



Department  
of Health

# Infected blood: reform of financial and other support

January 2016

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# Infected blood: reform of financial and other support Prepared by

The Department of Health, England

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# Introduction

- 0.1 Since 1988, government has voluntarily provided support for people affected by HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products. Over time the support system has become complex. It has also attracted criticism from those it is intended to help.
- 0.2 The Department of Health has listened to the concerns expressed, and has been considering how to reform the schemes. This consultation sets out our proposals for the reformed scheme and invites comments on them.
- 0.3 We feel there is a need for a more accessible and equitable system of care and support, that focuses on the welfare of infected individuals. The Department of Health recognises its responsibility to everyone infected as a result of NHS treatment and wants to tailor the approach accordingly.
- 0.4 In March 2015, the Prime Minister announced £25 million to ease transition to the reformed scheme. Following the Spending Review<sup>1</sup>, the Department of Health has identified up to an additional £100 million, during this Spending Review period, for the proposals in this document.
- 0.5 To date, over £390 million has been paid out through the schemes, in the UK, and we are projecting that a further £570 million<sup>2</sup> will be spent by the Department over the projected lifetime of the reformed scheme. The additional budget of up to £125 million described in paragraph 0.4, for England, will therefore bring the total spend to over £1 billion over the expected lifetime of the scheme.
- 0.6 Detail of the proposals can be found in Chapter Three.

## Invitation to respond

- 0.7 This consultation is being led by the Department of Health. It is open to anyone in the UK to respond to if they wish to do so.
- 0.8 You are invited to read this consultation and send in your views using the questionnaire at the end of this document. Views on this consultation are particularly invited from:
  - individuals and families who either have been, or are, beneficiaries of the existing schemes,

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<sup>1</sup> A Spending Review is the process by HM Treasury that sets Government budgets for a set period. The Chancellor announced the outcome of the Spending Review for 2016/17-2020/21 on 25 November 2015.

<sup>2</sup> This estimate is based on the payments made by the current schemes. Following scheme reform we expect to continue to have approximately the same budget as for the current schemes.

- clinicians and other healthcare professionals who have experience of the impacts of the HIV and hepatitis C infections on their patients' health.

0.9 Responses are not restricted to these groups. We welcome the views of any person or organisation that has an interest, directly or indirectly.

0.10 This consultation will be distributed widely so that as many of those affected as possible will have the opportunity to provide their comments and feedback. Once we have had opportunity to consider the responses to the consultation, we will publish a response and final plans for the reformed scheme.

# Chapter one: The current system of ex-gratia support

## Summary

There are currently five different organisations funded by the UK Health Departments to which affected individuals can apply for support. The companies (MFET Ltd and Skipton Fund Ltd) provide payments set by the UK Health Departments to infected individuals, while the charities (Macfarlane Trust, Eileen Trust and Caxton Foundation) provide support to infected individuals and their families on a discretionary basis in accordance with their own policies.

## Background to the existing system of ex-gratia financial support

- 1.1 Before heat treatment of blood products was introduced in 1985, and a screening test for blood donations was developed and introduced in 1991, patients were exposed to hepatitis C through treatment with NHS-supplied blood or blood products. Published data and scientific studies have estimated that around 4,700<sup>3</sup> people with bleeding disorders (such as haemophilia) and around 28,000<sup>4,5</sup> other people were exposed to hepatitis C in the UK.
- 1.2 In addition, before heat treatment of blood products and a screening test for blood donations was developed and introduced in 1985, around 1,200 people with bleeding disorders and 100 other individuals were infected with HIV through treatment with NHS-supplied blood products or blood transfusions in the UK. Many of those infected with HIV were also infected with hepatitis C.
- 1.3 Since 1988, successive governments have set up a number of schemes at different times to provide financial and other support. There are currently five schemes that make payments. The schemes are MFET Ltd, the Macfarlane Trust, The Eileen Trust, the Skipton Fund Ltd and the Caxton Foundation. Payments by MFET Ltd and the Skipton Fund Ltd are made in respect of infected persons. The Macfarlane Trust, Eileen Trust and Caxton Foundation support both infected persons and uninfected family members, including the bereaved. Each organisation makes different discretionary payments using their own criteria. Different arrangements are in place for patients whose disease has progressed to advanced liver disease (Hepatitis C Stage 2) from those with chronic infection without cirrhosis (Hepatitis C Stage 1).

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<sup>3</sup> UK Haemophilia Centre Doctors' Organisation (UKHCDO) 'Annual report 2011 & Bleeding Disorder Statistics for the Financial Year 2010/2011' P.65

<sup>4</sup> Soldan, Ramsay, Robinson et al. The contribution of transfusion to HCV infection in England. *Epidemiology and Infection* 2002. 128, 587-591 (corrected to UK)

<sup>5</sup> A Department of Health review published in 2011, estimated that 20% of those infected were still alive in 2003, this is in line with the data from the UK HCV National Register.

- 1.4 All payments are ex-gratia, which means they are funded voluntarily by Government. These payments are additional to any other income a person may receive, and are disregarded for the purposes of calculating income tax and eligibility for other state benefits. In other words, payments are neither taxable, nor do they affect a person's entitlement to any state benefits.
- 1.5 Historically, there were two schemes that made one-off lump sum payments to individuals infected with HIV. The Macfarlane Special Payments Trust (MSPT) provided a one-off payment of £20,000 to each person with a bleeding disorder infected with HIV. The Macfarlane Special Payments Trust No.2 (MSPT No.2) was an out of court settlement to the same group of people, and their families, and payments ranged from £2,000 to £60,500.
- 1.6 People infected with HIV through NHS-supplied infected blood have since received equivalent payments.
- 1.7 More information about the five current schemes is set out in the table (at figure 1) on the next page.

