



Equality Analysis

Infected blood: reform of financial and other support

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Prepared by the Infectious Diseases and Blood Policy Team, Department of Health

Introduction

The general equality duty that is set out in the Equality Act 2010 requires public authorities, in the exercise of their functions, to have due regard to the need to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

The protected characteristics are: age, disability, gender reassignment, pregnancy & maternity, race, religion or belief, sex and sexual orientation.

The general equality duty does not specify how public authorities should analyse the effect of their existing and new policies and practices on equality, but doing so is an important part of complying with the general equality duty. It is up to each organisation to choose the most effective approach for them. This standard template is designed to help Department of Health staff members to comply with the general duty.

Equality analysis

Title: Infected blood: reform of financial and other support

Consultation on reform of the ex-gratia payment schemes for individuals infected with HIV and/or hepatitis C before 1991 through treatment with NHS-supplied blood and blood products

What are the intended outcomes of this work?

1.1 This equalities analysis accompanies the consultation document on proposals to reform current payment schemes that Government set up since 1988 for people infected with, or affected by HIV and/or hepatitis C as a consequence of treatment with NHS-supplied blood or blood products before September 1991. Over time the support system has become complex, and has attracted significant criticisms from those it is intended to help. On 25 March 2015, the Prime Minister, David Cameron, and the Secretary of State for Health, Jeremy Hunt, expressed their sympathy for the pain and grief suffered by many infected people and their families and undertook to consult on how to improve the current payment schemes. The consultation seeks views on what a new system of financial and other support could include.

1.2 This equalities analysis provides an initial view of how the proposals set out in the accompanying consultation document might affect any group of people with particular protected characteristics (see paragraphs 4.1-4.8). The key elements being consulted on, and therefore considered in this equalities analysis are:

- to replace the current five schemes with one operated by a single body
- to keep eligibility for the reformed scheme broadly the same as it is for the current schemes
- to offer some early access to new hepatitis C treatment for those for whom the treatments are clinically appropriate on the basis of a treatment assessment and who are unlikely to receive it soon on the NHS
- to introduce individual assessments for those with hepatitis C stage 1 and for all new entrants to the scheme, to determine amount of a new annual payment, the highest level being the same as those that will be received by those with hepatitis C stage 2
- to retain annual payments (for HIV and/or hepatitis C stage 2) for those who currently receive them
- to seek views on whether to provide newly bereaved partners/spouses with a final payment equivalent to one further annual payment at the level their partner was receiving at the time of their death or to provide access to a discretionary fund or a choice of either

- to seek views on the future arrangements for those already bereaved, and whether that should be through a one-off lump sum or through continuation of a means tested discretionary fund, or a choice of either

1.3 This equalities analysis sets out some preliminary analysis of the key equality issues associated with the consultation proposal. We are offering an opportunity to comment on this by responding to the consultation.

1.4 Any feedback we receive will be used to update this analysis and inform our consideration of potential ways to mitigate adverse impacts. This is ongoing work in progress.

Who will be affected?

2.1 Those primarily affected by proposed reforms will be infected individuals and affected family members of infected individuals, particularly those who are/were financially dependent on support given by the schemes, such as spouses or partners who do not work full-time because of caring responsibilities, bereaved spouses or partners; dependent children.

Evidence *The Government's commitment to transparency requires public bodies to be open about the information on which they base their decisions and the results. You must understand your responsibilities under the transparency agenda before completing this section of the assessment. For more information, see the current [DH Transparency Plan](#).*

What evidence have you considered?

3.1 Evidence has been drawn from the following sources:

- Annual reports of the three charitable bodies that operate current support schemes for infected people and family members (The Macfarlane, Eileen and Caxton Trusts), www.macfarlane.org.uk and www.caxtonfoundation.org.uk. The Eileen Trust does not have a website, but can be contacted at: Alliance House, 12 Caxton Street, London, SW1H 0QS
- Other information that has been provided to DH by these three bodies and the two companies which provide financial assistance to infected people only (The Skipton Fund and MFET Ltd). The Skipton Fund website is www.skiptonfund.org. MFET Ltd does not have a website, but information can be found at: www.macfarlane.org.uk

3.2 The analysis has also been informed by:

- "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", published by the Department of Health in January 2011. This can be accessed at: <https://www.gov.uk/government/publications/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>

