood, including its response to the public consultation which ran earlier this year.

The then Parliamentary Under-Secretary for Public Health (Jane Ellison) also issued a Written Ministerial Statement ([HCWS88](#)) on 14 July 2016.

The response document went live on the Gov.UK website on 13 July 2016 and can be found at:

www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support

25 Jul 2016 | Written questions | House of Commons | 43206

6. Further reading and useful links

All Party Parliamentary Group on Haemophilia and Contaminated Blood

<http://www.publications.parliament.uk/pa/cm/cmhallparty/register/haemophilia-and-contaminated-blood.htm>

Infected blood: Government Response to Consultation on Reform of Financial and Other Support

13 July 2016

<http://qna.files.parliament.uk/ws-attachments/536373/original/20160713%20Consultation%20response%20final.pdf>

Infected blood: Government Response to Consultation on Reform of Financial and Other Support

July 2016

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/539993/Consultation_response_acc.pdf

The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood *Inquiry into the current support for those affected by the contaminated blood scandal in the UK* January 2015

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

Penrose Inquiry Final report

25 March 2015

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

Financial Review Group's Proposals Final report Scottish Infected Blood Forum

15th April 2016

<http://www.sibf.org.uk/download/financial-review-groups-proposals-final-report/>

Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215828/dh_125977.pdf

Contaminated Blood Campaign

<http://contaminatedbloodcampaign.co.uk/>

Haemophilia Society

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

Scottish Infected Blood Forum

<http://sibf.ninedesignstudio.co.uk/>

Hepatitis C Trust

<http://www.hepctrust.org.uk/news/mar-2016/scottish-government-accepts-reforms-contaminated-blood-financial-support>

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