

Contaminated Blood Backbench Debate Briefing

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Overview

On 13th July 2016, the previous Prime Minister David Cameron announced details of a reformed English support scheme for those affected by the contaminated blood scandal.¹ The Department of Health subsequently published its formal response to its consultation on the reformed scheme,² providing more detail.

This is the first opportunity that the House of Commons has had to debate the reformed scheme. This briefing is designed to provide MPs with all the details on how this scheme will affect all of those affected, and updates The Haemophilia Society's earlier briefing, published shortly after the details of the reformed scheme were announced. Whilst its focus is on the English announcements, it also looks at the Scottish announcements and provides the latest details on developments in Northern Ireland and Wales.

The new English scheme is an improvement on the proposals in the original January consultation.³ However, it still falls short of the support the affected community deserves and requires. Some groups of beneficiaries still look set to be worse off than they were before. There is also still considerable uncertainty over what the means-tested discretionary support will look like; and there are concerns that a profit-making private company – potentially Atos or Capita – looks likely to be contracted to run the new discretionary support scheme.

The Scottish scheme is comparatively more generous. The Scottish discretionary support scheme will also be better-administered, with patient involvement in governance; a goal to minimise means-testing and assessments; and a commitment to continue existing ongoing payments and ensure no beneficiary is worse off under the new support arrangements.

According to analysis conducted by The Haemophilia Society, the Department of Health could adopt many aspects of the Scottish scheme and still fall within its allocated budget. The APPG is calling for the Government to adopt these measures, particularly in relation to bereaved partners; and to reverse their plans for a profit-making private administrator of the discretionary scheme. Any additional funds required to support those affected could be found from the 2013 sale of the Government's stake in Plasma Resources UK.

¹ Rt. Hon. David Cameron MP, Hansard HC Deb 13th July 2016, www.theyworkforyou.com/debates/?id=2016-07-13a.284.2&s=contaminated+blood+speaker%3A10777#g290.3.

² Department of Health (July 2016), *Infected blood: Government Response to Consultation on Reform of Financial and Other Support*, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/54444/Consultation_response_acc.pdf, pp. 18-19.

³ Department of Health (January 2016), *Infected blood: reform of financial and other support*, www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support.

The English Support Scheme

Overview

The reformed English scheme is an improvement on the one announced in January, but further measures must be taken before it can satisfy the needs of beneficiaries.

There will be modest increases in the annual payment amounts for people with HIV, Hepatitis C at Stage 2 and those who are co-infected. The payments will once again be linked to CPI. However, the amounts still fall well short of the payments offered in Scotland and our fear remains that many primary beneficiaries will end up worse off as regular payments are phased out and discretionary support is less readily available.

We welcome the fact 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 – £3,500, rising to £4,500 in 2018 – does not reflect the impact that Hepatitis C has had on many of 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.

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 support for people who cleared Hepatitis C prior to the chronic stage or were infected with other viruses.

Elements of the New Scheme

Overview

The new English support scheme is to be implemented in three tranches:

- **In 2016/17**, people with Stage 1 Hepatitis C are to receive their first ever non-discretionary ongoing payments; and people with Stage 2 Hepatitis C, HIV and those co-infected are to receive modest increases to their own payments. The bereaved will also be able to apply for a £10,000 lump sum payment in March 2017. As we are currently well into this financial year, these payments will be backdated to 1st April 2016 as soon as they are announced. The latest we have been told is that they will come in Dec 2016 / Jan 2017.
- **In 2017/18**, the new Special Category Mechanism for people with Stage 1 Hepatitis C will come in place, enabling them to apply for the same annual payments as people with Stage 2 Hepatitis C if they feel the virus has particularly badly affected them. The new scheme administrator will also be put in place to run the new amalgamated discretionary support scheme, taking over from the five trusts.

- **In 2018/19**, there will be further increases in non-discretionary ongoing support for all primary beneficiaries. The discretionary funding regime will also be better-funded from this point.

The current English support is only guaranteed up to the end of the current Spending Review Period, in 2020/2021. The five trusts which currently operate support are still operational and will remain so until the new scheme administrator is put in place in 2017.