- “Inquiry into the current support for those affected by the contaminated blood scandal in the UK”, published by the All Party Parliamentary Group on Haemophilia and Contaminated Blood, January 2015, which can be accessed at: http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/all_party_parliamentary_group
- “The Final Report of the Penrose Inquiry”, published on 25 March 2015 at: <http://www.penroseinquiry.org.uk/finalreport/>

3.3 We welcome identification of additional evidence to inform the next revision of this Equality Analysis.

Disability

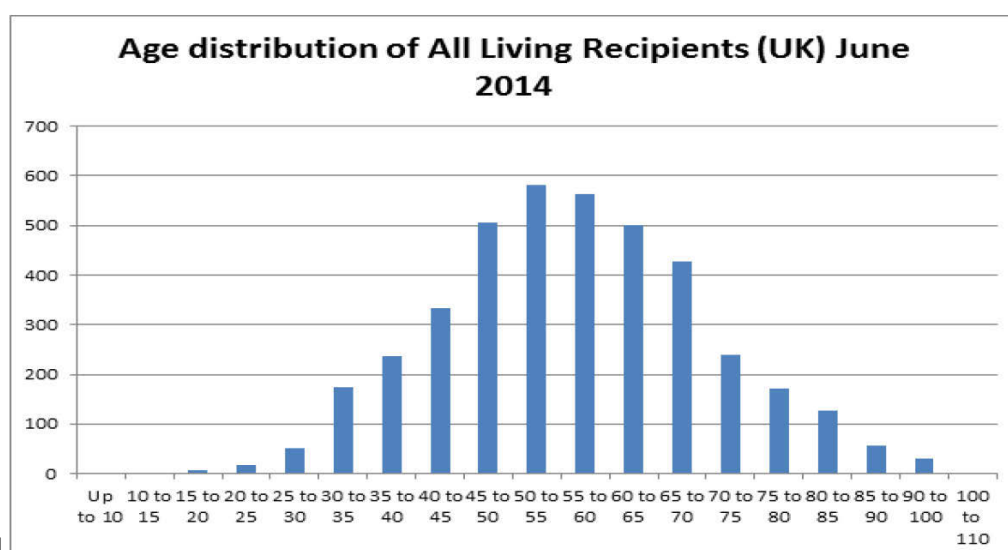
4.1 HIV is considered a disability under the Equality Act 2010. Hepatitis C is not, although some of those with hepatitis C are or may become disabled within the meaning of the Act. Some people who have been treated may be disabled as a result of the treatment they received causing residual health problems. Additionally, some scheme members may be disabled as a result of other conditions. At present all those with HIV automatically receive regular annual payments, as do some with hepatitis C.

Sex

4.2 The biggest single patient group infected are people with inherited bleeding disorders, nearly 90% of whom are male. As such, the majority of direct beneficiaries of the schemes are male, and the majority of bereaved spouses/partners are likely to be female.

Age

4.3 The overwhelming majority of individuals were infected before 1991, with the exception of a small number of people who were secondarily infected. The age profile of those still living with infection in June 2014 is:



4.4

Gender reassignment (including transgender), Religion or Belief, Sexual orientation, and Marriage and Civil Partnership

4.5 The bodies that operate the current payment schemes do not hold information on gender reassignment, racial background, religion or belief, and sexual orientation of claimants.

Race

4.6 Under the Equality Act 2010, race includes ethnic or national origins, colour or nationality. The bodies that operate the current payment schemes do not hold information on the racial background of their registrants.

4.7 With regards to national origins, we know that those affected by the infected blood tragedy reside across the UK but the consultation proposals apply to only those infected through a treatment received in England and so this equalities analysis assesses the impact on them.

Pregnancy and maternity

4.8 We do not have any information on pregnancy and maternity in relation to the affected community.

Engagement and involvement

5.1 This consultation seeks contributions of evidence from all stakeholders, and their views on the current evidence and equalities analysis. This analysis will be updated following the consultation to take account of the responses we receive. A pre-consultation engagement event with campaign group representatives was held on 5th October to seek views on what matters most by way of support under a new scheme. Further pre-consultation engagement was carried out with the All-Party Parliamentary Group on Haemophilia and Contaminated Blood on 5th November, and the staff of the schemes on 9th November.

