Department of Health

Infected blood: Government Response to Consultation on Reform of Financial and Other Support

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Title:
Infected blood: Government Response to Consultation on Reform of Financial and Other support

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Document Purpose:
Consultation response

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Target audience:

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

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Infected blood: Government Response to Consultation on 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 Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with National Health Service (NHS)-supplied blood or blood products. To date, over £390 million has been paid out to infected persons and their family members.

0.2 However, the system has attracted criticism from those it is intended to help. Responding to the need for a more accessible and equitable system of care and support that focuses on the welfare of infected individuals, the Department of Health launched a consultation on its proposals for reform of the current schemes on 21 January 2016[1]. While we particularly sought the views of the beneficiaries of the current schemes and their clinicians, the consultation was open to all to respond. Led by the Department of Health, the consultation was open to anyone in the UK who wished to respond. The consultation closed on 15 April 2016.

0.3 The government has listened carefully to the responses to its consultation. There were 1,557 formal responses to the consultation document as well as a backbench debate on the issue during the consultation period, 21 Parliamentary Questions tabled, and many individual letters to Ministers and the Department of Health. In drawing up our proposals for the new scheme, we have taken full account of this feedback. We have also taken into account the need to ensure that the new scheme is equitable and transparent in terms of its future operation; that it makes the best use of available funding and that it remains affordable and sustainable over the lifetime of this spending review period, providing support to those who most need it.

0.4 This document presents our analysis of the responses, our consequent decisions for a reformed scheme, and an overview of the transition arrangements. It has the following structure:

- Chapter One describes what we did - how we ran the consultation exercise, who responded and how we analysed the responses;
- Chapter Two explains the background to the consultation proposals and examines the public reaction to the proposals;
- Chapter Three describes the elements of the reformed system on account of what we have heard from respondents and other sources;
- Chapter Four explains the transition arrangements which will be put in place in 2016/17 and beyond; and
- Annex A illustrates what the reformed scheme will mean for individuals.

[1] The consultation document, equality analysis and impact assessment can be found here: https://www.gov.uk/government/consultations/infected-blood-reform-of-financial-and-other-support

Chapter One: What we did: How we ran the consultation exercise, who responded and how we analysed their responses

Summary

Our public consultation ran from 21 January to 15 April 2016 and contained 11 questions setting out our proposals for a new scheme of support for infected and affected individuals. The consultation was informed by a number of engagement events which set the scene to the consultation.

We received 1,557 consultation responses, of which 80% came from respondents in England, 10% in Scotland, 5% in Wales and 2% in Northern Ireland. The majority of respondents were registered with one of the current payments schemes (87%) and of those who declared their group, 58% were infected with hepatitis C and 6% with HIV. A large proportion of respondents were immediate family members of an infected individual (18%) and some were carers for infected individuals (2%).

Why are we proposing to reform the current system?

1.1 The consultation document explained that the current system has evolved in an *ad hoc* and incremental manner since it was set up. The five schemes[2] were established on an infection-specific basis and operate according to their own individual criteria.

1.2 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; and parliamentary debates and questions.

1.3 The challenge for the Department of Health is to create a reformed scheme that is equitable, takes account of medical advances and makes best use of available funding.

Engagement events which informed the consultation

1.4 To help inform the consultation, we held engagement events with a small representative reference group of campaigners, with Members of Parliament from the APPG on

[2] The five schemes cover discretionary support from three charities (the Macfarlane Trust, the Eileen Trust and the Caxton Foundation), and non-discretionary payments by MFET Ltd and Skipton Fund Ltd. For more detail, please see the consultation document.

Haemophilia and Contaminated Blood, and with the staff of the current schemes. The consultation document gives full details. In summary:

- 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. Those at the event agreed that the current schemes needed to change and proposed financial support that differs considerably from what is currently provided.
- 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 Members of Parliament on the consultation process and budget setting process.
- On 9 November 2015, we held an event for the staff of the current schemes. The staff said it would be more efficient and consistent if the five bodies were combined, and that any new scheme should offer some discretionary support based on need. Attendees also emphasised the positive relationships they had with many of the scheme beneficiaries.
- Further, over the consultation period, the Department of Health received 69 letters from people raising additional points which we have considered.

Launch of the consultation

1.5 When the consultation was launched on 21 January, letters were sent to all 3,482 registrants of the existing schemes to make them aware of the consultation. The letter provided details of how to access the consultation both online and in hard copy.

