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Infected blood: review of financial assistance

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Infected blood: review of financial assistance

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The four UK Health Departments

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Executive summary

- The four UK Health Departments are issuing this consultation to seek views on the principles that should underpin a reformed system of financial assistance for people who were infected with HIV and/or hepatitis C (HCV) as a consequence of treatment with NHS-supplied blood or blood products before September 1991.
- There are currently five separate organisations that make various types of ex-gratia payments to beneficiaries with HIV and/or hepatitis C on a UK-wide basis. These payment types include lump sums, non-discretionary annual payments and grants. However, not all infected individuals receive the same type or levels of payments. Concerns have been voiced that the current system is complicated and unfair. It does not adequately reflect the wide variation in the ill health of infected individuals.
- The Health Departments recognise these concerns, and in this joint document set out the case for change that is responsive to criticisms, reflects medical advances, and recognises that a new system must be financially sustainable both now and in the future.
- The document sets out the Health Departments' agreed set of principles for a new system; it should focus on those who are infected; it should be evidence-based, and should operate efficiently and effectively. We believe these principles could be met in a reformed, potentially unified, system by introducing individual clinical assessment for infected individuals, applying a set of common criteria.
- In the interests of equality and ongoing affordability, it is envisaged that the current schemes would be replaced. All regular discretionary payments (i.e. those made by the charities) would reduce gradually over a number of years before stopping to give people time to adjust, and funds would be redistributed to assist those who are infected. We are nevertheless be willing to listen to suggestions for possible future arrangements to assist uninfected family members in an equitable manner, subject to judgments by the four Health Departments on cost-effectiveness and affordability.
- This document describes some initial ideas about how a reformed system might operate and poses questions for your consideration. Responses to the questions should be submitted in the questionnaire published alongside this consultation document.

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Introduction

This section introduces the UK wide consultation issued on behalf of the four UK Health Departments.

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Chapter six: Impact Assessments including the Public Sector Equality Duty and the Family Test

vi This chapter refers to a consultation impact assessment, published alongside this document, for the current proposals, including looking at economic benefits. In addition, the chapter sets out the Health Departments' responsibilities under the Equality Act 2010 and invites the submission of any additional information that we can take into account to ensure that we fulfil our Public Sector Equality Duties and test a new scheme from a family perspective for the new Family Test announced in August 2014.

Chapter seven: responding to the consultation

vii This chapter sets out how you can respond to the consultation, including the criteria for this consultation and the confidentiality of information.

Introduction

1. The purpose of this consultation is to seek views on reforming the current support system for people infected with HIV and/or hepatitis C as a consequence of treatment with NHS-supplied blood or blood products before September 1991, and for their families. It is a UK wide consultation issued on behalf of the four UK Health Departments.

2. This consultation is not about the size of payments, but rather about the possible structure and operation of a new system.

3. The key considerations in developing the proposed way forward as set out in this consultation document have been a focus on assisting those living with HIV and/or hepatitis C in a fair and equitable way, making the system (for those infected) more responsive to medical evidence/advances, as well as overall system affordability in both the short and longer term. The Department of Health has identified a number of options that could address some of the various concerns about the payments schemes. These are set out at paragraphs 11-16 of the impact assessment published alongside this consultation, but in summary these include:

    - increasing the size of the first lump sum paid to those with hepatitis C;
    - extending the existing annual payments to those with hepatitis C who are not currently eligible for them (i.e. abolishing the stage 1/stage 2 distinction);
    - providing a final lump sum payment to both those infected and bereaved spouses/partners;
    - removing the funding for discretionary payments; or
    - replacing the three discretionary schemes with one single discretionary scheme.

4. However, with the exception of removing or replacing the discretionary schemes, none of these options were found to be affordable and nor are they evidence-based or responsive to medical advances. Discontinuing discretionary payments on its own was not considered sufficient to remedy the inequity in the different bases on which payments are made to affected individuals and so the only other one of these options identified as potentially affordable was to replace the existing discretionary schemes which are run by the charitable bodies with a single new discretionary scheme within the existing cost envelope. While this would potentially reduce inequity between the current discretionary schemes, it would require complete overhaul of the current system of discretionary payments to achieve that aim and it would not address concerns about current non-discretionary payments to infected individuals. As such, these options have not been taken further.