Summary of Analysis

6.1 In summary, we have identified a key equality issue with the proposals set out in this consultation. That is, where those with a disability as a result of infection are treated differently from others in a similar situation.

6.2 Specifically we have considered the potential impact of these proposals for financial support on those infected individuals who are disabled as a result of infection and currently receive annual payments, compared with those who may be disabled as a result of infection and who would receive annual payments based on an individual assessment. We recognise that different levels of regular payments to these two groups could potentially be discriminatory and would need to be justified.

- 6.3 To avoid the potential for the proposed reforms to be discriminatory, we are proposing to set the highest pay band for annual payment following individual assessment at £15,000. This would ensure those whose health is most negatively affected, which would likely include those disabled as a result of infection, will receive the same payment as those who receive annual payments of the current scheme.
- 6.4 We have also considered the potential impact of these proposals on those who are disabled and may not receive the same lump sum should they enter the scheme following reform as those currently on the scheme. This difference would be unrelated to the fact of disability, but would be a result of the date when they joined the scheme.
- 6.5 With regards to the proposal for access to the new treatment, should the proposal be feasible, it would only be available for those in the affected community with hepatitis C where this treatment is clinically appropriate, and where they have not already received, or expect to shortly receive, such treatment via the NHS. Therefore, not all of the affected community would benefit from this proposal but any difference in support offered would not be on the basis of a protected characteristic.
- 6.6 Those with HIV already have access to other forms of treatment and so the difference in non-financial support offered between those with hepatitis C and those with HIV would be on the basis of appropriate clinical treatments available, as opposed to any protected characteristic. We have considered whether focusing additional resources on those with hepatitis C stage 1 would have a negative impact on the promotion of good relations between groups, however on balance we believe this would increase the fairness of the schemes and so we hope it would help to promote good relations between groups.
- 6.7 We are keen to understand any other potential adverse impacts that may arise as a result of this proposal, which we have not foreseen. We are offering an opportunity to comment on this in the consultation survey, and we are also seeking views on how these proposals could advance equality of opportunity and foster good relations between groups. Any feedback we receive will be used to update this analysis and inform our consideration of potential ways to mitigate adverse impacts.
- 6.8 We have also included a diversity monitoring questionnaire which we would appreciate if you would complete. This can be found with the questionnaire published alongside this consultation document.

Detailed Analysis

Eliminate discrimination, harassment and victimisation, advance equality of opportunity between people who share a protected characteristic and foster good relations between those who share a protected characteristic and those who do not.

- 7.1 This analysis will take each of the key proposals put forward in the consultation document and set out the key equalities issues identified in relation to each. Please note that this is a preliminary analysis based on the evidence we currently have. The consultation provides an opportunity to gather further evidence on equalities issues and this analysis will be updated to reflect any new information gathered through the

consultation.

- ***The proposal to retain annual payments (for HIV and/or hepatitis C stage 2) for those who currently receive them***

- 7.2 All those currently with HIV and/or stage 2 HCV would continue to receive their annual payments at the level they currently receive them. Everyone in this cohort would be treated the same, and would receive the same size of annual payment, except those who are co-infected who would receive the annual payment for those with HIV as well as that for those with stage 2 HCV i.e. double what singly infected individuals receive.
- 7.3 We know that a significant proportion of this cohort are disabled as a result of infection so it is important to consider any negative impact that maintaining the current payments would have on them. Given there would be no change in the support they receive, we do not consider there to be any unintended negative impact.
- 7.4 We recognise that some of those in this cohort would not be disabled and, given that some with hepatitis C stage 2 in this cohort could receive treatment which would reduce the infection's impact on their health, the proportion of those who are not disabled in this cohort could reduce over the next few years. We do not propose any difference in treatment between those who are considered disabled and those who are not. We recognise that this approach does not take into account the specific challenges faced by those with a disability in this cohort. However, we consider this to be the most proportionate way to meet the expectations of current beneficiaries, and ensure those who have come to rely on the financial support (most likely those in a low income group) are protected from being adversely affected by reform. The intention is to ensure that all disabled people within the cohort will be treated the same regardless of whether they have HIV or hepatitis C.
- 7.5 With regards to the other protected characteristics of age, gender reassignment, pregnancy & maternity, race, religion & belief, sex and sexual orientation: We know that over 60% of current infected scheme beneficiaries are over 60 years old. The age range of infected individuals is from under 20 years old, to over 90 years old. The proposal would not differentiate on the basis of age and all those with HIV and/or hepatitis C stage 2 currently registered would be treated the same regardless of age. We know that over 60% of infected individuals are male but the proposal would not differentiate on the basis of gender and so we do not anticipate any negative impact for any group on the basis of gender. We do not have any specific information on the affected community in relation to gender reassignment, race, religion or belief, sexual orientation, marriage and civil partnership or pregnancy and maternity. We do not foresee any negative impact of this proposal specific to any of these groups because no one would be treated differently on the basis of any of these characteristics.
- 7.6 We welcome any comments or information in response to the consultation especially if there is any unintended adverse impact we have not identified, and we welcome any suggestions for addressing that impact.