1.6 Letters were also sent to almost 180 Members of Parliament who had raised the issue on behalf of their constituents over the past year to make them aware of the consultation. The Department of Health did not set up a helpline for the consultation as this is not normal government practice.

Information on consultation respondents

1.7 1,557 respondents replied to the consultation which closed on 15 April.

1.8 As the consultation was open to the public, anyone with an interest in scheme reform had an opportunity to respond. We asked two questions to allow us to get an understanding of the demographics of those who responded.

1.9 Firstly, we asked whether respondents were registered with one of the current payment schemes. The breakdown is set out below:

Registered with one of the current payment schemes	1350	87%
Not registered with one of the current	123	8%

payment schemes		
Prefer not to say/not answered	84	5%

1.10 Secondly, we were interested in how respondents had been affected by infected NHS supplied blood products; however, it was not obligatory for respondents to provide this information. Most respondents indicated which group they belonged to:

I have hepatitis C (from infected NHS supplied blood/blood products)	902	58%
I am HIV positive (from infected NHS supplied blood/blood products)	101	6%
I am immediate family (a widow, partner, child or parent) of someone infected with hepatitis C, HIV or both by NHS blood/blood products	283	18%
I am a carer for a person infected with hepatitis C, HIV or both by NHS supplied blood/blood products	31	2%
Prefer not to say/not answered	75	5%
Other	165[3]	11%

1.11 The current support schemes operate on a UK wide basis and our consultation was open to anyone in the UK who wanted to respond to it. The proposals for scheme reform that are described in the consultation document and this government response, principally, are for beneficiaries infected in England. We have also shared the information gathered through our consultation with the governments in Scotland, Wales and Northern Ireland. Chapter Four gives more information about how this will work during transition.

1.12 Across the UK, we received responses as follows:

England	1245	80%
Scotland	152	10%
Wales	77	7%
Northern Ireland	27	2%
Other/not answered	56	1%

Analysing the responses

1.13 The responses to the consultation provided a rich source of information on the views of the beneficiaries of the schemes and other interested parties. A small team was established to read and analyse the responses and to identify the key themes which emerged (see Chapter Two). Data derived from this analysis, and the personal stories provided by many people, were all recorded on Citizen Space, the digital tool government departments use to run their consultations. This enabled the Department of Health to get a better understanding of both the quantitative and qualitative aspects of the responses.

[3] Many of these are co-infected individuals, or individuals who have now cleared their hepatitis C virus.

Chapter Two: Analysis of Responses

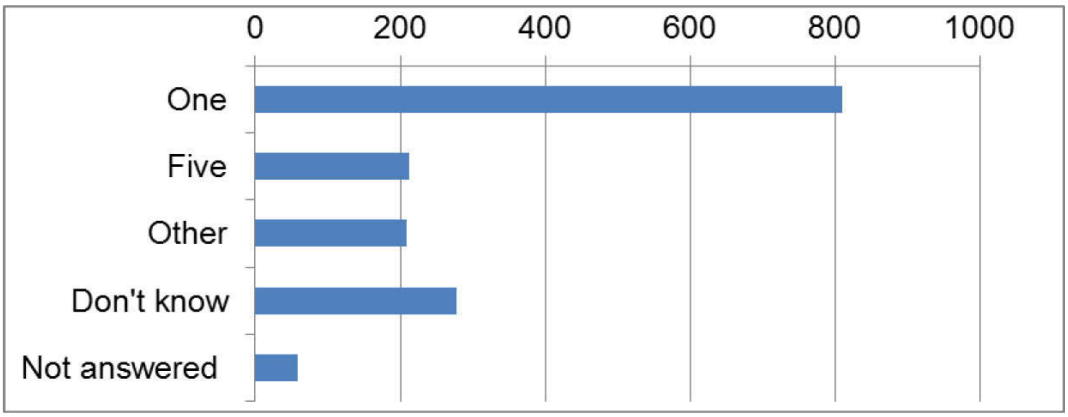
Summary

Our consultation questionnaire contained 11 questions about scheme reform, all tailored to address what government has been hearing from those affected over the past few years. Given the diversity of affected groups impacted by infected blood, and the fact that our engagement events and other evidence suggested a wide range of views across these groups about how best to reform aspects of the scheme, open questions provided the best way for all views to be expressed.

This chapter gives a short explanation of the rationale behind each of the 11 consultation questions and our analysis of the responses to these questions.

