

Guide to the *Infected blood: reform of financial and other support* consultation

Introduction

The Department of Health has now published its *Infected blood: reform of financial and other support* consultation.

The Haemophilia Society has serious concerns about the proposals contained in the consultation and how they will affect people in England. We recognised that many of our members share these concerns and are seeking advice on how to respond to the consultation. It is important to note that Scotland has undertaken its own consultation and we are awaiting news on the plans in Wales and Northern Ireland.

To help members to respond, we have developed the following guide to the consultation form.

Please note: members are encouraged to respond to the consultation in their own words, using their own experiences and reactions to the proposals. This is a guide only, designed to help members answer the questions, and to highlight some of the key concerns of The Haemophilia Society and the broader community on the proposals.

You can access the form online here <https://consultations.dh.gov.uk/blood-team/infected-blood> or call 0300 123 1002 to order a paper copy.

Consultation form

Section: About you

This section asks you basic questions about yourself, including which country you live in, your status and whether you are registered with any of the current schemes or charities.

Advice on the response

Fill this in as appropriate

Section: Questions on Chapter 3

1. Would you prefer five separate schemes (as now) or one scheme?

Advice on the response

The Haemophilia Society welcomes the proposal to reduce the number of schemes from five to one as we recognise that members have found the existing schemes confusing and complex. However, we have concerns that the existing bodies would continue to manage the new scheme. The consultation proposal does not specify if the new scheme would be run by a completely new team or staff and leadership at one of the current schemes.

Using the comments box you could:

- Outline your experiences of dealing with your current scheme(s) and any challenges you encountered
- Outline the priorities you would wish to see in the approach and operations of any new scheme, for example, the way the scheme is implemented should be easy to understand or that it should be accessible
- Outline your thoughts on who should run the scheme (current staff and leaders, or a new team)
- Say whether you think the new scheme should be independent (as now) or responsible to government for its spending and actions.

2. Do you have views on how the individual assessments should be undertaken?

Advice on the response

The consultation recognises that one of the biggest sources of criticism of the current schemes is that people with Stage 1 hepatitis C do not receive any annual payments. To remedy this, it proposes to introduce individual assessments for this group, to decide how much you may receive as a new annual payment. Individuals would be re-assessed every three years and would be allocated a 'band' to determine payment. The highest payment available would be £15,000.

Although the introduction of annual payments for people with Stage 1 hepatitis C is welcomed, criteria for the individual assessment has not yet been set. The Haemophilia Society has a number of concerns around the assessments and what impact this will have, including that:

- The consultation states that people would move to a lower band if their health has improved, resulting in a lower income and removing the element of financial security
- The consultation states these would be 'health-based assessments.' This could mean that other important factors such as the impact a person's illness has had on their family life, employment or education opportunities is not taken into account
- The assessment could also penalise people who may have successful treatment but will still have lived with the years of health issues, and the associated financial implications
- The assessments may be carried out by a private company who know little about the impact of hepatitis C on individuals, and could cost significant amounts of money to run the assessments

Using the comments box, you could:

- (If appropriate) Outline what you think the impact to your life would be of having regular health assessments, which determine the level of payment you receive
- Outline what you think of the proposal to have individual assessments
- Say what you think the assessments should take into account and why
- Suggest who you think should do the assessments

3. Should the reformed scheme include a lump sum payment of £20,000 when an infected individual joins the scheme?

Advice on the response

The Haemophilia Society believes that everyone entering the scheme for the first time should be eligible for a £20,000 lump sum. However, it has noted that subsequent annual payments for HIV and/or Stage 2 hepatitis will be capped at £15,000. In Scotland, equivalent annual payments could be set at £27,000 for mono infected and £37,000 for co-infected.

Using the comments box, you could:

Detail what initial payment you received and any amount you currently receive in annual payments (if appropriate), and what these payments mean to you.

- 4. Should the reformed scheme maintain the difference between those with HIV and hepatitis C by retaining the lump sum payment of £50,000 for progression to cirrhosis in relation to hepatitis C?**

Advice on the response

The Haemophilia Society believes this should be retained and is concerned that the Department is considering removing this payment.

Using the comments box, you could:

- (If appropriate) outline your experiences of progressing to having more serious health problems and the impact it has had on you and those close to you

- 5. Should the scheme offer the newly bereaved one final year of payment, or continued access to discretionary support, or the choice between these two options?**

Advice on the response

For partners/spouses who are newly bereaved, the consultation proposes that, once the reformed scheme is in place, partners/spouses would continue to receive, for one further year, the payment their infected partner/spouse was receiving at time of death, or alternatively affected people could access a discretionary fund.

The Haemophilia Society is concerned that the proposals do not go far enough to support widows, partners, carers and dependents, and that a one-off payment would not be sufficient. It has also noted that, rather than a one-off lump sum, or access to means-tested discretionary payments that have been offered to those who have been bereaved in England, in Scotland, spouses would be offered a pension of 75% of the relevant level of annual payment that was being received, providing them with a regular income for life

Using the comments box, you could:

- Share your views on what support you think should be offered to partners/spouses who are newly bereaved
- Query as to whether both a lump sum *and* access to a discretionary fund could be considered

6. Should the scheme offer those already bereaved a final lump sum or continued access to discretionary support, or the choice between these two options?