Non-Discretionary Support – Comparison of English and Scottish Payments

The table below shows the regular non-discretionary payments per year (before adjusting for inflation):

Annual Payment	Current	New English 16/17	New English 18/19	Scottish
Hep C, Stage 1	£0	£3,500	£4,500	£0*
Hep C, Stage 2	£14,749	£15,500	£18,500	£27,000
HIV	£14,749	£15,500	£18,500	£27,000
Co-infected, Stage 1	£14,749	£18,500	£22,500	£37,000
Co-infected, Stage 2	£29,498	£30,500	£36,500	£37,000

*but will receive lump sum of £30,000.

Payments are made monthly or quarterly in arrears with the £500 winter fuel payment, included in the figures above, paid in early Q4. The payments are available to all people who were infected in England or while serving in the Armed Forces. They do not require the recipient to still be resident in the UK and are still paid following successful treatment for their Hepatitis C infection.

Discretionary Support

We welcomed the government's announcement that discretionary support will not be discontinued as proposed in the consultation and noted that the discretionary support will be enhanced from 2018/19. However, the funding provided for discretionary support will not be sufficient to improve the support offered to all beneficiaries to the level currently available to families of people with HIV or co-infected.

The Government has yet to make clear what the average and maximum amount of discretionary support people will be able to receive. However, given the budget is currently £4.1million and under the 'enhanced' scheme will only be increased by around 25% it will not be suitably funded to ensure the support offered to all beneficiaries matches those currently registered with the Macfarlane Trust.

The Infected Blood reference group is considering the policy on access to discretionary support and what sort of support it will offer. It is expected that details of the new discretionary support scheme will be announced next year. In the meantime, the APPG Co-

Chair Diana Johnson MP has been unable to obtain assurance that a number of existing discretionary payments will be maintained under the English scheme.⁴

The discretionary support will also include non-financial support. This includes signposting to financial support and money management and may include provision or procurement of benefits advice and counselling. The new scheme will continue to reimburse primary beneficiaries for prescription pre-payment certificates.

The new scheme will ensure equal access to the support available for all groups of primary beneficiaries. However, discretionary support for people infected only with Hepatitis C will not be raised to match the current levels available to people who are co-infected. Instead, it is expected a more heavily rationed amount of top-up payments will need to be provided.

Single Scheme Administrator

The affected community will broadly welcome the replacement of the five trusts with a single scheme administrator. However, the news that this new administrator is likely to be a profit-making private company – something which was not mentioned in the consultation documents – will be met with considerable concern.

The tender process for a new scheme administrator started in September 2016. It was expected that following a transition period the new scheme administrator will take over in May 2017, but it appears that this deadline is now being pushed forward. The tender documents are now available online,⁵ and show that both Atos and Capita have attended Department of Health meetings to discuss potentially bidding for the contract.⁶

The original APPG Inquiry into the scandal, conducted in January last year, raised considerable concerns about the management of the discretionary scheme for those affected, based on a survey of nearly 1,000 people affected by the scandal. In particular, it highlighted the distressing means-tests many beneficiaries were subject to; and raised issues with a trust management which was unwilling to advocate for their beneficiaries.⁷

It will be of utmost importance that the new supplier understands the complex needs of scheme beneficiaries and deals with all correspondence in a sympathetic way. We do have concerns that if, as is likely, the successful bidder is a private company it is not clear how the discretionary aspects of the scheme will be delivered. While the DH will own and publish a set of principles for discretionary support and will hold the budget it will be up to the scheme administrator to consider applications for grants and other support.

⁴ See WPQ 45758, 13th September 2016, www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-09-08/45758/.

⁵ See WPQ 48802, 24th October 2016, www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-10-14/48802/.

⁶ These are listed as attendees of a 26th September Q & A session with DH officials. See 26th September 2016, *Infectious Blood pre-market engagement supplier day: minutes of discussion and A & A with participants*. www.contractsfinder.service.gov.uk/Notice/580180d0-5cf3-4eb1-b7c7-07241fc95e84.

