

11 April 2016

## Questionnaire Response Form

### Consultation - Infected Blood: Reform of Financial and Other Support

Please ensure you have read the consultation document before completing this questionnaire. You can complete this questionnaire online at:

<https://consultations.dh.gov.uk/blood-team/infected-blood>

Alternatively, you can complete this form. Once completed, please return to:

By post: Department of Health Room 104, Richmond House 79 Whitehall  
LONDON, SW1A 2NS

By e-mail: [infectedbloodreform@dh.gsi.gov.uk](mailto:infectedbloodreform@dh.gsi.gov.uk)

### About you

It would be helpful for us to know some information about you to help us analyse the results. If you provide this information we may also contact you to discuss any of your responses should we require further information. Filling in any personal information is optional.

**In which country do you currently reside? Please mark 'X' in only one box**

England	X
Scotland	
Wales	
Northern Ireland	
Other	

**Which of the following statements best describes your status? (Please tick all that apply)**

I have hepatitis C (from infected NHS supplied blood/blood products)	
I am HIV positive (from infected NHS supplied blood/blood products)	
I am immediate family (a widow, partner, child or parent) of someone infected with hepatitis C, HIV or both by an NHS blood/blood product	
I am a carer for a person infected with hepatitis C, HIV or both by an NHS blood/blood product	
Prefer not to say	
Other. Please specify	Member of British HIV Association (BHIVA) Executive Committee

**Are you registered with one of the current payment schemes / charities?**

Yes	
No	
N/A or Prefer not to say	N/A

### Questions on Chapter 3

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

One	
Five	
Other (please specify in box below)	X
Don't know/ unsure	

Please provide any comments below:

I don't feel it's appropriate for me to comment on this on behalf of BHIVA. However, I would support a change that reduces administrative costs if this releases more funds to support patients and others affected by infected blood.

**2. Do you have views on how the individual assessments should be undertaken? Please provide any comments.**

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

Yes	
No	
Don't know/unsure	X

Please provide any comments below:

Not appropriate for me to comment.
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**4. Should the reformed scheme maintain the difference between those with HIV and hepatitis C by retaining the lump sum payment of £50k for progression to cirrhosis in relation to hepatitis C?**

Yes	
No	X
Don't know/unsure	

Please provide any comments below:

HIV is also associated with long-term serious and life-threatening complications e.g. cancers, even when well-controlled by antiretroviral therapy. There is no cure for HIV, unlike hepatitis C, and with improvements in life expectancy, patients will need to take medication for several decades.
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**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?**

Yes	
No	
Don't know/unsure	X

Please provide any comments below:

Not appropriate for me to comment.
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**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?**

Lump sum	
Discretionary support	
Choice of either	

Please provide any comments below:

Not appropriate for me to comment.

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

Yes	X
No	
Don't know	

Please provide any comments below:

This should be a priority as would address many of the issues resulting from hepatitis C infection. The long-term benefits would likely outweigh costs when taking into consideration that the majority of those living are aged >50 years with a poor prognosis and likelihood of hospital admissions for hepatitis C-related complications if not treated.

**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?**

Yes	
No	
Don't know	

Please provide any comments below:

N/A

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

Yes	X
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No	
Don't know	

Please provide any comments below:

### Question on Chapter 5

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

Please provide any comments below:

### Overall

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

Thank you for completing the questionnaire.