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

2.1 The consultation document proposed to replace the existing five schemes with a single body. This was intended to reduce reported confusion around the five current schemes and the support provided by them, and to maximise funding available to support beneficiaries by minimising running costs. We were clear in the consultation that a new scheme administrator could continue to provide other support, including financial and non-financial advice, and that the change would be as simple as possible for beneficiaries. The chart below sets out the responses:



2.2 66% of respondents said that they would prefer one scheme over five schemes and of those who provided comments, the most common themes were:

- One scheme body would be more efficient than five
- One scheme body would be less confusing to navigate than five

2.3 A significantly smaller number of respondents (17%) said they would prefer five schemes over one, and of those who provided comments, the common themes were:

- Moving from the current schemes would be expensive and inefficient
- Moving from the current scheme would mean reduced financial support

- The current schemes and their staff provide a good service

2.4 17% of respondents who answered suggested an alternative scheme structure and of those who commented, the most common suggestions were:

- There should be two schemes: one for those with HIV and one for those with hepatitis C
- There should be two schemes: one for haemophiliacs and one for those infected via whole blood transfusions
- There should be separate national schemes
- The Department of Health should mirror the reforms Scotland is making

2.5 Additionally, many respondents commented that the service the scheme(s) provide is more important than its structure. Respondents mentioned that fairness, equal treatment, transparency, accountability, and qualified and caring staff were important factors.

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

2.6 In question 2, we proposed the introduction of individual assessments for those with hepatitis C stage 1 (and for individuals with hepatitis C and/or HIV who newly come forward to join the reformed scheme). The rationale for this proposal was one of the biggest sources of criticism in the current schemes, namely that people with hepatitis C stage 1 do not currently receive annual payments. We therefore proposed the introduction of individual assessments to determine an amount of annual payment based on the impact of the infection on each person's health, according to clear criteria that would be easy to understand, supported by relevant health professionals, and would not require extra clinical investigations. We also proposed that individuals would be re-assessed at regular intervals of three years (with the possibility of requesting re-assessment at any time).

2.7 Of those who responded to this question, 52% indicated that they did not want to be assessed. The most common reason for this was that respondents felt they should not have to prove that they are ill to receive an annual payment.

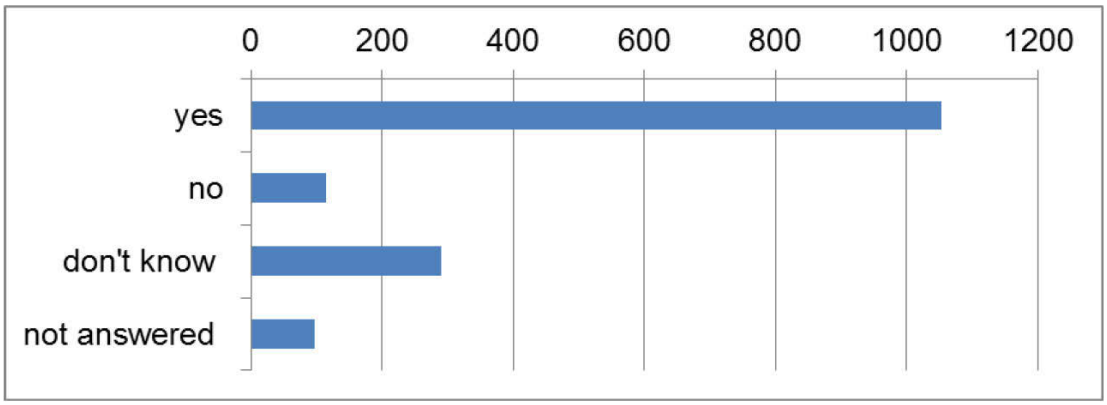
2.8 Only 4% of respondents were supportive of introducing individual assessments. The most common reason for this was that respondents considered that the scheme should take into account the individual circumstances of those infected.

2.9 Of those who provided comments on how the individual assessment should be undertaken, the most common themes were:

- Assessments should be light-touch, based on existing medical records and non-invasive
- Assessments should take account of the full life impact of infection, and not just the current health impact
- Assessments should be conducted by a specialist
- Assessments should be conducted by your own doctor or someone you are familiar with

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

2.10 We also sought views on whether the new scheme should continue to provide a lump sum payment of £20k to anyone who newly joins the scheme. This payment would be in recognition of the fact that the individual is chronically infected. The below chart illustrates the responses we received to question 3.



