

Equality Analysis – The Public Sector Equality Duty and the Family Test

Infected Blood: Consultation on Special Category Mechanism and financial and other support in England

Title:

Equality Analysis - The Public Sector Equality Duty and Family Test

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Document Purpose:

Equality Analysis

Publication date:

06 March 2017

Target audience:

- Patients, in particular people affected by Human Immunodeficiency Virus (HIV) and/or hepatitis C (HCV) through treatment with National Health Service (NHS)-supplied blood or blood products and including their family members
- The current five infected blood payment support schemes, Macfarlane Trust, Eileen Trust and Caxton Foundation, MFET Ltd, and Skipton Fund Ltd.
- Health care professionals
- GPs
- Nurses
- Doctors
- Royal Colleges
- Social care providers
- General public

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Equality Analysis – The Public Sector Equality Duty and Family Test

Infected blood: Consultation on Special Category Mechanism and financial and other support in England

Prepared by

The Department of Health, England

Introduction

Context

This document accompanies, and is published alongside of, the current consultation *Infected blood:* Consultation on Special Category Mechanism and financial and other support in England.

The infected blood scheme is for people affected by Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with National Health Service (NHS)-supplied blood or blood products.

This document covers how our consultation proposals affect the groups protected under the Equality Act 2010 and through the application of the 'Family Test'.

The Public Sector Equality Duty

The general equality duty 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 Family Test

In line with the Family Test (introduced in August 2014), we also need to understand and consider the nature of any impacts on families, both positive and negative, by the consultation proposals on infected blood beneficiaries and their families.

Equality analysis - The Public Sector Equality Duty and Family Test

Title: Infected blood: Consultation on Special Category Mechanism and financial and other support in England

Purpose of the consultation and this equality analysis

- 1.1 This equality analysis accompanies the government's consultation on the new *Special Category Mechanism and financial and other support in England.* This is part of the ongong reform of the 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.
- 1.2 The new consultation follows the announcements of July 2016 when the government published its response to the January 2016 consultation *Infected blood: Reform of financial and other support* and accompanying equality analysis. This consultation response proposed a package of support measures for those affected by the infected blood tragedy of the 1970s and 80s.¹
- 1.3 One of these support measures was the proposal for a new 'special appeals mechanism' for those with hepatitis C stage 1 infection who consider that the impact of their infection may mean they could qualify for hepatitis C stage 2 payments.
- 1.4 We should explain what we mean by hepatitis C 'stage 1' or 'stage 2' in the context of the infected blood scheme. Stage 1 means that a scheme beneficiary is chronically infected with hepatitis C and that this occurred, on the balance of probabilities, as a result of treatment with NHS blood or blood products prior to September 1991. Stage 2 means that the beneficiary's hepatitis C has developed to advanced liver disease. The current stage 2 indicators are: to have undergone, or to be on the waiting list to undergo, a liver transplant; to have been diagnosed with primary liver cancer; to have been assessed as having cirrhosis based on medical evidence; or to have been diagnosed with B-cell non-Hodgkin's lymphoma. The current consultation proposes to add a new hepatitis C related condition to the current stage 2 indicators, that is, type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN).
- 1.5 Progressing the special appeals mechanism for those with hepatitis C stage 1 infection, now called Special Category Mechanism (with appeal) (SCM), has been a priority since July. Because the SCM will be a completely new element of the infected blood *ex gratia* payment scheme, the current consultation invites scheme beneficiaries and interested parties to comment on the proposal.
- 1.6 Finally, the consultation provides an update on our work to reform the current discretionary support offered to scheme beneficiaries and their families, and invites respondents to tell us what type of discretionary support they would like to see in the reformed scheme.

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¹ The documents can be accessed at this site: https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support

What are the intended outcomes of this equality analysis?