**Figure 1. Table of current payment schemes**

Organisation	Year set up	Status of organisation	Who it supports	Types of support available
MFET Ltd	2010	Non-discretionary company limited by guarantee	People infected with HIV	<ul style="list-style-type: none"> <li>• Variable lump sum on entry</li> <li>• Annual payments (£14,749 in 2015/16)</li> <li>• Reimbursement for Prescription Pre-payment Certificate</li> </ul>
Macfarlane Trust	1988	Discretionary charity	People with bleeding disorders infected with HIV (including those co-infected with hepatitis C) and their families, including bereaved family members and dependents	<ul style="list-style-type: none"> <li>• Means-tested income top-ups</li> <li>• One-off grants</li> <li>• Means-tested winter payments</li> <li>• Other support, including benefits advice</li> </ul>
Eileen Trust	1993	Discretionary charity	People infected with HIV (including those co-infected with hepatitis C) through blood transfusion and their families, including bereaved family members and dependents	<ul style="list-style-type: none"> <li>• Means-tested regular payments</li> <li>• One-off grants</li> <li>• Winter payments</li> <li>• Beneficiary events</li> <li>• Other support, including benefits advice</li> </ul>
Skipton Fund Ltd	2004	Non-discretionary company limited by guarantee	People infected with hepatitis C Stage 1: chronic hepatitis C Stage 2: cirrhosis, primary liver cancer, b-cell non-Hodgkin lymphoma, liver transplant	<ul style="list-style-type: none"> <li>• Lump sum at stage 1 and stage 2</li> <li>• Annual payments for stage 2 (£14,749 in 2015/16)</li> <li>• Reimbursement for Prescription Pre-payment Certificate</li> </ul>
Caxton Foundation	2011	Discretionary charity	People infected with only hepatitis C and their families, including bereaved family members and dependents	<ul style="list-style-type: none"> <li>• Means-tested income top-ups</li> <li>• One-off grants</li> <li>• Winter payments</li> <li>• Other support including benefits advice</li> </ul>

# Chapter two: The case for change

## Summary

We know that the current payments system is widely criticised by some of those affected. Criticisms include the outdated and confusing funding structure and the differences in payments and policies.

The Department of Health has undertaken a number of pre-consultation engagement events as we felt it important to hear directly from some groups of people affected by the schemes.

There was general agreement among the groups at these events that scheme reform was needed.

We acknowledge and recognise the concerns we have heard from beneficiaries and others, and we intend to address these as far as reasonably possible in our proposals.

## Why are we proposing to reform the current system?

- 2.1 The current system has evolved in an ad hoc and incremental manner. The five schemes were established on an infection-specific basis and operate according to their own individual criteria.
- 2.2 In recent years, the UK Health Departments have aimed to improve the current system, including introducing annual payments for those with HIV (in 2009) and for those with the most serious liver disease from hepatitis C (in 2011). The Caxton Foundation was also set up in 2011 to provide charitable support for those affected only by hepatitis C, running alongside the longer standing Macfarlane and Eileen Trusts which provide charitable support for those affected by HIV (including those co-infected with HIV and hepatitis C).
- 2.3 However, we acknowledge that some of those affected still have criticisms of the schemes, and the way in which they are structured. The challenge for Government is to create a reformed scheme that is fair, responds to medical advances and makes best use of available funding.

## Concerns about the current payment schemes

- 2.4 Over the years, there has been criticism from different groups of beneficiaries and their representatives about the way that the current system has been set up and operates. This has been clearly set out in various ways, including the independent inquiry chaired by Lord Archer (February 2009); numerous campaigns; the All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood's *Inquiry into the current support for those affected by the contaminated blood scandal in the UK* (January 2015); letters to the Department of Health and Ministers, meetings with Ministers; Parliamentary debates and questions.

- 2.5 Some of the concerns raised regarding the current payment schemes have included:
- beneficiaries are not assessed on an individual basis
  - the needs of some people with chronic hepatitis C infection are not adequately met or are inconsistently met
  - infected beneficiaries have to deal with more than one scheme
  - the bodies operate different payment policies
  - the principle of applying for charitable payments that are means tested
- 2.6 To help inform this consultation, we held engagement events with a small representative reference group of beneficiaries, with MPs from the APPG on Haemophilia and Contaminated Blood, and with staff of the current schemes.
- 2.7 We want to thank everyone who took part in the pre-consultation engagement events, which were an important part of this process.

### **Beneficiary Reference Group Event**

- 2.8 On 5 October 2015, we arranged an independently facilitated one-off event with some members of three groups (Tainted Blood, the Contaminated Blood Campaign and the Haemophilia Society). The aim was to further inform our understanding of what matters most to members of these groups in terms of financial and non-financial support. We also wanted to hear why different types of support were of value.
- 2.9 We asked those attending to seek views and comments from members of their wider groups before the event so that their views were represented at the meeting. The independent facilitator then produced a report of this meeting. The three groups that attended have published this and it is available on their websites.
- 2.10 Those at the event agreed that the current schemes need to change. The financial support the group would like to see differs considerably from what is currently being provided. The attendees at the event identified a preferred monetary resolution, which would exceed what will be affordable within a new scheme.
- 2.11 We understand that those who attended do not represent the views of everyone affected. This consultation will afford everyone the opportunity to put their views across.

### **Ministerial meeting with the All Party Parliamentary Group (APPG) for Haemophilia and Contaminated Blood**

- 2.10 On 5 November 2015, the Parliamentary Under-Secretary for Public Health, Jane Ellison MP, met with members of the APPG for Haemophilia and Contaminated Blood to update MPs on the consultation process.