5. The four UK Health Departments have collectively agreed a set of principles and propose that any new system should be:

- **focused** on the provision of financial assistance to surviving infected individuals;
- **evidence-based** through being informed by scientific and medical knowledge of HIV and hepatitis C and the impact of these infections on the health of individuals; and
- **efficient and effective**, for example, by introducing a unified and transparent process administered by a single body across the UK.

Background

6. Since 1988, five organisations have been established at different times to make ex-gratia payments to individuals infected with HIV and/or hepatitis C on a UK-wide basis. Three of the five organisations can also provide financial assistance to uninfected family members. To date, the system has paid out over £365 million.

7. However, over the years, a number of concerns have been expressed by beneficiaries and those who advocate for them, about the current system being complicated unfair and inadequate; some of which are set out in Chapter two of this document.

This consultation

8. The four UK Health Departments, who between them fund the current system of financial support, agree there are grounds for replacing the current schemes with a new single scheme. Views on this consultation are particularly invited from individuals and families across the UK who either have been, or are, beneficiaries of the existing schemes, as well as clinicians who will be required to provide information to support the proposed individual assessments referred to in Chapters three and four. However, responses are not restricted to these groups and we welcome the views of any person or organisation that has an interest, directly or indirectly.

9. We are distributing this document widely so that as many as possible of those affected by these changes will have the opportunity to respond. **Please read this document all the way through and then respond to the separate questionnaire. The questions have also been included throughout this document. We advise that you refer back to the relevant sections of this consultation document when you complete the questionnaire.**

10. Responses to this consultation will be considered alongside a wider body of evidence to inform the development of a way forward. This wider body of evidence includes:

    - A [1]survey commissioned and published by the Scottish Government Health and Social Care Directorate on support needs for those infected with or affected by hepatitis C through NHS treatment in Scotland.

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[1] The survey commissioned by the Scottish Government closed on 29 August 2014. Further information can be found at http://www.scotland.gov.uk/topics/Health/Services/Blood

- A [2]survey commissioned by MPs and the All Party Parliamentary Group on Haemophilia and Contaminated Blood delivered through the research organisation YouGov.
- A [3]systematic review of the published clinical and scientific evidence base on the association between hepatitis C infection and certain extra-hepatic conditions, which has been completed by the Evidence for Policy and Practice Information-Centre at the Institute of Education, University of London.

The Penrose Inquiry

11. In 2008, Scottish Ministers announced a public inquiry, chaired by Lord Penrose, into the HIV and/or hepatitis C infections that were acquired through historic treatment with NHS-supplied blood and blood products in Scotland. The 'Penrose Inquiry', which was set up under the Inquiries Act 2005, has yet to publish its final report. The terms of reference for the Penrose Inquiry do not make reference to compensation, and do not permit the Chairman to consider payment of compensation either in relation to individuals or on a collective basis. Levels of compensation or ex-gratia payments are matters for Ministers to decide, or for courts to award in individual civil actions. There is no direct connection between the Inquiry and this consultation.

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[2] The survey commissioned by MPs and the APPG closed on 26 October 2014. We understand the APPG hope to publish the survey results during December 2014.

[3] A systematic review: this will be published by the review team in due course

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

1.1 This Chapter briefly sets out the existing financial support system.

Background to the existing system of ex-gratia financial support

1.2 Before heat treatment of blood products was introduced in 1985, and a test for hepatitis C was developed and introduced in 1991, [4]4,689 people with bleeding disorders such as haemophilia in the UK were exposed to hepatitis C as a result of NHS-supplied blood products during the 1970s and 1980s. Published epidemiological estimates suggest that up to [5]28,043 other individuals might have been infected with hepatitis C by whole blood transfusions in the UK.

1.3 Over roughly the same period, approximately 1,200 people with bleeding disorders and 100 other individuals were infected with HIV by NHS-supplied blood products or blood transfusions in the UK before the introduction of heat treatment of blood products, and the development and introduction of a test for HIV, in 1985. Some people were co-infected with both hepatitis C and HIV.

1.4 Beginning in 1988, the UK government has established a number of schemes at different times to provide financial and other support, as set out below.

Schemes that support those affected by HIV

The Macfarlane Trust

1.5 This is a charity, funded by the Department of Health in England and established in 1988 providing discretionary support to individuals with bleeding disorders who contracted HIV (including those co-infected with hepatitis C) as a result of treatment with plasma derived blood products, any person that they in turn may have inadvertently infected, and their families. It currently provides means-tested regular payments to infected beneficiaries and widows, annual fixed rate payments in respect of dependent children, a means tested winter payment, and a small number of individual grant payments. Its payments policies are set by its Trustees within the funds allocated by government. In addition to financial support it also provides benefits advice and in the past has hosted annual weekend events for its beneficiaries. For more information go to www.macfarlane.org.uk.