- 1.7 This analysis provides an assessment of the consultation's proposals on people who share characteristics protected in the Equality Act 2010 and in line with the Family Test. We will update this document after the consultation has finished in view of respondents' feedback on the consultation proposals and this equality analysis.
- 1.8 There are 4 elements to the consultation for considering in this analysis. They are:
 - The proposed expansion of the current hepatitis C stage 2 criteria with an additional condition, type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN).
 - The new Special Category Mechanism (with appeal) (SCM) to identify hepatitis C stage 1 beneficiaries whose infection has a substantial and long term adverse impact on their ability to carry out normal daily activities. The SCM would offer increased annual payments for a broad group of stage 1 beneficiaries equivalent to the annual payment level for beneficiaries with HIV or hepatitis C stage 2 disease.
 - Proposals to keep the scheme within budget in light of the increased annual payment for successful SCM applicants while preserving the discretionary fund as far as possible.
 - The type of support the reformed discretionary scheme would offer that is fair to all groups of beneficiaries.

Who will be affected by the consultation proposals?

2.1 Those primarily affected by the proposals will be infected individuals and family members of infected individuals, such as spouses or partners who have caring responsibilities, bereaved spouses or partners, and dependent children.

Decision on the new scheme administrator for the English infected blood scheme

Ministers have announced that the Business Services Authority (NHSBSA) will become the single new scheme administrator for the English scheme. In making this decision, ministers considered the impact this may have on the existing staff and the services of the five scheme bodies. This is explained in this document.

Evidence

What evidence have you considered?

- 3.1 Evidence for this equality analysis was drawn from the following sources:
 - The January 2016 consultation document Infected blood: reform of financial and other support, its accompanying equality analysis and impact assessment; our analysis of the consultation responses and publication of the July 2016 consultation response Infected blood: Government Response to Consultation on Reform of Financial and Other Support (with accompanying equality analysis and impact

assessment), all of which can be found here: https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support

- Parliamentary Questions and other associated correspondence, and the debate in the House of Commons on infected blood and blood products (24 November 2016).
- Annual reports of the three charitable bodies that operate current support schemes
 for infected people and family members (Macfarlane Trust www.macfarlane.org.uk,
 Eileen Trust and Caxton Foundation www.caxtonfoundation.org.uk), and those by
 two companies which provide financial assistance to infected people (The Skipton
 Fund www.skiptonfund.org, and MFET Ltd). The Eileen Trust does not have a
 website but can be contacted at: Alliance House, 12 Caxton Street, London, SW1H
 0QS. MFET Ltd does not have a website but information can be found at
 www.macfarlane.org.uk.
- 3.2 This analysis was also 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:
 <a href="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_parliam_entary_group.
 - The Final Report of the Penrose Inquiry, published on 25 March 2015 at: http://www.penroseinquiry.org.uk/finalreport/
- 3.3 The consultation questionnaire contains four open questions about the specific consultation proposals. To ensure we capture the impact our proposals may have on individuals or groups of people affected by the proposals who are protected under the equalities legislation and Family Test, a fifth question specifically asks respondents whether they are aware of any evidence that would show the policy proposals would negatively impact any particular groups of individuals.

The protected characteristics

Disability

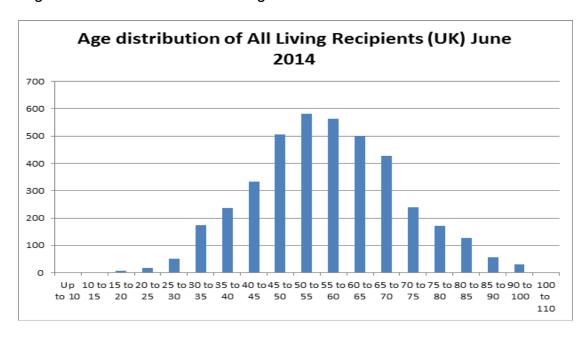
4.1 HIV infection is defined as a disability under the Equality Act 2010. Hepatitis C infection is not. Some people may be disabled as a result of their hepatitis C infection or treatment they received for their infection. Additionally, some scheme members may be disabled as a result of other conditions.