- 2.11 The Minister confirmed to members of the APPG at the meeting that financial support will be funded by the Department of Health. She outlined that this meant that the budget for a reformed scheme would be considered in the context of the overall Department of Health budget, after the outcome of the Spending Review had been announced.
- 2.12 A note from this meeting is also publicly available and can be found at [http://www.haemophilia.org.uk/what\\_we\\_do/influencing\\_advocacy/appg\\_minutes](http://www.haemophilia.org.uk/what_we_do/influencing_advocacy/appg_minutes)

### **Session with scheme staff**

- 2.13 On 9 November 2015, we held an event for the staff of the current schemes. We asked the staff to outline their experience of what works well, the challenge of providing appropriate levels of service under the existing schemes and what they think should be included in a reformed scheme.
- 2.14 The staff said it would be more efficient and consistent if the charities were combined and the companies were combined, and that any new scheme should offer some discretionary support based on need.
- 2.15 Staff of the scheme emphasised the positive relationships they had with many of the scheme members.

# Chapter three: Proposed elements of a reformed system

## Summary

This chapter sets out our proposals for a reformed scheme, taking account of views outlined in chapter 2. Final decisions will be taken in the context of feedback to this consultation.

The main elements of the proposals 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 access to new hepatitis C treatments for those considered clinically appropriate on the basis of a treatment assessment
- 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

3.1 We have heard and understood the concerns of the beneficiaries of the current schemes. We recognise that people want financial stability. The Department must ensure that the budget being allocated for a reformed scheme is used appropriately and equitably over the 5-year Spending Review period. The challenge is to identify the best approach that addresses as many concerns as possible. However this will need to be balanced against available funding and it will not be possible to meet everyone's expectations. We are therefore setting out here a range of options for support. We will need to find a balance between the elements proposed below to keep within the available budget and are keen to understand the relative priority that respondents place on different elements. Final decisions on the elements of the new scheme will take account of the consultation responses.

3.2 The proposals set out in this consultation are made on the basis that there is up to an additional £125m available over the next 5 years to assist eligible people who were infected in England.

3.3 There are a number of questions in this chapter. We welcome your views on the proposed elements and would welcome any other suggestions that you may have for scheme reform.

### **One Scheme**

3.4 Based on what we have heard so far, we propose to replace the existing five schemes with a single body. We have heard that there is some confusion around the five schemes and what support they each provide. Having one scheme will mean that all infected individuals can make contact with, and receive support from, the same organisation.

3.5 We would like to make sure that as much funding as possible will go to support beneficiaries and no more than needed is spent in running the schemes. Streamlining the five schemes into one should help reduce the running costs. The reformed scheme could provide other support, including financial and non-financial advice and possibly some element of discretionary payment.

3.6 We appreciate that moving to one scheme will be a change for beneficiaries. Should this proposal go ahead we will take steps to ensure that the change is as simple as possible for beneficiaries. Further information about transition to a new scheme can be found in chapter four.

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

#### **Eligibility for the scheme**

3.7 We propose that all infected individuals who are currently registered with one of the schemes will be automatically registered with the reformed scheme.

3.8 As in the current scheme the eligibility of new applicants would be based on an assessment of whether, on the balance of probabilities, a person was infected with HIV and/or chronic hepatitis C through treatment with NHS-supplied blood or blood products. In the reformed scheme, we suggest that the body administering the scheme would assess the eligibility of potential new entrants against the criteria.

3.9 Information on prevention of onward transmission of HIV and hepatitis C is now widely available. While people infected through historic treatment with NHS-supplied blood or blood products could not have prevented their own infections, they have individual responsibility for ensuring that they take steps to prevent onward transmission.

3.10 We therefore propose that people who are newly infected with either HIV or hepatitis C by an infected person after the start date of a reformed scheme would not automatically be eligible for financial support. We anticipate that such an application would need to be considered by a clinical expert. An application would need to include evidence that the person who likely infected the applicant was unaware of their own infection status at the time the subsequent infection took place. We anticipate that this change would not apply to anyone who has already been infected by another directly-infected person.

## **Making annual payments available to all those infected**

- 3.11 One of the biggest sources of criticism in the current schemes is that people with hepatitis C Stage 1 do not receive any annual payments. We recognise that this is widely perceived to be unfair.
- 3.12 We therefore intend to introduce individual assessments for those with hepatitis C stage 1, to determine an amount of a new annual payment. The assessment would consider the impact of hepatitis C on each person's health against set criteria. Criteria would be based on current medical and scientific evidence, and so be responsive to new evidence and medical developments.
- 3.13 Individuals with hepatitis C and/or HIV who newly come forward to join the scheme, and are eligible to do so, would also have the same individual assessment. This would consider the impact of hepatitis C and/or HIV, including as a result of treatment, on each person's health against criteria.
- 3.14 The process of assessment should be easy to understand, supported by relevant health professionals, and not require extra clinical investigations that are not part of routine clinical care. We intend that an expert advisory group is set up to advise on, and keep under review, the criteria and evidence to be included for these assessments. Final decisions on the criteria and evidence would be taken by the Department of Health.
- 3.15 It is too early to specify how assessments would be carried out, until the criteria and suggested evidence are agreed. However, we expect that the process would be managed by the reformed scheme, and could include a review of medical records and input from individuals' doctors.

## **Question 2: Do you have views on how the individual assessments should be undertaken?**

- 3.16 The outcome of an individual assessment would be used to determine the amount of annual payment a person receives. The payments would be made in so that people with similar health impacts are treated consistently.
- 3.17 Payment amounts would be set according to the band in which each person is allocated, so for example everyone assessed as band 2 (against whatever criteria are eventually set) would receive the same amount of financial assistance. Providing a more personalised payment for each individual would have a greater financial impact on the running of the scheme, and would therefore divert funds from the beneficiaries and would not be equitable.
- 3.18 We propose that individuals would be re-assessed at regular intervals. We recognise that people should also have reasonable periods of financial stability. We therefore anticipate 3 yearly intervals. People should also, with their clinician's support, be able to request re-assessment before their next scheduled review is due if their health has changed (better or worse) as a direct result of their infection(s) or treatment, or if the treatment landscape changes. Following a reassessment the allocation to a band would be reconsidered, so that people can be moved to a higher payment band if health has deteriorated or a lower payment band if health has improved.