⁷ All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood (January 2015), *Inquiry into the current support for those affected by the contaminated blood scandal in the UK*, www.haemophilia.org.uk/what_we_do/influencing_advocacy/appg_hcb_fr.pdf, Sections 3.1 to 3.4.

The Scottish scheme has an alternative option for a scheme administrator with more beneficiary involvement, and the original APPG Inquiry report contained similar recommendations. The APPG urges the Government to adopt an administrator along these lines ensuring beneficiary representation.

The Stage 1 / Stage 2 Hepatitis C Distinction

From 2017/18, there will be a Special Category Mechanism (formerly called the special appeals mechanism) for people at Stage 1 to apply for a higher level of support similar or equivalent to that provided to people at Stage 2. It is not clear at this stage how many of those who apply will be able to obtain Stage 2 payments, or how many of the people with Stage 1 Hepatitis C will apply.

The value and effectiveness of the new appeals mechanism will rest on how well it is equipped to look at the range of health impacts of Hepatitis C. It will be important that mental health impacts of Hep C are given equal weighting. There also need to be consideration of the impact of the manner of infection on an individual's health as well as the infection.

The DH convened infected blood reference group of current Alliance House staff and trustees and patient representatives has been considering this process and providing evidence to the blood policy team.

Funding Uncertainty Beyond the Spending Review Period

There is no certainty that support will continue after 2020/21 and there is as yet no details on how the scheme will be reviewed as the end of the 5-year period approaches.

This is a cause of considerable worry for many of those affected, who fear that the scheme will be curtailed or even ended after 2020/2021. The Government needs to provide some certainty in this area.

Groups who will be worse off

Overview

For primary infectees the new proposals are an increase on the amounts proposed in the consultation but still fall well short of the Scottish proposals. The Government had assured the affected community that no one would be worse off under the new scheme but we do not believe this will be the case.

We are disappointed that the annual payments were not set at a level that minimised the need for discretionary support and ensured that all the affected community could be removed from poverty.

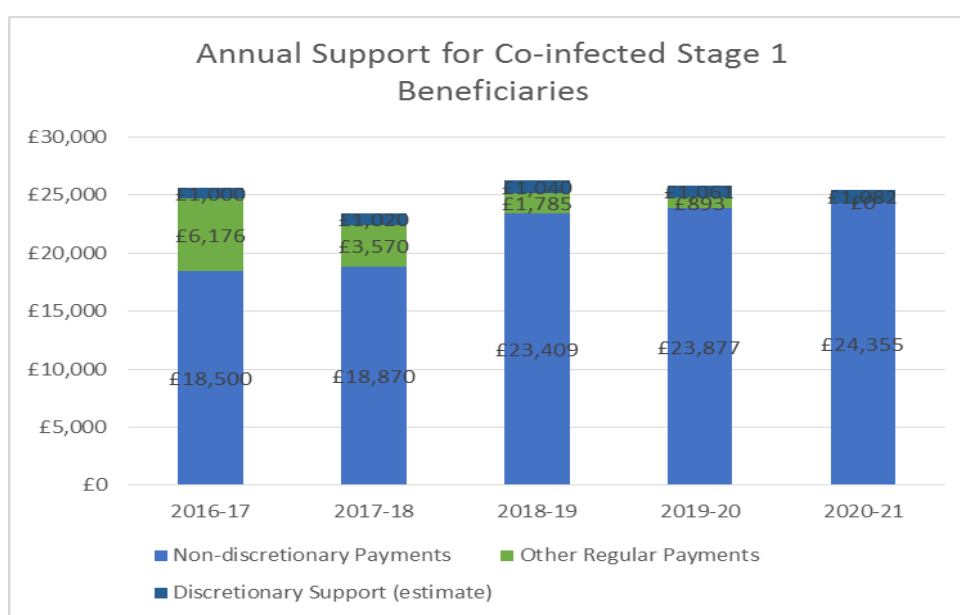
Furthermore the payments for co-infected people do not take into account the impact of being co-infected and instead simply add the two payments together. Co-infection can increase the rate of disease progression and risk of liver cancer and is associated with higher

morbidity and mortality versus mono-infection with either single virus. The Scottish scheme (see p. 11) does contain measures to address this.