Gender

4.2 The biggest single patient group infected with HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products are people with inherited bleeding disorders such as haemophilia, nearly 90% of who are male. As such, the majority of primary 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 living with infection in June 2014 is given in this chart:



Gender reassignment (including transgender), religion or belief, sexual orientation, and pregnancy and maternity

4.4 These protected characteristics are grouped because the bodies that operate the current payment schemes do not hold information on the scheme members in relation to gender reassignment, religion or belief, sexual orientation, pregnancy and maternity, or

marriage and civil partnership. We therefore do not have any information on these protected characteristics in relation to the affected community. The January 2016 consultation afforded no new evidence from respondents that these groups would be particularly affected by the proposals in the January 2016 consultation.

Race

- 4.5 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. We are not aware of any particular race issues associated with the scheme beneficiaries. The January 2016 consultation responses provided us with no new evidence.
- 4.6 With regards to national origins, we know that those affected by the infected blood tragedy were infected across the UK. The current consultation proposals apply only to those who fall into the English reformed scheme; that is, individuals infected through treatment in England (and the small number of people such as personnel from the armed forces who were infected abroad through their treatment with NHS-supplied blood products). Hence, this equality analysis is confined to an assessment of the impact on beneficiaries in the English scheme.

Engagement and involvement

- 5.1 In developing the proposals in the consultation *Infected blood: Consultation on Special Category Mechanism and financial and other support in England*, we have listened to scheme beneficiaries, the All-Party Parliamentary Group (APPG) for Haemophilia and Contaminated Blood, parliamentarians, wider stakeholders and sought advice from our Infected Blood Reference Group.
- The Reference Group is an advisory group of experts the Department of Health brought together to help inform and shape the policy on reforms in England. Members of this group include scheme beneficiary representatives, clinical experts, relevant charities (the Hepatitis C Trust and the Haemophilia Society) and the current scheme administrator.
- 5.3 The group provides expert advice and insight to support the Department of Health in developing and implementing the various elements of scheme reform. Importantly, members of the group also help us understand the impact of the reforms on the communities affected by it.
- 5.4 The Consultation on Special Category Mechanism and financial and other support in England seeks to capture evidence from all stakeholders on those impacted by our proposals. We also invite stakeholders' views on this equalities analysis, which is published alongside the main consultation document.

Summary of Analysis

6.1 We have identified a key equality issue which underpins the proposals set out in the

- consultation. That is, whether those with a disability as a result of infection are treated differently from others in a similar situation.
- 6.2 Under the reformed scheme in 2016/17, beneficiaries infected with HIV as a consequence of treatment with NHS-supplied blood or blood products receive regular annual payments (£15,500), as do those with hepatitis C albeit at different levels: those with hepatitis C stage 2 receive the same annual payment as those with HIV (that is, £15,500) and those with hepatitis C at stage 1 receive an annual payment of £3,500.
- 6.3 The introduction of the annual payment for hepatitis C stage 1 beneficiaries in 2016/17 was a key element of scheme reform in that it responded to one of the biggest sources of criticism in the unreformed schemes, namely that people with hepatitis C stage 1, nearly 75% of beneficiaries, did not receive annual payments. Since its introduction in April 2016, nearly 2,500 hepatitis C stage 1 beneficiaries were eligible to benefit from this new annual payment in recognition of their chronic infection.
- 6.4 In our July 2016 equality analysis we said that we understood that there can be a wide spectrum of ill-health associated with chronic hepatitis C infection, some of which may be prolonged and severe, and also that the older treatments for hepatitis C infection can occasionally have a long-term health impact. We said that we wanted to ensure those who are experiencing greater ill health and who are more likely to be disabled as a result of their infection receive the same level of on-going support. It was proposed therefore that we would introduce in 2017/18 a special appeals mechanism for people currently at stage 1 to apply for a higher level of payment, equivalent to the stage 2 payments.
- 6.5 The special appeals mechanism, now called Special Category Mechanism (with appeal) (SCM) forms the main element of the current consultation. We propose the SCM as a voluntary paper-based application process that would allow any stage 1 beneficiary who considers they are disabled because their hepatitis C infection (or its treatment) is having a substantial and long-term adverse impact on their ability to carry out regular daily activities the opportunity to apply for increased annual payments equivalent to those with HIV or stage 2 disease. We intend the SCM to benefit more hepatitis C stage 1 beneficiaries then initially envisaged (estimated 50-70%).
- 6.6 Successful applicants would receive higher annual payments at the same level as beneficiaries infected with HIV and those with hepatitis C stage 2 disease. For the reasons set out in the detailed analysis below, however, we no longer propose to offer successful applicants the £50,000 lump sum paid to stage 2 beneficiaries.
- 6.7 The consultation further proposes to expand the current stage 2 conditions by adding type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) to the current stage 2 indicators from April 2017. MPGN is a known complication of hepatitis C infection and has a comparable or even greater negative impact on life expectancy when compared to cirrhotic liver disease or its complications.
- 6.8 In summary, we expect more of the current hepatitis C stage 1 beneficiaries (50-70%) to benefit than under the July 2016 proposals in two ways through the SCM, which is expected to provide the higher level of annual payment to a greater percentage of stage 1 beneficiaries than previously envisaged, and through expansion of the criteria for stage 2 by including MPGN.