3.19 There would be a review procedure where any part of the process or outcome deemed to be inaccurate or unfair by an applicant could be examined.

3.20 We do not have detailed information on the severity of the impact that hepatitis C infection has on individuals' health. For that reason it is difficult to determine now what the different payment amounts might be. However, we intend that the highest payment would be £15k per annum in line with what is paid to those who already receive annual payments under the current scheme. The highest payments would be provided to those whose infection is having the greatest impact on their health. Someone who has cirrhosis (equivalent to current stage 2) would automatically receive the highest payment. Lower payments would be made to those with less severe health impacts.

### **Individuals who currently receive annual payments**

3.21 Individuals who are infected with HIV, or who have advanced disease (hepatitis C stage 2) currently receive annual payments that are linked to the Consumer Price Index (CPI). We propose that those individuals continue to receive annual payments which would be fixed at a flat rate of £15k per annum. This is an increase on the current amount. We propose that this payment would no longer be linked to the CPI. Those who are infected with HIV and hepatitis C stage 2 would continue to receive a payment for both infections, i.e. they would receive £30k per annum.

### **Lump Sums**

3.22 We propose that the new scheme would continue to provide a lump sum payment of £20k to anyone who newly joins the scheme, whether they have hepatitis C or HIV. This payment would be in recognition of the fact that the individual is chronically infected.

3.23 Currently those with hepatitis C who progress to an advanced stage of liver disease, referred to as stage 2, receive a lump sum payment of £50k. We are seeking views on the retention of this payment.

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

**Question 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?**

### **Partners / spouses bereaved in future**

3.24 We recognise that many beneficiaries dislike the principle of applying for charitable payments that are means tested.

3.25 Consequently we propose that those partners/spouses who are newly bereaved, once the reformed scheme is in place, would continue to receive, for one further year, the payment their infected partner/spouse was receiving at time of death. This would help them during a difficult time. This payment would not be means-tested and would be in addition to any other financial benefits available to newly bereaved individuals through the Department for Work and Pensions (DWP). After the year ends, the individual would cease to be eligible for other support under the reformed scheme.

3.26 We understand that some people may prefer to have access to a discretionary fund. The reformed scheme could contain either element or a choice between the two. We would welcome views on this.

**Question 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?**

#### **Those already bereaved and receiving regular support**

3.27 Those who are already bereaved have been entitled to apply for discretionary means tested payments. In view of the dissatisfaction that many have expressed about these arrangements we could offer an alternative in the form of a one-off, final lump sum. We anticipate that these lump sum payments could be equivalent to three times the value of the annual payment received in 2015/16 or £5k, whichever is the greater.

3.28 However, we recognise that some people may prefer to retain access to a discretionary fund. The reformed scheme could contain either element or a choice between the two. We would welcome views on this.

**Question 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?**

#### **Access to new hepatitis C therapies**

3.29 The NHS has begun treating those who are most ill under an interim arrangement that was put in place while NICE was completing/undertaking its appraisal of the new drugs. NHS England extended this arrangement in Summer 2015 so that certain patients with cirrhosis could benefit from the new drugs.

3.30 In February 2016, in accordance with NICE's recommendations, the NHS will begin to roll out access to treatment with three new drugs to people with and without cirrhosis. However, as there is a significant population of people who have hepatitis C in England, and the NHS will be prioritising access to treatment for all on the basis of clinical need, patients who are assessed as having a lower priority may have to wait before they can receive treatment through the NHS.

3.31 We would like to fund a separate scheme to enhance access to treatment for those infected as a result of treatment with blood products. Specifically we would like to focus on those who fall just outside of the current NHS roll out plans. However, depending on the level of interest expressed in response to this consultation, we will work to include as many people as is possible.

3.32 At this stage, we are interested in understanding how many Skipton Fund beneficiaries who have not yet started treatment would be interested in being considered for such a scheme. Depending on the level of response we will need to understand what could be feasible in each of the next few years. It is unlikely that we would be able to treat everyone at the same time, so patients within the scheme would also be prioritised on the basis of clinical need.

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

**Question 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?**

### **Other Support**

3.33 In view of the fact that our proposals provide an annual payment for all infected individuals we propose that in future discretionary payments should be available only for travel and accommodation related to ill health, for example reimbursing travel costs to a hospital other than an individual's local hospital. This will help to ensure that people are not financially disadvantaged in receiving their treatment, enabling them to be reimbursed through a simple expenses procedure, whilst also removing the sense that these individuals are reliant on charitable payments.

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

### **Review of scheme**

3.34 The Secretary of State for Health is under a duty to keep decisions under review and the Department will keep the effectiveness of the scheme, and its financial viability and allocation under review.

# Chapter four: Transition to a reformed scheme

## Summary

The detail of transition to a reformed scheme will not be clear until a decision is made on scheme reform. Transition will start following the announcement of the decision.

We recognise that any change brought about by our proposed reforms, must be done in a measured way to give those affected time to adjust to change, and at the same time provide no, or minimal, disruption to existing processes.

4.1 This chapter sets out the proposed principles concerning transition from the current to the reformed scheme.

## Principles for transition to a reformed scheme

4.2 Our initial intention for transition to a reformed scheme is on the basis that:

- a) The transition to the reformed scheme will be phased
- b) Processes will be put in place to ensure that individuals currently registered with one of the existing companies or charities are transferred to the reformed scheme with minimal involvement from the individuals
- c) Changes would be clearly communicated to all existing beneficiaries in advance, who would also be directed to access to other support, for example, advice on benefits and managing their finances.

4.3 If we proceed with the outlined options for scheme reform, it is our intention to set up an expert advisory group as quickly as possible. They would be given a short period of time to propose the criteria and evidence for the individual assessments. This is to ensure that we can start the individual assessments as quickly as possible.