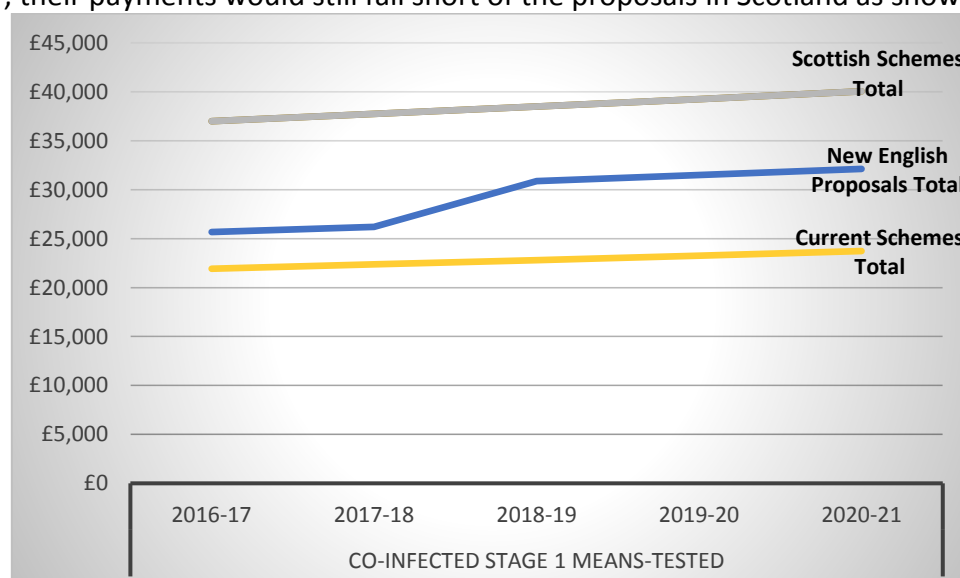
People receiving discretionary (but regular) top-up payments

For primary beneficiaries currently receiving regular/top-up payments the new proposals will be better than the current schemes only if they continue to receive means-tested discretionary payments. Currently most Macfarlane registrants receive regular top-up payments however, it seems unlikely that they will be able to continue receiving these payments given the modest funding increases for the discretionary fund.

As such, when non-discretionary ongoing payments are accounted for, most co-infected beneficiaries' total annual support will fall in real terms over the 5-year period (see below).



The current means-tested top-ups should continue for those with the greatest need, however, their payments would still fall short of the proposals in Scotland as shown below.



Dependents

Currently dependents of co-infected people and people with HIV are entitled to £1,200 a year. There is no mention of this in the new scheme.

Once there are common support arrangements for all beneficiaries, it is expected that dependents will be able to register for support from the discretionary budget however there will no longer be any regular payments for dependents.

Current Bereaved Partners

For partners who are currently bereaved and in receipt of financial support this will be maintained in 2016/17. However, the budget for discretionary support does not appear to be sufficient to ensure the support available to bereaved partners of people infected with Hepatitis C will be increased to match the support available to bereaved partners of co-infected people.

Instead, under the new scheme, bereaved partners (including those who are themselves primary beneficiaries) will be entitled to a one-off payment of £10,000 which they must apply for before 1st March 2017. The payment will be processed before the end of the financial year.

It is expected that people currently bereaved who are receiving regular payments will see these reduced and replaced by grants for emergencies. This will remove income from people who rely on it for their standard of living. This contradicts previous Government promises that no one would be worse off under the new scheme.

We also assume that people who are bereaved in the future will not be entitled to discretionary support at the same level as those currently bereaved. It is inconceivable that the Government's budget for discretionary support will be sufficient to top-up all bereaved partners' income to £19,000 as is currently the case for people registered with Macfarlane. Additionally, the new one-off support for the bereaved is only available if the HIV or Hep C contributed to their partner's death. This will mean that some bereaved partners will not be entitled to the one-off payment and others will have to go through onerous processes to prove the contribution of the virus to their partner's death. This is the first time that such a distinction has been made between different types of bereaved partners. It is not a logical distinction, given that the basis for supporting the bereaved is the fact that they often sacrificed much to be with their infected partners – for these purposes, the precise reasons why their partner died are not relevant.