- 6.9 To ensure the scheme remains within its funding envelope until April 2021, we no longer propose to introduce the fixed increases in annual payments from 2018/19 which were proposed in July. Instead, annual payments will remain at current levels until 2020/21 but will increase in line with the Consumer Price Index (CPI) to compensate for any loss in value of this payment. The impact of this is explored in the detailed analysis below.
- 6.10 The final consultation element asks for beneficiaries' preferences for fair and consistent support from the reformed discretionary scheme. To ensure fairness of support for all groups of beneficiaries, including those with protected characteristics, we also wish beneficiaries to be aware that we cannot guarantee that regular, fixed, support currently received by some beneficiaries would continue in the reformed discretionary fund going forward.
- 6.11 We believe that our proposals are fair and reasonable, and necessary in order to preserve levels of support provided to beneficiaries including through the discretionary fund, which we know is valued by beneficiaries and their families.
- 6.12 However, we are keen to understand any potential adverse impacts that may arise as a result of our proposals and which we have not foreseen in the detailed analysis in the next section.

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 section takes each of the four consultation proposals in turn and considers any potential equality issues related to each along with mitigating actions we considered.
- 7.2 It looks at our reform through the lenses of disability, age and gender, where appropriate. Regarding the other protected characteristics of gender reassignment, race, religion or belief, sexual orientation, pregnancy and maternity, and marriage and civil partnership, these are not considered in detail as we hold no information about beneficiaries in relation to these characteristics. We do not foresee any negative impact from our proposals specific to any of these groups because beneficiaries would not be treated differently on the basis of any of these characteristics.

Expansion of stage 2 criteria for those with advanced hepatitis C infection

- 7.3 Under the reformed scheme, those with chronic hepatitis C infection (stage 1) who develop advanced, cirrhotic, hepatitis C related liver disease (stage 2) continue to receive a one-off lump sum payment of £50,000 (as well as receive the higher annual payment). The £50,000 payment is a recognition of the fact that development of a stage 2 condition not only reduces the quality of life but also substantially and negatively impacts on the life expectancy of those suffering from one of the stage 2 conditions.
- 7.4 With the help of our Reference Group, including those with expertise in hepatitis C, we reviewed the current stage 2 conditions. On their advice, we propose to add type 2 or 3

cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) to the current stage 2 indicators from April 2017, following the addition of B-cell non-Hodgkin's lymphoma in 2011. This would mean that hepatitis C stage 1 beneficiaries who have been diagnosed with MPGN would be able to apply for the higher annual payment and £50,000 lump sum payment through the existing stage 2 process currently operated by the Skipton Fund.

- 7.5 Going forward, we will keep the scientific literature under periodic review for possible inclusion of other hepatitis C related complications to the stage 2 criteria based on life expectancy.
- 7.6 These measures are intended to ensure that our payment scheme remains responsive to individuals' health status and in line with experts' advice in 2011, namely that the needs of those with advanced liver disease from hepatitis C merit higher levels of support. We consider that expanding the stage 2 criteria is fair and will help foster good relations between disabled scheme beneficiaries at stage 2 disease and those with MPGN, treating both of these groups the same on account of their reduced life expectancy.
- 7.7 We do not consider that there would be a negative impact from the expansion of the stage 2 criteria on beneficiaries based on age or gender (or any of the other protected characteristics).