4.4 The new payment amounts will be confirmed once the individual assessments have been completed. There will be a dedicated amount of time for the completion of the assessments.

## **Data Transfer**

- 4.5 Under the existing schemes, beneficiaries already provide certain personal information (name, address, HIV/hepatitis C status, bank details, etc.) to the relevant five organisations. If a new single body was introduced to replace these schemes we would look to transfer a registrant's details from the existing schemes to the reformed scheme. The exact mechanism for this will be determined when a decision has been made about the administration of the reformed scheme. However, this will be done sensitively and in accordance with data protection legislative guidance. Of course, everyone will be notified in writing in advance and consent will be sought from everyone this affects.
- 4.6 The transfer of information would enable a new body to verify eligibility of each individual to avoid delays with payments during the transition period. Personal information would be transferred and stored securely in compliance with the Data Protection Act 1998.

# Chapter five: The Public Sector Equality Duty and The Family Test

## Summary

This chapter sets out the Department of Health's responsibilities under the Equality Act 2010, and refers to the 'Family Test' recently introduced to be applied in the process of developing new policy. Government believes complying with the Public Sector Equality Duty and applying the Family Test should lead to better overall outcomes for people affected by these reforms.

This chapter provides a summary of the analysis done so far in relation to the proposals set out in this consultation, and seeks any additional comments or information that could be used to build on this analysis.

## The Public Sector Equality Duty

- 5.1 The general equality duty that is set out in the Equality Act 2010 requires that public authorities, in the exercise of their functions, have due regard to the need to:
  - a) Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
  - b) Advance equality of opportunity between people who share a protected characteristic and those who do not
  - c) Foster good relations between people who share a protected characteristic and those who do not
- 5.2 The protected characteristics are: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation.
- 5.3 We have given due regard to equality issues during our thinking on reforming the system. Please see the Equality Analysis published alongside this document for full details.
- 5.4 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.
- 5.5 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.

- 5.6 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.
- 5.7 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.
- 5.8 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.
- 5.9 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.
- 5.10 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.
- 5.11 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.

### **The Family Test**

- 5.12 In line with the Family Test (introduced in August 2014), we need to understand and consider the nature of any impacts on families, both positive and negative, of the principles that we have proposed.
- 5.13 We recognise that bereavement causes significant emotional stress, and can also cause financial stress. We are proposing that current scheme beneficiaries who are bereaved spouses/partners are offered the option of a lump sum payment or the continued access to a discretionary pot of money. We are also seeking views on whether, to avoid additional financial stress being experienced by anyone newly bereaved following scheme reform, they would prefer to continue to receive their partner's payments for one year before exiting the scheme, or to have on-going access to a discretionary fund.

5.14 We are keen to understand any other impact that the proposals in this consultation may have on families. We are offering an opportunity for those affected to comment on this in the consultation survey and any feedback we receive will be used to update this analysis.

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

# Chapter six: Responding to this consultation

## How to get involved in the consultation

- 7.1 The consultation will run for 12 weeks, from 21 January 2016 to midnight on 15 April 2016. We welcome responses from any interested person, organisation or business.
- 7.2 Respondents are encouraged to provide their views online but responses can be made in any of the following ways:

Completing the online form at:

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

Filling in the questionnaire by downloading it at:

[www.gov.uk/government/consultations](http://www.gov.uk/government/consultations)

Emailing your responses to:

[infectedbloodreform@dh.gsi.gov.uk](mailto:infectedbloodreform@dh.gsi.gov.uk)

Posting your response to:

Department of Health,  
Room 104 Richmond House,  
79 Whitehall,  
London,  
SW1A 2NS.

The Department cannot respond specifically to individual consultation responses.

## 7.3 Comments on the consultation process

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact:

Address:

Consultations Coordinator  
Department of Health  
2E26, Quarry House  
Leeds  
LS2 7UE

Email:

[consultations.co-ordinator@dh.gsi.gov.uk](mailto:consultations.co-ordinator@dh.gsi.gov.uk)

**Please do not send consultation responses to this address.**

## Confidentiality of information

- 7.4 We will manage the information you provide in response to this consultation in accordance with the Department of Health Information Charter available at [www.gov.uk/government/organisations/department-of-health/about/personal-information-charter](http://www.gov.uk/government/organisations/department-of-health/about/personal-information-charter)
- 7.5 Please be aware that, under the Freedom of Information Act, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.
- 7.6 Information held by the Department of Health may be accessible primarily under the Freedom of Information (FOI) Act 2000 and the Data Protection Act 1998. Every request for information has to be considered separately and a decision made on whether the information should be released or whether exemptions against its release apply. In the majority of cases where personal data is concerned the data will be withheld under section 40 of the FOI Act 2000 (personal information). Any decision on release would be considered against whether its release would contravene any of the data protection principles as set out in the Data Protection Act 1998.
- 7.7 The Department will process your personal data in accordance with the Data Protection Act 1998 and in the majority of circumstances this will mean that your personal data will not be disclosed to third parties. However, the Department will send an anonymised synthesis of responses from beneficiaries in each part of the UK, to the respective Health Departments in the Devolved Administrations.