Overlooked groups

People who were infected but did not reach the chronic stage of Hepatitis C

So called 'self-clearers' were people who were infected with Hepatitis C but cleared the virus prior to treatment. Despite clearing the virus these people can exhibit symptoms due to their previous infection including fatigue, mental health issues and diabetes. This group

of people have never been entitled to any support including the £20,000 lump sum given to all other people infected with Hepatitis C.

People infected with other viruses

In addition to HIV and Hepatitis C many people were also exposed to Hepatitis B, D or E. For some people this has led to them requiring continuous monitoring of their liver function. The impact of these viruses has not been considered and no mention of them is made in the Government's new scheme. These likely comprise an extremely small group of people, who could be supported at minimal cost to the Department of Health.

Also many people have received letters saying they are at risk of vCJD. The impact of this on people's mental health and on their ability to be treated by the NHS is not considered in the new scheme.

Bereaved Parents

The new scheme still does not offer any support for bereaved parents. Not only do they not receive any ongoing payments but it may be that they will continue to not have access to the discretionary support scheme. As a minimum, we see no reason why bereaved parents should be treated any differently to bereaved partners.

The Devolved Administrations

Scotland

Non-Discretionary support

The Scottish scheme is expected to be more generous than the English for most if not all beneficiaries. There is a potential that those who are currently registered at Stage 1 Hepatitis C but who would be successful in obtaining Stage 2 payments under the reformed English scheme could receive higher payments. However, The Scottish Government is also committed to reviewing the Stage 1/2 Hepatitis C distinction.

Every other category of beneficiary would receive better non-discretionary support, as outlined in the table on p. 4. The support for those with Stage 1 Hepatitis C who would not be successful in the Special Category Mechanism will also be higher: they will receive a £30,000 lump sum payment as opposed to ~£21,400 in annual payments over the 5 year period.

The bereaved will also get 75% of their partner's previous entitlement upon their death under the Scottish scheme – for the first time entitling this group to non-discretionary, guaranteed support. The English scheme makes no such provision.

Finally, it is also worth noting that the Scottish scheme has better measures in place to account for the effects of co-infection. Those with Stage 1 Hepatitis C and HIV will receive the same as those with both Stage 2 Hepatitis C and HIV, in recognition of the fact that co-infection has compounded the affect that both viruses have had on their lives.

Discretionary Support

The Scottish discretionary support scheme will be better-funded than the English scheme, with its funding set to more than treble,⁸ whereas the English scheme will see a more modest 25% increase in 2018/19. In addition, because of higher levels of non-discretionary support it will also have a more well-supported body of beneficiaries, potentially allowing it to focus on those who aren't accounted for in the non-discretionary support system.

The details on the administrator of the Scottish discretionary scheme – the so-called "Support and Assistance Grants" scheme – also look more promising than under the English proposals. As recommended by the Scottish Government-commissioned Financial Review Group, the scheme will have the following features:⁹

- Have an independent appeals mechanism, "which involves patient representatives."
- Patient involvement in governance/oversight of the scheme.

⁸ See Scottish Government, 18th March 2016, *Extra £20 million for infected blood support*, news.gov.scot/news/extra-20-million-for-infected-blood-support.

⁹ Financial Review Group, 17th December 2015, *Contaminated Blood: Financial Support: Conclusions and Recommendations*, <http://www.haemophilia.org.uk/news/view?id=51&x%5B0%5D=news/list>, pp. 4-5.

- “All commitments made by the Eileen Trust, Macfarlane Trust and Caxton Foundation to make regular payments, including winter fuel payments, should be honoured by the new fund under the existing terms of payment.”
- “All assessments, but particularly means-testing, should be minimised and simplified as much as possible.”
- There is a general guarantee that no individual will be worse off under the Scottish proposals than they currently are now.

Wales

Primary beneficiaries in Wales are set to receive the same support as people infected in England, but it is not presently clear what support the bereaved and other beneficiaries will be able to obtain.

