Date 14/04/2016

Infected Blood: reform of financial and other support - questionnaire

## 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

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 | The Haemophilia Society is the only UK wide charity for people affected by bleeding disorders. Many of our members are directly affected by this tragedy.  |

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

|  |  |
| --- | --- |
| Yes  |  |
| No  |  |
| N/A or Prefer not to say | X |

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:

|  |
| --- |
| For years our members have highlighted how the current schemes are not fit for purpose, that the schemes are too complex to navigate and people do not always feel they are treated with dignity and respect. This was further highlighted by the APPG inquiry in 2015 and in correspondence to many MPs. In light of this one new organisation that is simple to navigate and focusses on the needs of their beneficiaries without needing to feel they are begging for assistance would be preferable. However beneficiaries of the MFET and Macfarlane Trust tell us the organisations were set up as part of an out of court settlement and cannot be changed without agreement of the beneficiaries. Despite wishing for a different scheme, they would not accept a scheme that provided less security and support than the current scheme. As the proposed scheme does not provide sufficient long term support to widows and partners, nor does it provide any support to parents of deceased children, dependent children or other family members included in the current scheme. We also note from a meeting with DH officials that this is a five year scheme that will be reviewed and reassessed at the end of the spending period rather than the current lifelong scheme, this is not a suitable alternative proposal and would not be accepted.Any new scheme must provide as a minimum the same level of ongoing support to everyone currently entitled to register as the current scheme, and should provide significantly more support than currently available to enable beneficiaries to live with dignity and security. Our members and the 2015 APPG inquiry have highlighted concerns around the current schemes and have called for any new scheme to be independent of the current schemes.One of the criticisms of the current scheme is that they are difficult to hold to account and there is no appeal process if people believe they have been treated unfairly. Any new scheme would need to have a clear independent appeal process. |

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

|  |
| --- |
| Although the introduction of annual payments for people with Stage 1 hepatitis C is welcomed, The Haemophilia Society has a number of concerns around the assessments and what impact this will have, including that:The consultation makes no provision for people who have been infected with other hepatitis viruses (e.g. Hep B) and blood born viruses (e.g. vCJD) that impact everyday life and health care. These should be equally addressed. The consultation states that people would move to a lower band if their health has improved, resulting in a lower income and removing any financial securityThe 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. Having lived with an infection for 20+ years many people will have had multiple treatment cycles that have had a lasting negative impact on employment, education and the ability to work. Nor do these assessments appear to take into account the impact on relationships, carer burden or family income. 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. This will discriminate against people who have successful treatment who are currently virus free and physically better than they have been for most of their life.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. This will lead to inappropriate decisions, based on the health status of a person on the day they are assessed, rather than reflecting on the lifetime impact of the virus and the financial impact on a family. This will cause a great deal of distress to the people being assessed, who have already experienced the devastating impact of the disability benefit assessments. An in-depth knowledge of the long term impact of living with hepatitis C; and frequently a multitude of other viruses due to contaminated blood will be essential to make an informed decision. This may should also include an understanding of the impact these viruses have on someone with a bleeding disorder, as the cumulative impact of multiple conditions should be addressed if an assessment process is implemented. The Society believe many of the community infected with hepatitis C are disabled as defined in the Equality Act 2010.  It is unlawful for the government to treat them differently to other members of the community who have contracted a different virus as a result of contaminated blood, unless that difference can be objectively justified.  The Equality Impact Assessment published by the government confirms that no difference in treatment is justifiable.  We therefore call on the government to ensure there is true equality of treatment between disabled members of the community who carry the HIV virus and those who carry the HCV virus throughout any new scheme.  However it is essential that no reduction in funding is implemented for those already receiving support and additional funding is found to address the current discrimination.With the information available it is impossible to make an informed decision about how this will impact individuals and whether this is a viable option. The majority of people are very concerned they will be considerably worse off financially due to the removal of discretionary payments, and the focus on current health. By requiring a new assessment every three years any financial stability is removed. For many families this may be their sole income, so long term financial planning and security will become impossible. Point 12 of the impact assessment states; Another option was to increase the size of the one-off payment available to individuals with Stage 1 hepatitis C. The payment would rise from £20,000 to £50,000, in line with the payment available to individuals with Stage 2 hepatitis C. Preliminary analysis found that this option would not reflect the wide spectrum of ill health in this group.The Society agrees that this does not reflect the differing impact of Hepatitis C on individuals' on-going health and so some form of assessment and additional ongoing payment mechanism should be available in addition to a lump sum. We would ask that the Government consider following the lead of the Scottish Government by providing a lump sum payment to bring the level of support for everyone infected with Hepatitis C to £50,000 as a minimum but, to also include ongoing annual payments for those with ongoing need.Point 14 of the Impact assessment states; Analysis found that while this option would provide access to annual payments to the non-cirrhotic hepatitis C cohort, it would also result in a reduction in payments for all beneficiaries already in receipt of two annual payments, and likely also for some in receipt of a single annual payment, and that payments for dependants, spouses and widows would need to be tapered down before stopping in order to prioritise available funding for infected individuals. The Society does not believe it is appropriate to discriminate against beneficiaries already in receipt of funding who are dependent on this income to provide support to another group with significant need. Additional funding should be provided to enable a fairer level of funding for all. It is important to remember that most beneficiaries who currently receive discretionary payments are on a low income and have had their education and work opportunities severely restricted for their whole life. Many have already reached retirement age, this means even if their health now improves their employability is very low and opportunities or alternative income sources are exceptionally limited.Point 66 of the Impact assessment states; The number of individuals likely to be eligible for the highest band for new annual payments is unknown. Coupled with the demand effect above, there is a risk that the total sum of payments made exceeds the financial envelope that is available for this scheme. Before assessments take place, Government would set the total amount available dependent on financial pressures in that year. Once assessments take place, and after the numbers of individuals within each band are confirmed, the payments could be set to try to ensure the total does not exceed the financial envelope.The Society is extremely concerned that this demonstrates that any payment for people with Hepatitis C will be based on affordability not need, which could be seen as discriminating against people with Stage 1 compared to all other beneficiaries.The proposals do not seem to take into account the impact that living with HIV and HCV may have had on an individual's employment prospects and quality of life prior to joining the scheme. For example, ongoing loss of income due to impact on career progression. |