Eileen Trust

1.6 This is a charity, funded by the Department of Health in England and established in 1993 providing discretionary support to individuals who contracted HIV (including those co-

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[4] UKHCDO 2011 'UKHCDO Annual report 2011 & Bleeding Disorder Statistics for 2010/2011' P.65

[5] Soldan, Ramsay, Robinson et al. The contribution of transfusion to HCV infection in England. Epidemiology and Infection 2002. 128, 587-591 (corrected to UK)

infected with hepatitis C) as a result of a transfusion with whole blood, and for their families. The Trust provides financial support in the form of means tested regular payments to some beneficiaries, one-off grant payments, and a fixed rate winter payment. Its payment policies are set by its Trustees. In addition to financial support, the Trust also hosts an annual weekend event for its beneficiaries.

MFET Ltd

1.7 This is a company limited by guarantee, funded by the Department of Health in England and established in 2010 which provides non-discretionary annual payments (£14,574 in 2014/15) to all those infected with HIV as a result of treatment with NHS supplied blood or blood products, and any person that they in turn may have inadvertently infected. The size of this payment is set by the Department of Health, and it is currently uprated annually in line with the Consumer Price Index (CPI).

1.8 MFET Ltd also reimburses the cost of an annual prescription pre-payment certificate (PPC) to enable an individual living in England to receive free prescriptions. The eligibility criteria require individuals to be in receipt of annual payments from MFET Ltd, reside in England and be not otherwise exempt from prescription charges.

1.9 Historically, there were also two other schemes (the Macfarlane Special Payments Trust and the Macfarlane Special Payments Trust No.2) that made one-off lump sum payments to those infected with HIV, with the awards varying. MSPT was a flat rate payment of £20,000 to each individual with a bleeding disorder infected with HIV, and MSPT No2 was an out of court settlement to the same group of individuals and their families where payments varied from £2k to £60,500. Equivalent payments were subsequently made in the early 1990s to individuals who do not have a bleeding disorder who were infected with HIV through NHS treatment with blood or blood products.

Schemes that support those affected by hepatitis C

Skipton Fund Ltd

1.10 This is a company limited by guarantee, funded by the UKHDs and established in 2004 which provides non-discretionary payments to individuals infected with hepatitis C as a result of treatment with NHS supplied blood or blood products. The fund makes payments in two stages:

- Stage 1: a single lump sum of £20,000 for all individuals with chronic hepatitis C;
- Stage 2: an additional non-discretionary lump sum of £50,000 and an annual payment (£14,574 in 2014/15, currently uprated annually by the Consumer Price Index (CPI)), for individuals with cirrhosis, primary liver cancer, B-cell non-Hodgkins Lymphoma or who have undergone, or are on the waiting list to undergo, a liver transplant.

The size of the annual stage 2 payment is set by the four UK Health Departments, and is currently uprated annually in line with the CPI.

1.11 The Skipton Fund also reimburses the cost of an annual prescription pre-payment certificate (PPC) to enable an individual living in England to receive free prescriptions. The eligibility criteria require individuals to be in receipt of at least the Skipton Fund first stage payment of £20,000, reside in England and be not otherwise exempt from prescription charges. For more information go to www.skiptonfund.org/payments

Caxton Foundation

1.12 This is a charity funded by the UKHDs established in 2011 providing discretionary support to all individuals infected with hepatitis C through treatment with NHS-supplied blood or blood products, and their families. It operates on the basis of providing means-tested grants and a fixed rate winter payment. Its payments policies are set by its Trustees. In addition to financial support it also pays for referrals to debt and benefits advisors. For more information go to www.caxtonfoundation.org.uk

Summary

1.13 To date, the collective system has paid out over £365 million. All payments are *ex-gratia*, which means they are voluntarily made by government. These payments are additional to any other source of income an individual may receive, and are disregarded for the purposes of calculating income tax and eligibility for calculating other state benefits. In other words, payments are not taxable and nor do they affect a person's entitlement to any state benefits for which they are eligible.

SEE QUESTIONS 1-4 IN THE QUESTIONNAIRE

Q1. In what capacity are you responding to this questionnaire?
Q2. In which country do you currently reside?
Q3. If you are a scheme beneficiary, what is your status?
Q4. If you are a scheme beneficiary, please tell us from which organisations you have ever received payments or other forms of support.