- ***The proposal to introduce individual assessments for those with hepatitis C stage***

1 and for all new entrants to the scheme, to determine amount of a new annual payment, the highest level being the same as those that will be received by those with hepatitis C stage 2

- 7.7 The proposed new aspect of the scheme would align the highest level of payment with those suffering the most severe health impact. Any difference in payment between those who newly join the scheme and those with hepatitis C stage 1 would reflect the health of the individuals concerned. We would seek advice from an advisory panel about the criteria of the health assessment.
- 7.8 The proposals would mean those with hepatitis C stage 1, including those currently registered with the schemes, would receive support on the basis of an individual assessment. The current scheme does not provide regular financial support for them. We recognise that many of those with stage 1 HCV suffer significant health impacts as a result of their infection. We have considered whether focusing additional resources on this cohort would have a negative impact on the promotion of good relations between groups, however on balance we believe this would increase the fairness of the schemes and so we hope it would help to promote good relations between groups.
- 7.9 Those with HIV and/or hepatitis C stage 2 who newly join the scheme following reform would not be treated the same as those with the same disease who are currently in the scheme. The proposals could mean that they receive a different lump sum when joining the scheme than that received by those currently in the scheme. We know that a significant proportion of this cohort could be disabled as a result of infection. However, the difference in treatment between them and those on the current scheme would be unrelated to the fact of disability. Rather, the difference would be on the basis of timing of when they came into the scheme. Also, since we are proposing that those newly joining the scheme would have annual payments set following individual assessment, they may receive less money annually than those in the current scheme. This is most likely to be true when someone who newly joins the scheme is in relatively good health (given the individual assessment payment bands would be linked to the infection's impact on health) and would not be on the basis of any protected characteristic.
- 7.10 However, given a proportion of this cohort (those with hepatitis C stage 1, or with HIV and/or hepatitis C stage 2 who newly join the scheme) could be disabled as a result of infection, we recognise it is important to consider any potentially discriminatory impact of the proposed reforms. To avoid the potential for the proposed reforms to be discriminatory, we are proposing to set the highest pay band for annual payment following individual assessment at £15,000. This would ensure those whose health is most negatively affected, which would likely include those disabled as a result of infection, will receive the same payment as those who receive annual payments of the current scheme. We hope this would help advance equality of opportunity.
- 7.11 For those who are co-infected who newly join the scheme, the proposals would mean they receive payments following a health assessment. These payments could be different from those received by people who are co-infected and currently registered. However, this difference in treatment would be unrelated to any protected characteristic, including disability, but would be a result of the date when they joined the scheme.

7.12 With regards to the other protected characteristics of age, gender reassignment, pregnancy & maternity, race, religion & belief, sex and sexual orientation: We know that over 60% of current infected scheme beneficiaries are over 60 years old and the age range of beneficiaries is from under 20 years old, to over 90 years old. The proposal would not differentiate treatment on the basis of age and all those with hepatitis C stage 1 or who newly join the scheme would be treated the same regardless of age. We know that over 60% of infected individuals are male but the proposal would not differentiate treatment on the basis of gender and so we do not anticipate any negative impact for any group on the basis of gender. We do not have any specific information on the affected community in relation to gender reassignment, race, religion or belief, sexual orientation, marriage and civil partnership or pregnancy and maternity. We do not foresee any negative impact of this proposal specific to any of these groups because no one would be treated differently on the basis of any of these characteristics. Overall, given that those with hepatitis C stage 1 have not received any support previously, we consider that the proposed reforms would have a positive financial impact on them. We welcome any information on how these protected characteristics impact on those within the affected community in the consultation.