# Questionnaire Response Form

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

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

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

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

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

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

### About you

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

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

England	<input type="checkbox"/>
Scotland	<input type="checkbox"/>
Wales	<input type="checkbox"/>
Northern Ireland	<input type="checkbox"/>
Other	<input type="checkbox"/>

**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)	<input type="checkbox"/>
I am HIV positive (from infected NHS supplied blood/blood products)	<input type="checkbox"/>
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	<input type="checkbox"/>
I am a carer for a person infected with hepatitis C, HIV or both by an NHS blood/blood product	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>
Other. Please specify	<input type="text"/>

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

Yes

No

N/A or Prefer not to say

**Questions on Chapter 3**

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

One

Five

Other (please specify in box below)

Don't know/ unsure

**Please provide any comments below:**

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

**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

**Please provide any comments below:**

**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	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know/unsure	<input type="checkbox"/>

**Please provide any comments below:**

**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?**

Lump Sum	<input type="checkbox"/>
Discretionary Support	<input type="checkbox"/>
Choice of either	<input type="checkbox"/>

**Please provide any comments below:**

**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:**

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

Yes

No

Don't know

**Please provide any comments below:**

**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:**

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

Yes

No

Don't know

**Please provide any comments below:**

**Question on Chapter 5**

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

**Please provide any comments below:**

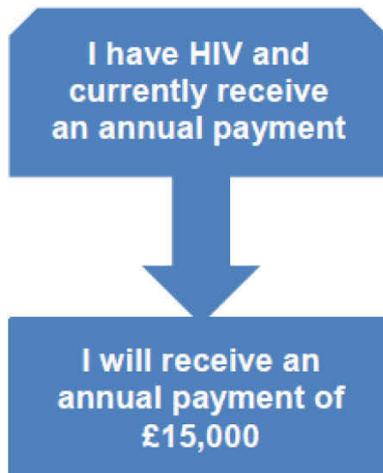
**Overall**

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

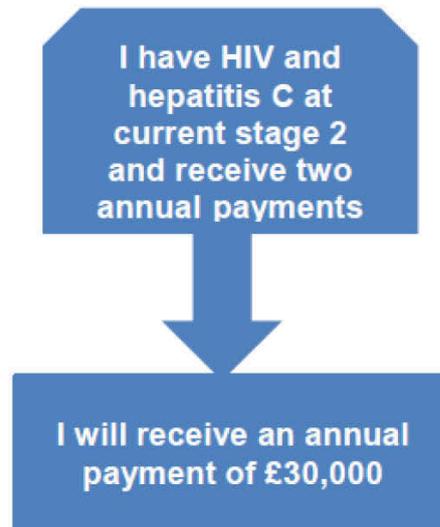
**Thank you for completing the questionnaire.**

## What does this mean for me?

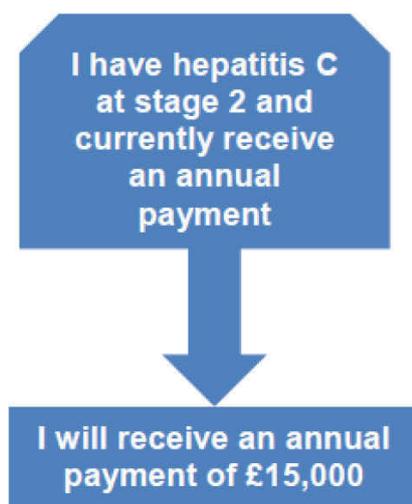
### 1. Current Registrants with HIV



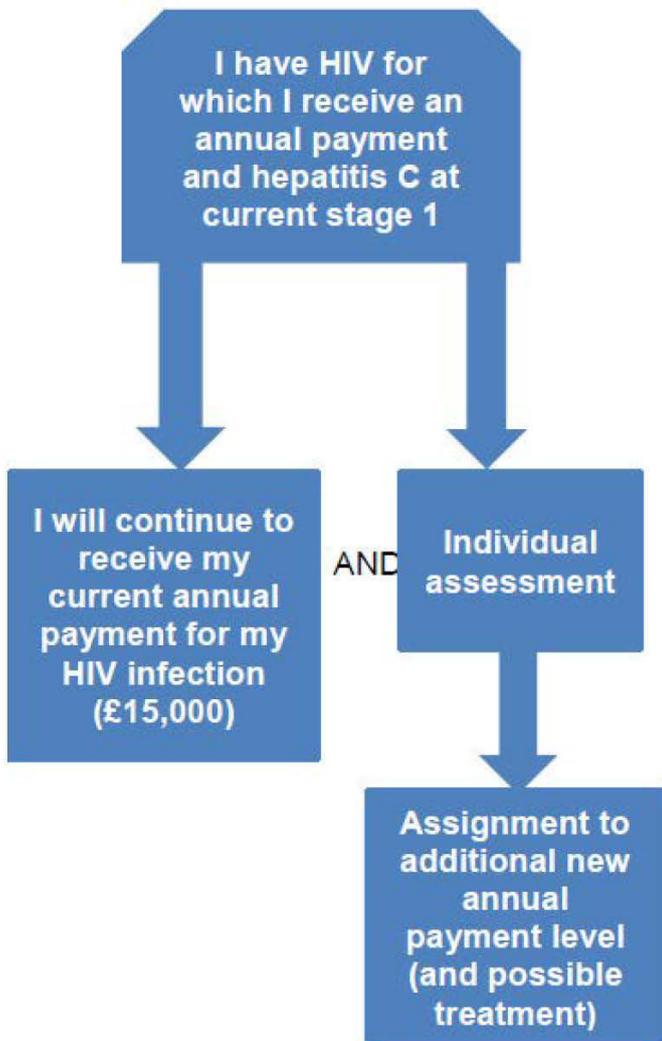
### 2. Current registrants with HIV and hepatitis C stage 2



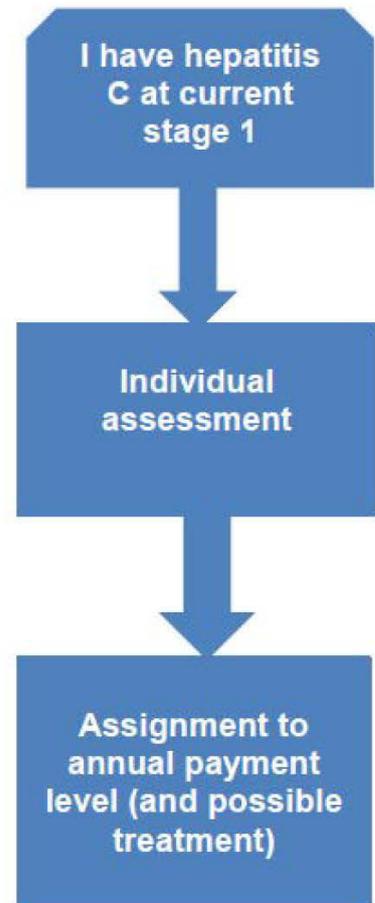
### 3. Current registrants with hepatitis C at stage 2