The Special Category Mechanism (with appeal) (SCM) for those with hepatitis C stage 1

- 7.8 In developing the criteria and process for the SCM, we listened to scheme beneficiaries' expectations about what this new process should offer, consulted with experts and our Reference Group, and took into account the government's obligations under the Equality Act 2010.
- 7.9 Specifically, we have thought about the SCM in the context of considering the financial support for those infected individuals who are disabled as a result of HIV infection and who receive the higher annual payment of £15,500, compared with individuals who have hepatitis stage 1 infection who may be disabled as a result of their hepatitis C and who receive the baseline annual payment of £3,500. We recognise that different levels of regular payments to these two groups could be seen as unfair where they are in a similar position.
- 7.10 We therefore developed the SCM to give hepatitis C stage 1 beneficiaries who consider they are disabled because their hepatitis C infection (or its treatment) is having a substantial and long-term adverse impact on their ability to carry out regular daily activities the opportunity to apply for the same annual payment as those with HIV or hepatitis C stage 2 disease (£15,500).
- 7.11 The SCM is designed to recognise those with hepatitis C stage 1 who are disabled because they:
 - have been diagnosed with one of a number of set hepatitis C related conditions, which our experts have advised us would cause people with these conditions to experience a substantial and long-term adverse impact on their daily lives; or
 - can show that the hepatitis C infection or its treatment has a substantial and long-

term adverse impact on their mental health, and/or that fatigue due to hepatitis C infection or its treatment has a substantial and long-term adverse impact on their daily lives.

- 7.12 We anticipate that the SCM will benefit more hepatitis C stage 1 beneficiaries than initially envisaged. Each stage 1 beneficiary will have the opportunity to apply for higher annual payment via our proposed simple and straightforward SCM process. We consider that by broadening the group of stage 1 beneficiaries eligible to apply for the SCM when compared to our July proposal, this (a) advances equality of opportunity for all those at stage 1 infection who are disabled in that they experience a substantial and long-term adverse impact on their ability to carry out regular daily activities and (b) fosters good relations between those in the scheme who are disabled as a result of their infection(s).
- 7.13 Successful SCM applicants would receive higher annual payments at the same level as beneficiaries infected with HIV or those with hepatitis C stage 2 disease. However, we no longer propose to offer successful applicants the £50,000 lump sum paid to stage 2 beneficiaries.
- 7.14 This is for affordability and fairness reasons. Not only would it not be affordable under the available budget, it would also be inconsistent with the rationale for the £50,000 lump sum payment based on reduced life expectancy (see paragraph 7.3). We therefore propose to reserve the £50,000 payment for those beneficiaries who develop one of the stage 2 conditions in recognition of the impact upon life expectancy that stage 2 beneficiaries experience. In contrast, disabled stage 1 beneficiaries who are successful under the SCM do not suffer from the same reduction in life expectancy as a result of their hepatitis C.
- 7.15 Therefore, we consider that there are material differences between the two groups of beneficiaries (that is, those with hepatitis stage 1 who pass the SCM and those with stage 2 disease) which justifies treating them differently regarding the £50,000 payment on account of life expectancy. We consider this also supports the continuation of good relations between different groups of disabled beneficiaries.
- 7.16 Should a successful SCM applicant go on to develop one of the stage 2 indicators (including the new MPGN condition which we propose to add to stage 2), they would qualify for £50,000 through the existing stage 2 process.
- 7.17 In conclusion, we consider that our proposals will have a positive effect on disabled hepatitis C stage 1 beneficiaries in two ways through the SCM which is expected to provide the higher level of annual payment to a greater percentage of stage 1 beneficiaries than previously envisaged and through the aforementioned expansion of the criteria for stage 2 by including MPGN.
- 7.18 We do not consider that there would be a negative impact from the SCM on other scheme beneficiaries based on the other protected characteristics.