Chapter two: the case for change

2.1 This chapter explains why the UK Health Departments believe there is a case for reform of the current system of financial support provided through the five separate schemes described in Chapter one. Although we can only briefly summarise here some of the main issues that those affected by the tragedy of HIV and hepatitis C infections have highlighted to us, much more information is available on the websites of the various groups that represent them.

Why are we proposing system reform now?

2.2 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.

2.3 In recent years, the UK Health Departments have worked to improve the current system, including introducing annual payments for those with HIV (in 2009) and for hepatitis C (in 2011), and establishing the Caxton Foundation to provide discretionary support for those affected only by hepatitis C, operating alongside the discretionary schemes already established for those affected by HIV. However, we acknowledge that many of those affected still have significant criticisms of the schemes, and the way in which the system is structured. The four UK Health Departments acknowledge these criticisms. We consider that a more radical reform of the system would be needed to address as far as reasonably possible the issues and criticisms that have been raised by beneficiaries and their advocates, and to put the system on a footing for the future that is both responsive to medical advances and sustainable in financial terms.

A new system should address beneficiaries' criticisms as far as reasonably practicable

2.4 Over the years, there have been repeated criticisms from different groups within the beneficiary community about the way that the system has been set up and operates. Beneficiaries have conveyed their dissatisfaction through a number of different routes, including through an independent inquiry chaired by Lord Archer, which published its report in 2009; numerous campaigns; letters to the four UK Health Departments and Ministers; and through meetings with Ministers. Some of the current criticisms that we have been made aware of include:

- individuals not being assessed on an individual basis;
- the needs of some people with chronic hepatitis C infection are not adequately met;
- infected beneficiaries have to deal with more than one scheme;
- the three discretionary bodies operate different payment policies;
- the principle of having to apply for charitable discretionary payments; and
- means testing for discretionary payments.

There has also been criticism about the general size of payments. However, this consultation is about the structure and design of a proposed new system within the overall budget of the existing system.

We have taken account of these criticisms in developing the proposals for a new system described in Chapter three.

Q5. Do you have any criticisms of or concerns about the current system that we have not covered in the above list?

Q6. Are there any non-financial elements of support (see chapter one) in the current system that you value?

A new system should be responsive to medical advances

2.5 Since the first scheme was established, scientific and medical knowledge has advanced, enabling treatments and other forms of medical intervention to be developed and improved. For example, many of those who are HIV positive now live with a long-term condition that is generally stable, due to the effective medicines available. For those with hepatitis C, the spectrum of ill-health varies significantly, ranging from life-threatening conditions through to mild ill-health and asymptomatic infection. Some people with hepatitis C have been successfully treated by interferon, although interferon-based treatments can have other detrimental health impacts that may affect some people over a long period. The advent of new directly-acting hepatitis C therapies which are now becoming available means that in the near future, more people may be successfully treated for hepatitis C, with fewer side effects.

However, the current system of financial support does not adequately reflect this wide variation in ill health. For instance, everyone with HIV and those who meet the Skipton Fund stage 2 eligibility criteria receive the same flat-rate annual payment regardless of the degree of ill-health they experience. Some are very ill and others less so. Others with hepatitis C who are currently not eligible for annual payments may nonetheless be experiencing significant ill-health as a result of their infection.

A new system should be financially sustainable

2.6 At the same time, as the schemes are funded from the UK health budgets, we need to consider long term affordability of any proposals. The health system has a budget for this year and 2015/16. Future funding decisions will be determined by the next Government in the upcoming spending review which will take place in 2015. In the meantime it is important to remember that the health system needs to be developing new ways of working to ensure it is sustainable both now and in the future, given that the overall fiscal position suggests public finances will remain tight for some years to come. And it is in this context that we need to look again at all current and future spending plans and assess what is realistic, affordable and sustainable, in line with this consultation.

The Consumer Price Index (CPI)

2.7 To ensure financial sustainability over the long term, costs need to be controlled. In a reformed system therefore, payments would not automatically be linked to CPI. This does not rule out future payment increases, if additional funding is justified and available.

Summary

2.9 In summary, we recognise beneficiaries' concerns and are committed to addressing them as far as reasonably practicable to create a fair, responsive and financially sustainable system for the future.