2.11 As the above chart shows, the majority (72%) of respondents who answered this question thought that the reformed scheme should include a lump sum of £20k when an infected individual joins the scheme. Of those that commented, the main themes were:

- Everyone should get this lump sum, not just those infected who newly join (14% of those who answered 'yes' said this)
- The lump sum should be increased to more than £20k (8% of people who answered 'yes' said this)

2.12 Only 8% of respondents who answered this question thought that the reformed scheme should not include a lump sum of £20k when an infected individual joins the scheme. Of those that commented, the main theme was:

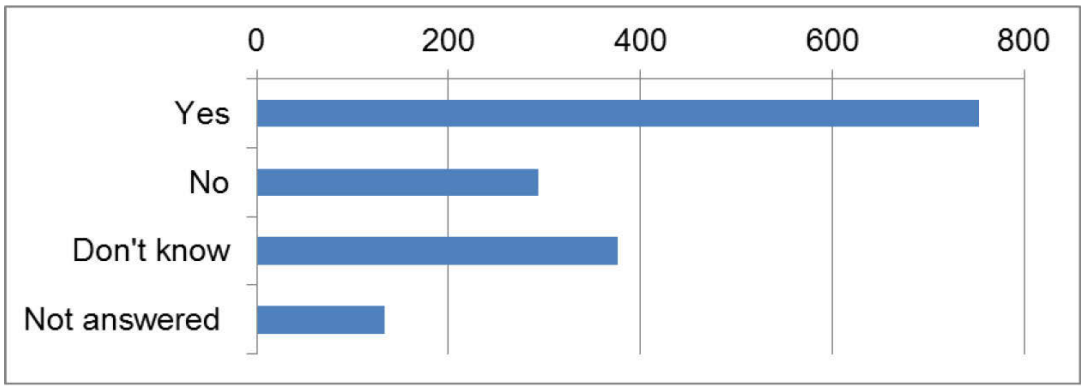
- A lump sum of £20k is too little, it should be increased (47% of people who answered 'no' said this)

2.13 20% of respondents said they did not know whether the reformed scheme should include a lump sum of £20k when an infected individual joins the scheme. Of those that commented, the main themes were:

- A lump sum of £20k is too little, it should be increased (21% of people who answered 'don't know' said this)
- Everyone should get this lump sum, not just those infected who newly join (11% of people who answered 'don't know' said this)
- The Department of Health should mirror the reforms of the Scottish Government (7% of people who answered 'don't know' said this)

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?

2.14 In question 4, we sought views on the retention of the £50k lump sum payment (see chart below).



2.15 Overall, 53% of respondents who answered this question thought that the reformed scheme should 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.

2.16 Those respondents who identified themselves as having hepatitis C (that is, those who would be most likely be affected by the proposal) and answered this question, the most common responses were:

- 496 (58%) said the payment should be retained
- 179 (21%) said it should not be retained
- 166 (19%) said they did not know
- 43 also said that receiving a lump sum when their health had deteriorated enough to be eligible for stage 2 was not helpful

2.17 20% of respondents who answered this question thought that the reformed scheme should not differentiate between those with HIV and hepatitis C and remove the £50k lump sum for progression to hepatitis C stage 2.

2.18 Of respondents who provided comments, 25% thought that all infected individuals should be treated the same, and conversely 24% thought that the lump sum should be maintained but increased to more than £50k.

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?

Question 6: Should the scheme offer the existing bereaved a final lump sum or continued access to discretionary support, or the choice between these two options?

2.19 In our consultation document, we proposed 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.

After the year ended, the individual would cease to be eligible for other support under the reformed scheme. However, we also recognised that some people might prefer to have access to a discretionary fund and proposed that the reformed scheme could contain either element or a choice between the two (question 5).

2.20 We also consulted on the introduction of a one-off, final lump sum as an alternative to on-going discretionary support for bereaved partners already receiving regular support from the schemes. We suggested that the 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. However, we also recognised that some people might prefer to retain access to a discretionary fund. We proposed that the reformed scheme could contain either element or a choice between the two (question 6).