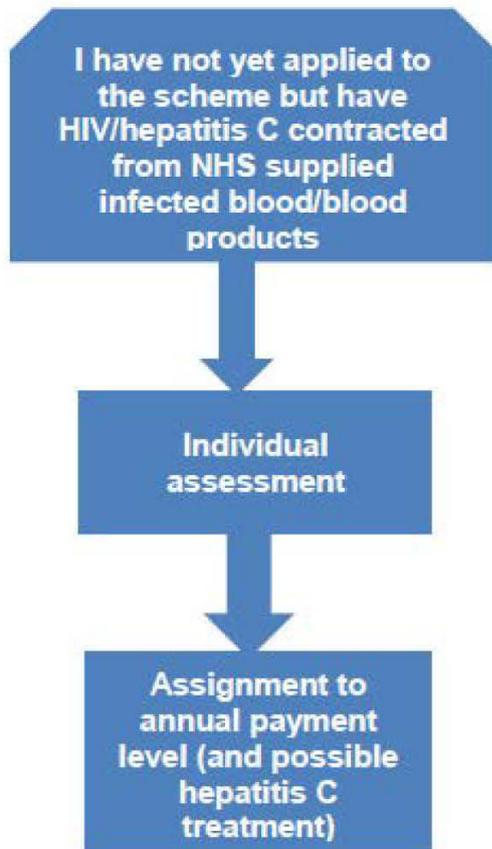
4. Current registrants with HIV and hepatitis C at stage 1



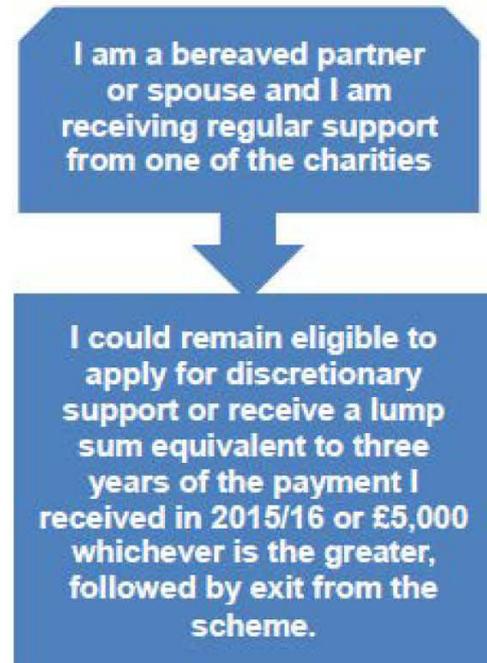
5. Current registrants with hepatitis C at stage 1



6. Future registrants of the scheme



7. Bereaved partners/spouses



8. Partners/spouses of infected individuals



# Contact details for the current schemes

## **MFET Ltd**

Alliance House  
12 Caxton Street  
London  
SW1H 0QS

## **The Macfarlane Trust**

Alliance House  
12 Caxton Street  
London  
SW1H 0QS  
[www.macfarlane.org.uk](http://www.macfarlane.org.uk)  
Tel: 020 7233 0057

## **The Eileen Trust**

Alliance House  
12 Caxton Street  
London  
SW1H 0QS

## **Skipton Fund Ltd**

PO Box 50107  
London  
SW1H 0YF  
[www.skiptonfund.org](http://www.skiptonfund.org)  
Tel: 0207 808 1160

## **Caxton Foundation**

Alliance House  
12 Caxton Street  
London  
SW1H 0QS  
[www.caxtonfoundation.org.uk](http://www.caxtonfoundation.org.uk)  
Tel: 0207 233 0057

# Glossary of Terms

AM	Assembly Member (Wales)
APPG	All Party Parliamentary Group
DH	Department of Health
DWP	Department of Work and Pensions
FOI	Freedom of Information
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HMRC	HM Revenue and Customs
MLA	Member of Legislative Assembly (Northern Ireland)
MP	Member of Parliament
MSP	Member of Scottish Parliament
NHS	National Health Service
PPC	Prescription Pre-Payment Certificate
UK	United Kingdom

## **For the purposes of this document:**

Discretionary payments: those made by the Macfarlane Trust, the Eileen Trust and the Caxton Foundation.  
Payments which the charities provide that are based on their own policies.

Non-discretionary payments: those made by MFET Ltd and Skipton Fund Ltd  
Payments which the companies provide that are set by the UK Health Departments.

# Diversity Monitoring Questionnaire

In order that the UK Health Departments can monitor the effectiveness of this consultation to ensure it is open to all sections of the community, we have designed an optional Diversity Questionnaire with the intention of having a separate, confidential record about the protected characteristics within the Equality Act 2010 listed below:

- Age
- Disability
- Race – this includes ethnic or national origins, colour or nationality
- Religion or belief – this includes non-belief
- Sex
- Sexual orientation
- Marital status
- Pregnancy/maternity

To assist us in this, it would be helpful if you would take the time to complete this optional questionnaire in full. After completion, please return the questionnaire along with your responses to this consultation to Department of Health, Room 104 Richmond House, 79 Whitehall, London SW1A 2NS, or, email to: [infectedbloodreform@dh.gsi.gov.uk](mailto:infectedbloodreform@dh.gsi.gov.uk)

**The information contained in this questionnaire will be treated as confidential and will be used for monitoring purposes. All questions are optional.**

## Your Information

The Data Protection Act 1998 gives rights to individuals in respect of personal data held about them by others and as directed by the Act, you should know the following:

The Department of Health is the Data Controller and is registered with the Information Commissioner for the purposes of the Data Protection Act 1998 (DPA).