SEE QUESTIONS 5-6 IN THE QUESTIONNAIRE

Chapter three: Principles for a new system

3.1 This chapter sets out proposed principles for a new system of financial assistance, focused on the impact of infection on individuals' health. It is worth noting that payments under any new system would, as they currently are, continue to be additional to any other sources of income a person may have.

The proposed principles

3.2 As set out in the introduction, the four UK Health Departments have collectively agreed a set of principles and propose that any new system should be:

- **focused** on the provision of financial assistance to surviving infected individuals;
- **evidence-based** through being informed by scientific and medical knowledge of HIV and hepatitis C and the impact of these infections on the health of individuals; and
- **efficient and effective**, for example, by introducing a unified and transparent process administered by a single body across the UK.

Q7. To what extent do you agree or disagree that payments in a new system should be focused primarily on those with HIV/hepatitis C? (This would mean that all of the available money is used to assist individuals infected with HIV/hepatitis C).

How might these principles be applied?

Equitable access and individual assessment for those infected (evidence-based)

3.3 We would propose to replace the current five schemes with a new system of financial assistance to which all those living with infection would have equitable access.

3.4 We consider it would be fair to include within this group those whose hepatitis C infection has been successfully treated, if there is adequate evidence that they are suffering residual ill-health as a direct result of treatment.

3.5 We propose that the impact of infection on each person's health (both physical and mental) could be evaluated via individual clinical assessment against a set of common criteria. Whilst it is premature to specify which criteria would be most appropriate, they should be based on current medical and scientific evidence, and so be responsive to developments in the evidence base.

3.6 It would be our intention that in such a system, the highest levels of financial assistance would go to those suffering the most severe health impacts as a consequence of infection or treatment, with decreasing levels of payment to those with less severe impacts. Whilst those with no or very few symptoms would not likely receive financial assistance, they would remain eligible for assistance should their health deteriorate.

Periodic re-assessment for everyone would enable decisions to be made on whether payments to each individual should be increased or decreased, according to whether health deteriorates or improves.

Q8a. To what extent do you agree or disagree that it is reasonable for individual assessments to be on the basis of the impact of HIV and/or hepatitis C on an individual's overall (physical and mental) health?

Q8b. If you disagree/strongly disagree, on what do you suggest the assessment be based?

3.7 Some of those with HIV and/or hepatitis C currently receive payments from the discretionary bodies (i.e. the charities). In some instances these payments are made on a regular basis, while others are not. Some payments are determined by personal or household income, while others are not. Continuation of these payments would not align with a new system of financial assistance based on impact of infection on a person's health, and nor in a new system would it be fair to continue these payments for those that already receive them, whilst not making them available to others whose circumstances may be similar. Discretionary payments would not therefore continue for those infected in a reformed system, although payments made regularly would be phased out to give people time to make adjustments to their new financial circumstances.

Scheme structure and approach to payments (efficient and effective)

3.8 We propose a single scheme to be operated by a single new body, instead of the current five. We hope that a proposal to streamline the administration, in order to keep running costs as low as possible, will be welcomed without compromising support being offered. Our aim would be to maximise the proportion of available funding to go to beneficiaries rather than to the running of multiple schemes. Nevertheless, it is important to recognise that there would be a cost associated with the assessment process, and there would be no new money for this.

3.9 On completion of the individual assessments, we envisage people being grouped together with others whose health impact is assessed to be broadly similar. Those in the same group or band would receive the same level of payment. We consider this would be a pragmatic approach that would also provide efficient use of resources. More detail on how we envisage a new payments system would work is provided in Chapter four.

Q9. To what extent do you agree or disagree with the proposal to group people into 'payment bands' according to the outcome of their individual assessments? (This would mean that everyone in the same band would receive the same level of financial assistance).

What would focusing a new system primarily on the infected mean for payments to uninfected family members

3.10 A consequence of the proposal to replace the current five schemes with a single new one would be the gradual withdrawal of funding from the existing schemes over a period of time (not currently determined). This would impact on all those who currently receive payments and other forms of support from those bodies.

3.11 Uninfected family members are currently treated differently by the three discretionary (charitable) bodies who are responsible for deciding their own payments policies. All three charities make some payments to and in respect of uninfected family members. The Macfarlane Trust provides regular payments to some widows/bereaved partners by topping up their personal annual income to a total of £19k, and also makes annual payments in respect of uninfected children of both infected and uninfected beneficiaries. The Eileen Trust makes regular payments to some uninfected beneficiaries and all beneficiaries can apply for grants. The Caxton Foundation provides only individual grants. Current provision for uninfected family members is therefore unequal.