Annual payments

7.19 To avoid the potential for the proposed reforms to be seen as unfair, we intend the SCM to benefit more hepatitis C stage 1 beneficiaries then initially envisaged.

- 7.20 To ensure the scheme remains within its funding envelope until April 2021, this means that we will not be able to offer the fixed increases in annual payments from 2018/19 proposed in July. Instead, annual payments will remain at current levels until 2020/21 but will increase in line with CPI to compensate for any loss in value of this payment.
- 7.21 We recognise that this would impact most on those who are disabled due to HIV, those with hepatitis C stage 2 disease and the co-infected (approximately 17% of all scheme beneficiaries)² while those at hepatitis C stage 1 who are successful at the SCM would receive recompense through the annual payment uplift to the higher level³ (approximately 30-42% of all beneficiaries).
- 7.22 The alternative to fixing the annual payment levels would be to reduce or even cut the discretionary fund for beneficiaries and their families, as well as the payment for the bereaved. However, we do not consider this would be appropriate. Through our January 2016 consultation, we heard that the majority of respondents appreciate the availability of discretionary support provided by the current schemes. We are committed to a scheme which provides, wherever possible, discretionary support in aid of those who need it most (see below our proposal for future discretionary support). We therefore intend to maintain the discretionary fund as far as possible, although if a large number of individuals who were not previously eligible receive the higher annual payment through the new SCM, there is likely to be less funding available for discretionary support.
- 7.23 We also reflected on the possibility of reducing the payment level of the higher annual payment currently received by beneficiaries with HIV and/or hepatitis C stage 2 disease. However, we remain committed that infectees should be no worse off than they are in 2016/17 as a result of changes in annual payment levels. We have therefore discounted this option.
- 7.24 We consider our proposal for the fixed annual payments is fair and reasonable. To mitigate any negative impact, we would ensure that the reformed discretionary scheme (see below) would be responsive to the needs of all beneficiaries. This would include the needs of those with protected characteristics and in particular the needs of disabled HIV and/or hepatitis C stage 2 disease beneficiaries (approximately 17% of all beneficiaries) on account of the fact that they are likely to be most impacted by the move to fixed annual payment levels.

Reformed discretionary support

7.25 We heard clearly through the January 2016 consultation that many people rely on the support provided through the current discretionary schemes. In going forward, we will harmonise the existing discretionary support available to all those affected by this tragedy, including infected individuals and their family members.

7.26 At present, there are three charities, the Macfarlane Trust, Eileen Trust and Caxton Foundation, established in 1988, 1993 and 2011, respectively, which make discretionary

² Those with HIV or hepatitis C stage 2 would remain at £15,500 rather than receive an uplift to £18,500; those who are co-infected with HIV and stage 2 would remain at £30,500 and not receive the uplift to £36,500.

³ The SCM offers an uplift of £12,000 from the annual payment of £3,500 to £15,500 per year.

payments to beneficiaries and their families. The charities make different payments using their own criteria, which has raised concerns of fairness of support between different groups of beneficiaries.

- 7.27 We are committed, therefore, to designing the reformed discretionary scheme to meet the needs of beneficiaries that is fair to all groups of beneficiaries. The consultation asks respondents' views on which of the below types of support they would find most useful:
 - Discretionary payments for travel and accommodation relating to ill health;
 - Payment of prescription pre-payment certificates;
 - Winter fuel payment for bereaved family members;
 - Means tested grants for dealing with unexpected/immediate problems and acute events or health problems which are difficult or impossible to plan for and where not available elsewhere;
 - Means tested income top-ups;
 - Means tested supplementary support for orphaned dependants and the children of primary beneficiaries who are under 21 and in full time education;
 - Non-financial support such as NHS, Social Care and Welfare system referral/signposting services; money management advice; counselling for primary beneficiaries and their partners/spouses and children; career advice/support/coaching.
- 7.28 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 are therefore likely to be female. We do not foresee that there would be any negative impact from our proposal for the reformed discretionary scheme on beneficiaries as the types of support listed above would not differentiate on the basis of gender, age, disability or any of the other protected characteristics.
- 7.29 In moving to the reformed discretionary scheme, due consideration will be given to those currently relying on discretionary payments. Beneficiaries should however be aware that, to ensure fairness of support for all groups of beneficiaries, there is no guarantee of regular, fixed, support from the reformed discretionary fund going forward. Any reduction of regular support would happen over a reasonable period of time during which those affected could be expected to adjust to the change.
- 7.30 The proposed reform of the discretionary support does not differentiate on the basis on any protected characteristic, but we are interested to hear from respondents regarding any unintended negative impacts we have not so far considered.
- 7.31 In conclusion, we believe that our proposals are fair and reasonable, and necessary in order to preserve levels of support provided to beneficiaries, including through the discretionary fund, which we know is valued by beneficiaries and their families.