- ***The proposal to offer some early access to new hepatitis C treatment for those for whom the treatments are clinically appropriate on the basis of a treatment assessment and who are unlikely to receive it soon on the NHS***

7.13 Should the proposal be financially and practically feasible, it would only be available for those in the affected community with hepatitis C where this treatment is clinically appropriate, and where they have not already received or expect to shortly receive treatment via the NHS. Therefore, not all of the affected community would benefit from this proposal but any difference in treatment would not be on the basis of a protected characteristic. Those with HIV already have access to other forms of treatment and so the difference in non-financial support offered between those with hepatitis C and those with HIV would be on the basis of appropriate clinical treatments available, as opposed to any protected characteristic.

7.14 Some eligible individuals would be treated before others. This would not be on the basis of a protected characteristic but on the basis on clinical assessment. Health needs would be determined as part of the health assessment to ensure a consistent approach is applied to all. As such, there would be no issue of direct discrimination.

7.15 We understand this proposal could apply to a proportion of registrants of the current schemes whose hepatitis C has not yet progressed to severe forms of liver disease such as cirrhosis and who are eligible for the new treatments. We are keen to understand any potential adverse impacts that may arise as a result of this proposal, which we have not foreseen, and how we can foster good relations between people who have a protected characteristic and those who do not. We are offering an opportunity to comment in response to the consultation.

7.16 With regards to the other protected characteristics of age, gender reassignment,

pregnancy & maternity, race, religion & belief, sex and sexual orientation: We know that over 60% of current infected scheme beneficiaries are over 60 years old and the age range of beneficiaries is from under 20 years old, to over 90 years old. The proposal would not differentiate treatment on the basis of age. We know that over 60% of infected individuals are male but the proposal would not differentiate treatment on the basis of gender and so we do not anticipate any negative impact for any group on the basis of gender. We do not have any specific information on the affected community in relation to gender reassignment, race, religion or belief, sexual orientation, marriage and civil partnership or pregnancy and maternity. We do not foresee any negative impact of this proposal specific to any of these groups because no one would be treated differently on the basis of any of these characteristics. We welcome any information on how these protected characteristics impact on those within the affected community in the consultation.

- ***Seeking views on whether to provide newly bereaved partners/spouses with a final payment equivalent to one further annual payment at the level their partner was receiving at the time of their death or to provide access to a discretionary fund or a choice of either; and seeking views on the future arrangements for those already bereaved, and whether that should be through a one-off lump sum or through continuation of a means tested discretionary fund, or a choice of either***

- 7.17 We know the biggest single patient group infected are people with inherited bleeding disorders, nearly 90% of whom are male. The majority of bereaved spouses/partners of those with bleeding disorders who died from or with infection are therefore likely to be female. The proposed reforms do not differentiate on the basis on any protected characteristic, but it is important to consider any unintended negative impacts.
- 7.18 We are seeking views from those currently bereaved, and those who may be bereaved in the future following scheme reform on how best we can support them. To support the newly bereaved spouses/partners, we are seeking views on whether they would prefer that for one year they would continue to receive any regular payments received by the infected person, access to a discretionary fund, or a choice of either. For those who would not have been eligible for means-tested financial support under the current scheme, the first option would be financially beneficial for them. However, for those newly bereaved (most likely to be female) from a low income group, the first option may have a negative impact since support would be linked to the payment their partner would have received annually, as opposed to being means-tested support.
- 7.19 We are seeking views from those currently bereaved on how we could best support them in a way that would minimise any negative impact that reforms may have for them.
- 7.20 We welcome any comments or information and in particular from affected individuals and those with a protected characteristic in response to the consultation. Should there be an unintended adverse impact we have not identified we would welcome any suggestions about addressing those issues. These comments will be used to update this equalities assessment following consultation.

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For the record

Name of person who carried out this assessment: Rachel Devlin

Date assessment completed: 11 January 2016

Name of responsible Director/Director General: Helen Shirley-Quirk

Date assessment was signed: 12 January 2016