3.12 We have given careful consideration to payments made to uninfected family members under the existing system and the need to address two important issues – equitable treatment and ongoing affordability. In the interests of equity overall, we could not support continuation of this type of payment to some under a new system, whilst not making it available to others, and it is not affordable within the Health Departments' current budgets to extend the current most generous regular payments to all uninfected family members on an equivalent basis.

3.13 Consequently, should system reform proceed, we do not propose a new system would include regular discretionary payments. We recognise that this would be hard for those who would lose money. In order to give people time to make adjustments to their new financial circumstances the gradual reduction would be done over a period of years, and we are willing to listen to suggestions on how else those affected could be assisted in an equitable manner, subject to judgments by the four UK Health Departments on cost-effectiveness and affordability.

Q10. How important do you think it is for a new system to include some financial assistance for uninfected individuals? (This would mean that the money available each year would be shared between infected and uninfected individuals).

Q11. If you wish, please provide suggestions for possible future arrangements (apart from regular payments) to assist uninfected family members that could be provided in an equitable manner, subject to judgments by the four Health Departments on cost-effectiveness and affordability.

Uninfected spouses/partners who suffer bereavement in future

3.15 Should system reform proceed, we propose that each newly-bereaved spouse or partner would continue to receive the same level of payment paid to their infected spouse for a year after death, in order to help them during a difficult time. This 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). For information about bereavement benefits see www.gov.uk/browse/benefits/entitlement

Summary

3.16 Under a reformed system, we propose that financial assistance should focus on those living with infection or suffering residual ill-health as a direct consequence of successful treatment for their infection. If reform were to be implemented as described in this document, this would mean:

<u>For those living with infection</u>

- The current system of non-discretionary payments (SKF and MFET) would be replaced with a new system of graduated payments, based on periodic assessment of the severity of the impact of infection(s) on the health (physical and mental) of each individual.
- The current system of discretionary payments for those infected would end, although those receiving regular payments now (such as income top-ups and regular payments for children) would see them gradually reduced until stopping;
- There would be no new discretionary payments to infected individuals in a reformed system.

<u>For uninfected family members</u>

- There would be no regular discretionary payments in the new system.
- The current system of discretionary payments would end, although those receiving regular payments now (such as income top-ups) would see them gradually reduced until stopping.
- We are willing to listen to suggestions for possible future arrangements to assist uninfected family members in an equitable manner, subject to judgments on cost-effectiveness and affordability.
- Newly-bereaved spouses or partners would continue to receive the payment made to their deceased spouse or partner for a further year after death.

SEE QUESTIONS 7-11 IN THE QUESTIONNAIRE

Chapter four: How might a new system operate?

4.1 Having outlined the principles that could underpin any new system, this chapter discusses how a new system might operate.

What might an individual assessment involve?

4.2 We are proposing that the individual assessment introduced in Chapter three would need to show that a person's health is affected in a specific way that is more likely than not to be a result of their HIV and/or hepatitis C infection. We intend that the process of assessment should be easy to understand, supported by relevant health professionals, and not generate additional clinical investigations beyond those that are part of normal clinical care. If the proposed system reform proceeds, we intend to set up a working group of experts and patient representatives to advise what individual assessment could comprise.

4.3 Our early views are that assessment could be carried out by an individual's GP, comprising a specially designed questionnaire which could be completed using their patient's medical records. A GP should have up-to-date knowledge of their patient's condition and a view on any interdependent condition(s) affecting their patient's physical and mental health as a direct result of their infection. We recognise that there will undoubtedly be instances where some assessments would be less straightforward, including the causal link to HIV and/or hepatitis C. In these cases, the assessment may need to involve the patient's medical specialist.

4.4 The four UK Health Departments intend that any health professionals undertaking these assessments would be appropriately remunerated. This would need to be discussed with the British Medical Association (BMA), the body responsible for negotiating fees for medical practitioners with central government. These costs will need to be met from the overall funding available from the four UK Health Departments for the ex-gratia financial assistance system in a given year.

Payment bands informed by individual assessments

4.5 There would likely be a number of broad bands or categories to reflect the wide spectrum of ill health, with different levels of payment attached to each. Those in the same band would receive the same level of payment. The largest payments would be made to those experiencing the most severe ill health as a result of their infection(s).