The 'Family Test'

7.32 In line with the Family Test (introduced in August 2014), we have considered the nature of any impacts on families, both positive and negative, of the consultation proposals discussed above. The family test asks us to consider the following five questions:

- 1. What kinds of impact might the policy have on family formation?
- 2. What kind of impact will the policy have on families going through key transitions such as becoming parents, getting married, fostering or adopting, bereavement, redundancy, new caring responsibilities or the onset of a long-term health condition?
- 3. What impacts will the policy have on all family members' ability to play a full role in family life, including with respect to parenting and other caring responsibilities?
- 4. How does the policy impact families before, during and after couple separation?
- 5. How does the policy impact those families most at risk of deterioration of relationship quality and breakdown?
- 7.33 We recognise that being affected by the infected blood tragedy causes significant emotional stress to infected individuals and their families, and can also cause financial stress for families. For family members, the main element of support comes from the discretionary scheme, in addition to the regular annual support for infected beneficiaries. We received letters describing the positive effect discretionary support has on families and we have heard from Members of Parliament who have expressed concerns about the discretionary support continuing including on behalf of their constituents.
- 7.34 As is set out above, we are committed to a scheme which provides, wherever possible, discretionary support in aid of those who need it most, and we wish to protect the discretionary fund as far as possible. The new discretionary scheme will continue to include elements of financial and non-financial support for infected individuals as well as their affected family members.
- 7.35 We therefore consider that our commitment to protect the discretionary scheme as far as possible is likely to impact positively on beneficiaries and their families going through key transitions such as bereavement, change to caring responsibility, or when they experience times of financial hardship.

Scheme administrator

- 7.36 In 2017/18, the NHS Business Services Authority (NHSBSA) will become the single scheme administrator for the English scheme. We considered the impact of this on the staff of the current 5 schemes and the support it will provide to beneficiaries. We do not consider that there will be any impact on beneficiaries or their families.
- 7.37 In considering the protected characteristics, the specification for the scheme administrator will ensure that it:-
 - Is fully compliant with employment law regarding the staff of the existing schemes, and complies with the PSED.
 - When delivering its services, complies with the PSED to ensure its services are as
 accessible to beneficiaries with protected characteristics as they are to beneficiaries
 without protected characteristics (for example by providing information in a variety of
 formats and languages if needed).
- 7.38 We do not consider that the decision to appoint NHSBSA impacts negatively on any person because of their protected characteristics.

Conclusion

- 8.1 This analysis provides an assessment of the consultation *Infected Blood: Consultation on Special Category Mechanism and financial and other support in England* proposals on people who share characteristics protected in the Equality Act 2010 and the Family Test. We will update this document after the consultation has finished in view of respondents' feedback on the proposals and on this equality analysis.
- 8.2 We are keen to understand any other potential adverse impacts that may arise as a result of our proposals, which we have not foreseen.
- 8.3 Therefore, stakeholders are encouraged to take the opportunity to comment on this in the consultation survey, and we are also seeking views on how our 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.

For the record

Name of person who carried out this assessment: Infected Blood Policy Team

Date assessment completed: 14 February 2017

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

Date assessment was signed: 14 February 2017