Advice on the response

For people who are already bereaved and receiving regular support, the consultation asks for views on offering either a one-off lump sum equivalent to three times the value of the annual payment received in 2015/16 or £5,000, whichever is the greater, or retaining access to a discretionary, means-tested payments.

The Haemophilia Society is concerned that for people who are already bereaved, receiving a one-off lump sum would mean losing out on significant regular financial support. However, there has also been great dissatisfaction expressed at the current system of discretionary payments, which are means-tested. The proposal gives no indication of the level of support that would be offered if a means tested discretionary payment is accepted, leaving people with no financial certainty.

Using the comments box, you could:

- (If appropriate) detail what you currently receive as someone who is bereaved, and what you would estimate you would receive under the proposed scheme
- Query as to whether both a lump sum *and* access to a discretionary fund could be considered
- State your feelings on the impact of this proposal
- If you have already been bereaved, but received no payment at all, how you should be included in this proposal.

7. Should providing access to treatment for those with hepatitis C be part of the reformed scheme?

8. If you are a beneficiary of the current scheme, infected with hepatitis C would you be interested in being considered for access to treatment under the scheme?

Advice on the response

The scheme proposes to offer some access to new hepatitis C treatments for those considered clinically appropriate on the basis of a treatment assessment, funded from a 'separate scheme'.

The new generation of hepatitis C treatments are a significant step forward in treatment and the opportunity to provide access to people who received contaminated blood is welcomed by The Haemophilia Society.

However, the NHS will be required to provide treatment to everyone with early stage disease where treatment is appropriate from the end of February 2016. The Haemophilia Society is concerned that funding for enhanced access to treatment for those affected will be taken from the existing budget for financial support, when it should be funded through the NHS. There is also concern that people will be treated outside the NHS system and no information is given on how people will be supported through treatment. The proposal also suggests treatment will be more expensive than if delivered by NHS England. The Haemophilia Society believes that this is unacceptable.

Using the comments boxes, you could:

- Express concern that funding treatment could be at the detriment of the financial support available in these proposals
- Express concern that if you are entitled to treatment via NHS England, this proposal suggests you may not receive access to the drugs in a timely way and your treatment may cost more than other patients.

9. Should discretionary payments be available for travel and accommodation relating to ill health?

Advice on the response

The consultation states that under the new scheme, people who currently receive annual support should have their payments uplifted to £15,000 but any CPI linking will be removed. Additionally, those who are currently registered with the schemes with Stage 1 hepatitis C, will be offered an individual assessment to determine the amount of a new annual payment (up to £15,000). However, the consultation also proposed that in future, discretionary payments will be stopped apart from 'travel and accommodation related to ill health'.

We know that currently, people receive a range of discretionary payments including: small lump sums; regular winter fuel payments; payments to the children of beneficiaries; vouchers for use at specific shops; prescription charges; and a range of other regular ongoing payments. The Haemophilia Society is very concerned that removing these payments will mean that people could lose thousands of pounds of support each year that they are totally reliant upon.

Using the comments box, you could:

- (If appropriate) Detail how much you currently receive in discretionary payments, per year and whether these are in fact regularly paid and your household depends on them.
- Estimate how much you might lose if you no longer had access to discretionary payments (apart from 'travel and accommodation related to ill health')
- Describe the impact the removal of discretionary payments will have on you and your family.
- Outline your concerns about the removal of index linking and its impact on your income over time.

10. Are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?

Advice on the response

The specific groups that The Haemophilia Society has concerns about, are:

- **People currently receiving discretionary payments.** Under the reformed scheme, people could be financially worse off, due to losing access to most discretionary payments
- **People receiving annual payments for HIV and advanced hepatitis C.** Annual payments for people with HIV and advanced hepatitis C will decrease in value

over time. Although these annual payments will increase from £14,749 to £15,000, they will no longer be linked to the Consumer Price Index

- **People that may be subject to individual assessments.** Under the revised scheme people may lose out on the amount they receive over time, as a result of the individual assessment. The assessments could also penalise people who may have successful treatment but will still have lived with the years of health issues, and the associated financial implications.
- **Tax and means tested benefit exemption.** Currently all money paid via the schemes is exempt for tax and means tested benefits. The new proposal does not state this will continue, which could have a significant impact on income.
- **All beneficiaries in England.** If more generous proposals are accepted by the Scottish Government, people in England will receive much lower incomes under the revised scheme, than those in Scotland

Using the comments box, you could:

- Highlight your concerns if you fit into any of the categories above
- If you think you may stand to lose out under the new scheme, you could make an estimate of how much this might be a year
- You could also comment on any other support such as benefit advice that you think may be removed in the new system

11. Do you have any other comments that you wish to make?

Advice on the response

You can use this box to add in anything else you feel should be considered by the consultation team.

For your information, The Haemophilia Society is calling for the period of consultation to be withdrawn until the full impact of these proposed reforms is understood, and before any changes to the scheme are finalised, to prevent many of the most disadvantaged people losing out on the support they rely on.

For more information, please visit our website: <http://www.haemophilia.org.uk/> or email us at info@haemophilia.org.uk

Consultation details

The *Infected blood: reform of financial and other support* consultation is available on the Department of Health's website here:

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

Contact details

Email: infectedbloodreform@dh.gsi.gov.uk

Address: Blood Policy Team, Department of Health, Room 104, Richmond House, 79 Whitehall, London SW1A 2NS

The consultation closes for responses at **15 April 2016, 11.45pm**