4.6 The payment levels for each band would be set on an annual basis, in the context of the overall funding available from the four UK Health Departments for that year. It is important to note that under a system of financial assistance based on individual assessment, some beneficiaries may receive less than they receive under the current system, while others may receive more. In addition, the payments that any person were to receive under the new system could go up or down over time, if their state of health changes and they were assessed as meeting the criteria for a different payment band.

Although the proposed new system would be expected to provide regular payments for many more people, this approach is not intended to guarantee that an infected individual would receive financial assistance for life. The fact and level of payments to the infected individuals would be entirely dependent on the degree of ill-health attributable to infection and periodical re-assessments.

How often should an individual assessment be undertaken?

4.7 No decision has been made on what frequency of individual assessments would be most appropriate, although we consider annual re-assessment would be too frequent for patients and their clinicians, and not the best use of resources. Nor are we wedded to the idea that the same frequency of re-assessment is necessarily appropriate for everyone. Our view is that:

a) beneficiaries should have reasonable periods of financial stability, balanced with the need for the scheme to be responsive to changes in health;

b) individuals should, with their clinician's support, be able to request re-assessment before their next review is due if their health has changed (better or worse) as a direct result of their infection; and

c) frequency of re-assessments should be kept under review.

Appeals

4.8 Any new system would have an independent appeals mechanism, through which any aspects of the process deemed to be unfair could be examined. We do not think it appropriate for an appeals mechanism to re-examine assessments made by clinicians, but it would examine decisions made by the body that operates the scheme.

New entrants – eligibility criteria and process

4.9 As a result of raising awareness through publishing this consultation, there is a possibility that eligible individuals who have yet to apply to one or more of the existing ex-gratia schemes may come forward. Individuals are advised to contact the relevant schemes for further details on eligibility and how to apply for support. Please see chapter one for contact details.

4.10 Eligibility for the current system is based on an assessment of whether, on the balance of probabilities, a person was infected with HIV and/or hepatitis C by treatment with NHS supplied blood or blood products, making them a 'qualifying person'. Should system reform go ahead, it is our intention the eligibility criteria for scheme entry will remain the same. Under any new system, we propose that assessment of eligibility of potential new entrants against scheme criteria would be undertaken by the body responsible for administering the scheme.

Summary

In summary, this chapter presents the four UK Health Departments' initial views on how the principles for system reform might operate. Detailed work would be required to inform all aspects of a new system.

Chapter five: Transition to a new scheme

5.1 This chapter sets out the principles concerning transition if a new scheme is introduced.

Principles for transition to a new scheme

5.2 Work on shaping any new system will be done by the four UK Health Departments collectively with patient representatives, the medical and other specialist health care professions, and key parties, taking into account responses to this consultation. Because of financial pressures on health budgets, we need to shape a new system within certain parameters. These parameters include delivering a new system at existing funding levels, or lower, in future.

5.3 Our initial intention for transition to a new system of financial support is on the basis that:

- infected individuals who currently receive no regular support would be prioritised for assessment under a new scheme;
- infected individuals currently receiving annual non-discretionary payments would have these payments guaranteed for a minimum of two years before any change;
- those infected individuals assessed to receive a lower level of payment would move gradually to their newly assessed payment band;
- infected individuals in receipt of regular discretionary payments (described in Chapter one) via the current three charities would see the payments reduced gradually over a number of years (depending on their circumstances) before stopping;
- uninfected family members in receipt of regular discretionary payments would see the payments reduced gradually over a number of years before stopping as the focus of financial assistance moves to those infected;
- the new system would be phased in over a maximum period of five years; and
- changes would be clearly communicated to all existing beneficiaries, who would also be directed to access other support, for example, advice on benefits and managing their finances.

Administrative arrangements

5.4 Under the existing schemes, beneficiaries already provide certain personal information (name, address, HIV/hep C status, bank details, etc) to the relevant five organisations. We anticipate that any reformed system of financial assistance would be managed by a single body. In order to ensure a smooth transition, all beneficiaries would be contacted to request their consent to allow the five organisations to transfer the minimum personal information required that they hold to the new body. 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, subject to an individual's consent, would be transferred and stored securely in compliance with the Data Protection Act 1998.

Summary

In summary, we recognise that any change to an individual's financial circumstances, brought about by our proposed reforms, must be done gradually over a number of years giving those affected time to adjust to change.

Chapter six: Impact Assessment, the Public Sector Equality Duty and The Family Test

6.1 This chapter alludes to a consultation impact assessment, sets out the Health Departments' responsibilities under the Equality Act 2010 and refers to the recent introduction of a Family Test to be applied in the process of developing new policy. The submission of additional information on all three assessments are covered in the questionnaire.