**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:

|  |
| --- |
| The Haemophilia Society believe an infected individual should receive a lump sum of £50,000 when joining the scheme, whatever virus they were infected with.The Society is also concerned that the proposals do not address individuals who were infected with HCV but cleared the virus prior to screening (sometimes known as self-clearers) and who therefore never produced evidence of active virus. Although, these individuals may have ongoing symptoms caused by the infection they are not currently eligible for ongoing payments nor did they receive a lump sum due to their infection. We believe they should be included in this scheme and receive financial support due to the impact of infection.The multitude of viruses many people were infected with including HIV, Hepatitis B, vCJD and Hepatitis E appears to have been completely overlooked in this consultation, many of these are not curable and have a significant impact on the daily lives and healthcare of those infected, or who have been informed they have been exposed to these viruses. The long term health implications of many of these viruses is unknown therefore, lifelong provision needs to be considered here.The Haemophilia Society firmly believes infected partners should also have access to the scheme. Accidental exposure and infection can occur through activities of daily living, even when people are exceptionally cautious and do all they can to protect family members.  |

**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 |  |
| Don’t know/unsure | x |

Please provide any comments below:

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| --- |
| The Haemophilia Society believes everyone infected due to contaminated blood should receive a lump sum of £50,000, so all stage 1 beneficiaries should receive a £30,000 top up immediately, removing the need for this payment. However, it is also noted that subsequent annual payments for HIV and/or Stage 2 hepatitis will be capped at £15,000. In Scotland, equivalent annual payments have been set at £27,000 for mono infected and £37,000 for advanced Hep C co-infected. The burden of illness when infected with multiple viruses is significant, and although treatment may be available the impact of multiple infections is significant and must be recognised. The Society believe people should not be penalised for living in England. |

**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:

|  |
| --- |
| 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, parents, carers and dependents, and that a one-off payment would not be sufficient or acceptable. We also note 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 will 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. The Society suggests this would be a reasonable level of payment.Without further details on what the discretionary support for bereaved would consist of we do not believe it is currently possible to recommend one option over the other. If the government were to go ahead with a choice between the two options it is difficult to imagine how recently bereaved individuals would be able to effectively decide which option was better suited for their future situation.  |

**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:

|  |
| --- |
| The Haemophilia Society is exceptionally concerned that for people who are already bereaved, receiving a one-off lump sum would mean losing out on significant regular financial support. Members tell us this will be up to £5000 PA. 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. We note that in Scotland, spouses will 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.The Society suggests this would be a reasonable level of payment and should be based on what the infected person would have received had they died following implementation of the new scheme - i.e. 75% of the annual payment appropriate for the type of infection.  |

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

|  |  |
| --- | --- |
| Yes |  |
| No  | X |
| Don’t know |  |

Please provide any comments below:

|  |
| --- |
| The NHS are required to provide treatment to everyone with early stage disease where treatment is appropriate. NHS England have confirmed that a diagnosis of a bleeding disorder, mental health issues, or other conditions may mean people with Hepatitis C infected via contaminated bleed could be prioritised for the new generation of Hepatitis C treatment and so there should be no requirement for an alternative access scheme. 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 and if a separate scheme were to be implemented the DH should negotiate to pay the same rates as NHS England for drugs. Having met with several of the pharmaceutical suppliers they confirmed they have not been approached to discuss price, but they would be willing to do so.The Society are concerned that treatment outside the Operational Delivery Network could lead to sub-standard care, which would be unacceptable.Money that has been allocated to treatment provision must be reallocated to providing financial support to individuals.The Department of Health frequently quote a large number of people who were potentially infected with Hepatitis C via blood transfusions but have never been identified. Several look back exercises however, have only identified a small number of these people. The Society are concerned that large amounts of money may have been put aside for accelerated treatment for 'potential' infections, reducing the level of support for those already identified. The Society believes this money could be reallocated to ensure ongoing payments are raised to enable ongoing regular payments for all. |