The diversity information you provide will enable the Department of Health to monitor that we meet our legal obligations under the Equality Act 2010. Effective monitoring is an important tool for measuring performance and progress towards equality and diversity goals and in ensuring a truly inclusive working environment. This information is only used for research and statistical analysis.

Diversity information is defined by the DPA as “sensitive”. It is not mandatory to supply “sensitive” information, but should you do so it will not affect your responses to this consultation in any way.

The information you give will be held on both manual and electronic systems by the Department of Health.

Thank you for your co-operation.

## DIVERSITY MONITORING FORM

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SURNAME:

FIRST NAME:

Prefer not to say

Date: .....

### AGE

What is your age? Please mark 'X' in one box only

16-19

20-24

25-29

30-34

35-39

40-44

45-49

50-54

55-59

60-64

65+

## DISABILITY

A disabled person is defined under the Equality Act 2010 as someone with a **'physical or mental impairment which has a substantial and long term adverse effect on that person's ability to carry out normal day-to-day activities.'**

Do you consider yourself to be disabled under the Equality Act 2010? Please mark 'X' in the appropriate box.

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>	Don't know	<input type="checkbox"/>

If **YES**, please indicate by marking 'X' in the appropriate box for all that apply; otherwise proceed to the next section.

- |          |                          |                                       |
|----------|--------------------------|---------------------------------------|
| <b>A</b> | <input type="checkbox"/> | Hearing impairment                    |
| <b>B</b> | <input type="checkbox"/> | Visual impairment                     |
| <b>C</b> | <input type="checkbox"/> | Speech impairment                     |
| <b>D</b> | <input type="checkbox"/> | Mobility impairment                   |
| <b>E</b> | <input type="checkbox"/> | Physical co-ordination difficulties   |
| <b>F</b> | <input type="checkbox"/> | Reduced physical capacity             |
| <b>G</b> | <input type="checkbox"/> | Severe disfigurement                  |
| <b>H</b> | <input type="checkbox"/> | Learning difficulties (e.g. dyslexic) |
| <b>I</b> | <input type="checkbox"/> | Mental ill health                     |
| <b>J</b> | <input type="checkbox"/> | Progressive conditions                |
| <b>K</b> | <input type="checkbox"/> | Other (please specify)                |

--

<b>L</b>	<input type="checkbox"/>	Prefer not to say
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## ETHNIC ORIGIN

These categories were used in the 2011 Census and are listed alphabetically. Which groups do you most identify with?

Please mark 'X' in only **ONE** box in column A and only **ONE** box in column B

### COLUMN A

- (A)  British or Mixed British
  - (B)  English
  - (C)  Irish
  - (D)  Scottish
  - (E)  Welsh
  - (F)  Any other? (please specify)
- 

### COLUMN B

#### ASIAN

- (A)  Bangladeshi
  - (B)  Indian
  - (C)  Pakistani
  - (D)  Any other Asian background (please specify)
- 

#### BLACK

- (E)  African
  - (F)  Caribbean
  - (G)  Any other Black background (please specify)
- 

#### CHINESE

- (H)  Any Chinese background (please specify)
- 

#### MIXED ETHNIC BACKGROUND

- (I)  Asian and White
  - (J)  Black African and White
  - (K)  Black Caribbean and White
  - (L)  Any other Mixed ethnic background (please specify)
- 

#### WHITE

- (M)  Any White background (please specify)
- 

#### ANY OTHER ETHNIC BACKGROUND

- (N)  Any other ethnic background (please specify)

## SEX

Please state your sex:

Female

Male

Is this the sex you were assigned at birth?      Yes      No

Prefer not to say

## SEXUAL ORIENTATION

Which group do you most identify with? The options are listed alphabetical order.

Please mark 'X' in **one** box only:

(A)  Bi-Sexual

(B)  Gay woman/lesbian

(C)  Gay man

(D)  Heterosexual/straight

(E)  Other

(F)  Prefer not to say

**RELIGION OR BELIEF**

What is your religion or belief (including non-belief)? Please mark 'X' in the box below as appropriate.

Agnostic	<input type="checkbox"/>	Pagan	<input type="checkbox"/>
Atheist	<input type="checkbox"/>	Sikh	<input type="checkbox"/>
Bah'ai	<input type="checkbox"/>	Rastafarian	<input type="checkbox"/>
Buddhist	<input type="checkbox"/>	Scientologist	<input type="checkbox"/>
Christian – Catholic	<input type="checkbox"/>	Shinto	<input type="checkbox"/>
Christian – Protestant	<input type="checkbox"/>	Zoroastrian	<input type="checkbox"/>
Christian – Other	<input type="checkbox"/>	No religion or belief	<input type="checkbox"/>
Hindu	<input type="checkbox"/>	Prefer not to say	<input type="checkbox"/>
Humanism	<input type="checkbox"/>	Any other religion or belief	<input type="checkbox"/>
Jain	<input type="checkbox"/>		
Jewish	<input type="checkbox"/>		
Muslim	<input type="checkbox"/>		

Please specify below, if you wish.

**HOW DID YOU GET DETAILS OF THIS CONSULTATION?** Please mark 'X' in the appropriate box(es) below:

**Publication**   
 (Please specify which)

.....  
 .....

**GOV.UK Website**

**Other Website**   
 (Please specify from which website(s))

.....  
 .....

**Word of Mouth**

**Other**   
 (Please specify)

.....

## MARITAL STATUS

What is your marital status? Please mark 'X' in the box below as appropriate.

Single

Married

Civil partnership

Separated

Divorced

Widowed

Co-habiting

Other, please specify

Prefer not to say

## PREGNANCY/MATERNITY

I would describe myself as (please mark 'X' in the relevant box):

Pregnant

Maternity (recently given birth, within the last three months)

Not pregnant or not applicable