Consultation Impact Assessment

6.2 An early stage impact assessment, insofar as is possible with the data and assumptions currently available, has been published alongside this consultation. Comments on this are welcome through the consultation questionnaire

SEE QUESTION 12 IN THE QUESTIONNAIRE

Q12. Do you have any comments on the Impact Assessment which has been published alongside the consultation?

Public Sector Equality Duty

6.3 The Department of Health has responsibilities under the Equality Act 2010, and specifically, has to comply with the Public Sector Equality Duty.

6.4 The Duty covers the following protected characteristics: age, disability, gender reassignment, pregnancy and maternity, race (includes ethnic or national origins, colour or nationality), marriage and civil partnerships, religion or belief (includes lack of belief), sex and sexual orientation.

6.5 There are three main parts to the duty and public bodies must, in exercising their functions, have due regard to all of them. They are:

- the need to eliminate unlawful discrimination, harassment and victimisation;
- 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 who do not.

We have given equalities consideration and due regard throughout our early thinking on reforming the system. We recognise that there may be considerable public interest in the proposal and would like to draw your attention to the specific equality questions in the questionnaire.

The Family Test

6.6 The introduction of a Family Test was announced by the Prime Minister in August 2014. The objective of the Test is to introduce an explicit family perspective to the policy making process, and ensure that potential impacts on family relationships and functioning are made explicit and recognised in the process of developing new policy. As we are proposing a change to existing policy, we have included questions to help us understand the impact this change in policy will have on families.

6.7 We acknowledge that the reform to the existing payment schemes being proposed in this consultation, will impact families. We need to understand and consider the nature of those impacts, positive and negative, more carefully. The Family Test Questions have been developed in collaboration with experts in this field to guide those considerations. Government believe by applying the family test and complying with the Public Sector Equality Duty should lead to better overall outcomes for people affected by these reforms.

SEE QUESTIONS 13-16 IN THE QUESTIONNAIRE

Q13. Do you think the changes being proposed will impact on you positively or negatively?

Q.14. Can you please explain how? (we will take this into consideration alongside any anonymised responses)

Q15.Do you think the changes being proposed will affect your family life when implemented? For example, if you are wishing to have children, get married, about to be separated or divorced, suffered bereavement, recently been made redundant from work or you have new caring responsibilities.

Q16. If you have answered yes to question 15, where any of the examples provided applies to you, how will the changes impact you/your family? (we will take this into consideration alongside any anonymised responses)

Chapter seven: Responding to this consultation

How to get involved in the consultation

7.1 The consultation questions are set out throughout this document. The consultation will run for 12 weeks, from xxxx to midnight on xxxx 2014. 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:
- http://consultations.dh.gov.uk/newpaymentscheme_xxxx
- Filling in the questionnaire by downloading it at:
- www.gov.uk/government/consultations
- Emailing your responses to: **[DN: add mailbox address]**
- Posting your response to:

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

Comments on the consultation process itself

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

Contact Consultations Coordinator
Department of Health
2E08, Quarry House
Leeds
LS2 7UE

e-mail consultations.co-ordinator@ GRO-C

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

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 All information held by the Department of Health is accessible under the Freedom of Information (FOI) Act 2000. 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 s.40, 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.

Annex A

List of groups and individuals, other than the general public, who will be invited to shape the new system of financial assistance

Beneficiaries and their families

The current schemes:

- Macfarlane Trust
- Eileen Trust
- Caxton Foundation
- Skipton Fund Ltd
- MFET Ltd

The Haemophilia Society

Haemophilia Scotland

The Scottish Infected Blood Forum

The Hepatitis C Trust

Campaign Groups (Tainted Blood, Manor House Group and the Contaminated Blood Campaign)

All Party Parliamentary Group on Haemophilia and Contaminated Blood

Interested MPs

Interested MSPs

Health Professionals and their representative organisations

Other Government Departments (DWP, HMRC, HMT)

GLOSSARY OF TERMS

HCV	Hepatitis C
HIV	Human Immunodeficiency Virus
NHS	National Health Service
UK	United-Kingdom
CPI	Consumer Price Index
PPC	Prescription Pre-Payment Certificates
BMA	British Medical Association
GP	General Practitioner
DH	Department of Health
DWP	Department of Work and Pensions
FOI	Freedom of Information