This is an interim measure, and in the longer-term the Welsh scheme might have some differences from the one operated in England. The Welsh Government is currently consulting with beneficiaries on the options, and it is expected that the Welsh scheme will again change in 2018/19.

Northern Ireland

There has been no announcement from Northern Ireland so people infected will remain on the current schemes until further notice.

Whilst this arrangement will be workable so long as the English scheme remains unreformed, it could become untenable once the transition arrangements for the new English administrator are complete – at which point the existing discretionary charities could be closed down.

It is vital that the Northern Ireland Executive address this as soon as possible, and urgently outline details of the Northern Irish support scheme.

Other Issues

Hillsborough-style independent panel

At Prime Minister's Questions on 14th September, the APPG Co-Chair Diana Johnson MP asked the new Prime Minister Theresa May to consider a Hillsborough-style independent panel into the contaminated blood scandal.¹⁰ The Prime Minister promised to give this proposal an open mind.

On 30th September, she subsequently wrote to Diana Johnson MP setting out her reasons for opposing such a panel. Diana Johnson MP subsequently wrote back reiterating the need for an inquiry, and giving a comprehensive outline of the arguments in favour. These letters are available on the Haemophilia Society's website.¹¹

It is vital that if an independent panel is set up, it does not delay providing new support to those affected by the scandal. There is no reason why such a panel would have to impede the development of such support, and the Government should avoid language which implies that it could.

There is room for some flexibility on the precise nature of the panel which could be set up. It is not necessary for an independent panel to be held alongside an inquest or to take the form of a Statutory Inquiry under the Inquiries Act 2005. But nor would the goals of an independent panel be impeded if, for reasons outside of the APPG's control, the Department of Health was forced to hold an inquest or a statutory inquiry.

The cost of funding the Scottish scheme in England

The Haemophilia Society has carried out analysis exploring the cost of funding the Scottish scheme in England. It shows that the Scottish scheme could be funded within England and fall within the Department of Health's allocated budget for every fiscal year save the first – only in 2016/17 would additional funds be required to operate the scheme, to pay for the lump sum payments for those with Stage 1 Hepatitis C.

Whilst the Department of Health has allocated between £46.2 and £46.6 million a year for the new scheme,¹² looking at the financial commitments that have already been made it seems likely that it will under-spend on this.

This is deeply problematic, because if funds for the English scheme are not spent on beneficiaries, the money would have to be given back to the Treasury. It is not known whether any over-spend would have to be given back in each fiscal year, or by the end of the Spending Review period in 2020/2021.

¹⁰ Diana Johnson MP, Hansard HC Deb 14th September 2016, www.theyworkforyou.com/debates/?id=2016-09-14c.889.0&s=hillsborough+speaker%3A11647#g898.4.

¹¹ Haemophilia Society, 12th October 2016, *Correspondence regarding an Independent Panel to consider the Contaminated Blood Scandal*, www.haemophilia.org.uk/news/view?id=81&x%5B0%5D=news/list

¹² WPQ 45717, 16th September 2016, www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-09-08/45717/.

Potential funding sources for an improved scheme

Any additional funding required for an improved support scheme could easily come from one or both of two sources.

Firstly, in 2013, the Department of Health sold the Government's 80% stake in Plasma Resources UK to Bain Capital, for £230 million. The APPG Co-Chair Diana Johnson MP has asked whether a portion of the funds from this sell-off could be used to support the affected community.

Initially, the APPG was told that Treasury rules prevented this from happening because money from sell-offs is categorised in capital spending rather than revenue spending. However, the Department of Health regularly transfers money from its capital budget over to its revenue budget: it would merely have to make a similar transfer in order to make use of the funds from Plasma Resources UK.

Diana Johnson MP has written to the new Under-Secretary of State for Public Health, Lord Prior of Brampton, reiterating her calls for the funds from the sale of Plasma Resources UK to be used in this way.

Secondly, there may still be money held in reserves by the three charities which administer support for those affected by the scandal. As these charities are legally separate entities, it would have to be arranged for these funds to be transferred to a new support scheme.