**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:

|  |
| --- |
| Not Applicable |

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

|  |  |
| --- | --- |
| Yes | X |
| No  |  |
| Don’t know |  |

Please provide any comments below:

|  |
| --- |
| 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.We have been contacted by large numbers of members who are exceptionally concerned that they will lose significant amounts of essential payments. The distress and anxiety is such that several people are concerned they will have to leave their home with nowhere to go, and have required emergency mental health care.Examples includeA couple who are both infected with dependent children stand to lose £12,000 per annum. This includes £100 per month per child in ongoing support currently provided by the MacFarlane trust. A person with HIV stands to lose £5000.In addition to one-off cash payments for large and rare expenses, a person with HIV who earns less than £7600 per year stands to lose £5676 a year in ongoing payments currently provided as top-ups by the MacFarlane Trust.A widow or widower of an individual who was infected with HIV stands to lose ongoing payments topping up their income to £19,000 per annum.A person with advanced Hepatitis C stands to lose winter fuel payments as well as ongoing means-tested regular payments of £2000 per annum.We welcome the government's commitment in the debate on the 12th April that in a new scheme all people with Stage 1 Hepatitis C will receive annual payments. However, it is not clear whether payments (currently only discretionary) to people with Stage 1 Hepatitis C will increase or decrease following this change without further information on the proposed payment bands and the nature of the individual assessment criteria.The Society believes this is totally unacceptable and nobody should be left worse off from any future scheme. |

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:

|  |
| --- |
| 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. Concern about this has led to significant impact on many people's health with many reporting a deterioration in both their mental and physical health due to concern over their future.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. The decision to freeze the payments in monetary terms at £15,000 per year will substantially reduce the value over time. Assuming that CPI inflation continues at its current 20 year average of 2.02% the value of the annual payments will have dropped by over £2,500 per year in 10 years' time.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.Parents of children who died in the early years have never received payment and continue to grieve and are severely impacted by their loss. They have not been recognised in this scheme either.Women who were infected with HIV by their husband/partner have received payment as primary beneficiary, however if their husband/partner died they have never received any payment for their husbands death as other widows have. This has not been addressed in this proposal. 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. Everybody currently registered with a scheme that is entitled to one off grants, counselling and benefits advice. These elements have been removed in the current scheme. All beneficiaries infected in England. As the more generous proposals have been accepted by the Scottish Government, people infected in England will receive much lower incomes under this reformed scheme.The Society believes that it is important to take a holistic view of beneficiaries needs. The Society support the view of the APPG inquiry in 2015 which recommended that a public health doctor should make a comprehensive assessment of the needs of beneficiaries. The Society also wrote to the Department of Health in March 2015 to suggest a system for developing a comprehensive consultation process including the expertise of an actuary to assess the lifetime cost impact of infection. We continue to believe this is essential to providing an appropriate levels of financial support.A review of needs should take into account the additional costs of living with haemophilia, other bleeding disorders, HCV,HIV and the multiple other viruses that the community were infected with as well as allowing beneficiaries to live comfortably, rather than simply above the poverty line. |

Overall

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

|  |
| --- |
| A recent study undertaken by The Haemophilia Society in partnership with the University of Chester shows the significant impact of contaminated blood infection on individuals with severe haemophilia. The Cost of Haemophilia across Europe a Socioeconomic Study (CHESS), includes detailed data from 1,285 haemophiliac patient records. These data were transposed into a targeted dataset by 139 Haematologists followed by patient reported outcomes. Patients diagnosed Hepatitis and HIV - Blood Born Virus (BBV) were compared with the remaining patients without an infection.The odds ratio of a mental health issue for people with a BBV vs the unexposed group is 1.5.The population of people with a BBV unable to work is 5 times higher than those not infected.The average count of concomitant conditions (diabetes, fibromyalgia, hypertension, osteoporosis) excluding BBVs, is on average 0.87 higher amongst the BBV group, when compared to the non-infected group. On average patients without BBV's require less caregiver support than patients from the BBV group. This is an odds ratio of 1.24 greater likelihood of caregiver assistance.The exploratory analysis conducted suggests a greater level of unmet need among BBV patients when compared to the wider Haemophiliac population.There are greater risks, within the BBV population, of acquiring/developing concomitant conditions, in particular mental health issues.Whilst the overall study is aimed at understanding the burden of severe haemophilia among adults, which in isolation is a highly burdensome condition, this analysis suggests there is increased burden to patients with BBV comorbidities.In July 2015 The Haemophilia Society wrote to the Secretary of State for Health to say taking money from an NHS budget and thus adversely affecting patients would be inappropriate and would add to the considerable distress those affected already experience. We believe that since the additional resources will be to correct the errors of past governments, funding should be from the Government Contingency Fund, and those affected should never be made to feel responsible in any way for reduced NHS funding elsewhere. We call on the Government and particularly The Prime Minister to right this wrong by providing significant increased funding from Central Government to provide enough resources for whole affected community to live with the dignity and security they deserve.  |

Thank you for completing the questionnaire.