2.21 Responses to question 5 and 6 were broadly the same:

In response to question 5:

- 70% of respondents who answered this question wanted to have a choice
- 18% of respondents who answered this question wanted to have a lump sum
- 12% of respondents who answered this question wanted to have on-going access to discretionary support

In response to question 6:

- 69% of respondents who answered this question wanted to have a choice
- 19% of respondents who answered this question wanted to have a lump sum
- 12% of respondents who answered this question want to have on-going access to discretionary support

2.22 The majority of respondents did not provide comments, but of those who did the most common responses were:

- Around 10% said they wanted both a lump sum and access to discretionary support
- Around 27% wanted a more generous offer for the bereaved or support akin to that being provided for the bereaved by the Scottish Government
- Around 16% implied they wanted a support scheme that was responsive to their circumstances such as their financial need, the impact of bereavement on them, or the needs of dependent children

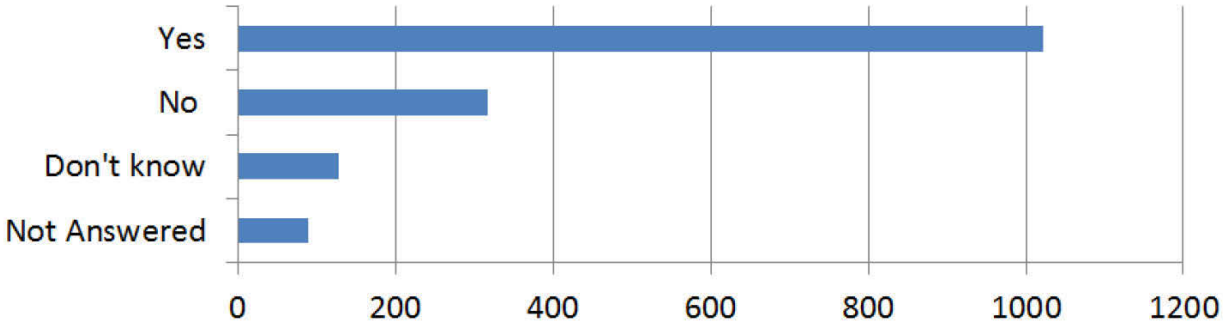
Question 7: Should providing access to treatment for those with hepatitis C be part of the reformed scheme?

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?

2.23 Access to new hepatitis C therapies has been improving since the summer of 2015 and, from February 2016, the NHS has rolled out access to treatment with three new drugs to people with and without cirrhosis. The NHS will be prioritising access to treatment for all on the basis of clinical need in line with NICE guidelines and patients who are

assessed as having a lower clinical need may have to wait before they can receive treatment through the NHS.

2.24 We proposed, therefore, to fund a separate scheme to enhance access to treatment for those infected with hepatitis C as a result of treatment with blood products (question 7). The below chart shows the responses:

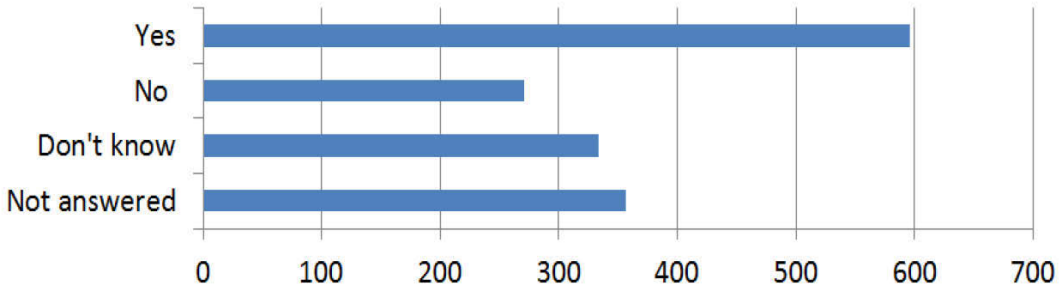


2.25 As the table above shows, the majority (70%) of respondents said that access to treatment was important and wanted it to be considered as part of the overall approach to assisting the beneficiary community; while 22% of respondents thought that access to treatment should not be provided under the scheme.

2.26 Many respondents caveated their response:

- 38% said that treatment should be provided by the NHS and not this scheme
- 9% said they should be prioritised for NHS treatment
- Some respondents commented that providing treatment through this scheme amounted to making beneficiaries pay for their treatment

2.27 We also asked if current beneficiaries who are infected with hepatitis C would be interested in being considered for accelerated access to treatment under the scheme (question 8) as shown in the chart shown below:

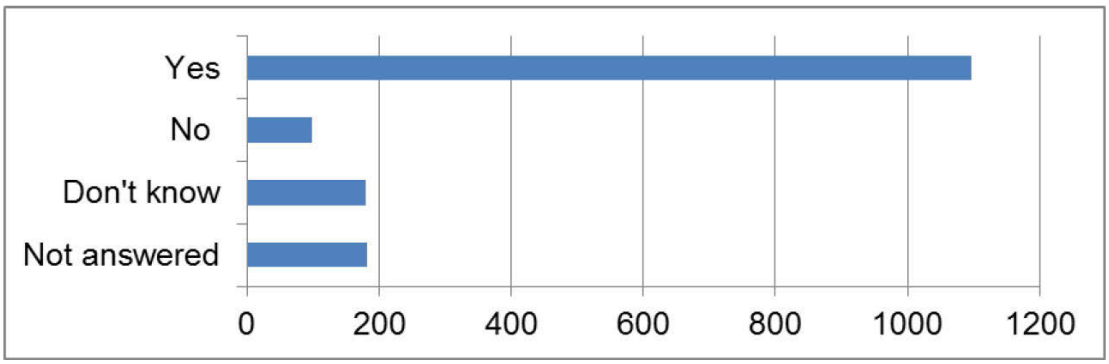


2.28 As the above chart shows:

- 47% of respondents who answered question 8 said they would be interested in receiving treatment as part of this scheme
- 23% of respondents said they would not be interested in receiving treatment as part of this scheme
- 28% of respondents did not know

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

2.29 In question 9 we sought views about other support to beneficiaries. In view of the fact that our proposals included annual payments for all infected individuals (a new annual payment for those infected with hepatitis C stage 1 and the continuation of annual payments for those with stage 2 and HIV), we proposed that in future discretionary payments may 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 was to ensure that people are not financially disadvantaged in receiving their treatment. The below chart shows respondents' preferences:



2.30 As the above chart shows, the majority of respondents (80%) answered 'yes' to retaining discretionary payments for travel and subsistence, with only 7% saying 'no'. 635 respondents provided comments on question 9 on a variety of issues:

- 165 said that discretionary payments should cover more than just travel and accommodation costs (26%)
- 130 said that discretionary support should not be provided at all – instead annual payments should be enough that discretionary support is not needed, or a large lump sum should be provided instead (20%)
- 69 people who commented thought that the current levels of discretionary support should either be maintained or increased, with 19 people specifically supporting keeping the discretionary scheme as it is (11%)
- 33 said discretionary payments should be made on the basis of financial need (5%)
- Around 33 respondents indicated that applying for grants feels like begging, and they want discretionary support to be more easily accessible (5%)
- Many respondents provided examples of the type of cost they would like a discretionary scheme to cover:
    - Insurance (health and travel)
    - Home adaptations
    - Prescription costs
    - Respite/holidays
    - Home care
    - Winter payments

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

Question 11: Do you have any other comments that you wish to make?

2.31 Question 10 asked about the impact of our proposals on any particular group of individuals. 1,165 (75%) respondents answered this question. In relation to particular groups of people, especially those with protected characteristics under the Equality Act 2010, the most common concerns were:

- Those who are disabled as a result of their infection may receive less under proposed reforms than they currently do, and many disabled people already have to go through various forms of assessment for government support so subjecting them to another assessment would not be fair
- Those scheme beneficiaries who are in old age rely more on discretionary support, such as winter fuel payments, than other beneficiaries
- The intention to break to the link to CPI could have a more negative impact over time on the youngest scheme beneficiaries
- There is no provision for support for carers under proposed reforms
- The majority of the bereaved are women, and so women are disproportionately affected by reforms to support for the bereaved
- The 'working poor' are least likely to benefit from a discretionary scheme based on an income threshold
- The proposed eligibility criteria in relation to those who are secondarily infected are not fair

2.32 1,258 (80%) of respondents left comments in question 11. Responses touched on a wide range of issues but the most common concern was around individuals being financially worse off as a result of reforms. Many respondents noted that breaking the link between annual payments and CPI would mean that over time they would be financially worse off, and similarly many were concerned that reforms to the discretionary aspect of the scheme would impact negatively on their financial situation.

Conclusion

2.33 From this analysis, it is clear that the fundamental principles of our consultation proposals are supported. That is, that a reformed scheme should focus available resource on those whose health is most affected, and that the system of support should be simple, equitable and responsive to individuals' circumstances. Through the consultation responses we have heard a range of perspectives, and we reviewed our consultation proposals against what the majority of respondents would like from a reformed scheme. On this basis, we have decided on a package of reforms, based on the same principles of the consultation and tailored to reflect the voices of the majority of consultation respondents as far as possible, taking account of equity, affordability and feasibility. This is set out in the next chapter.

Chapter Three: The elements of the reformed system

Summary

This Chapter sets out our decisions for scheme reform in response to what we heard in the consultation responses, other correspondence received and from other stakeholders. It also highlights areas where we do not plan to make changes.

The government has listened carefully to the consultation responses set out in Chapter Two, considered pre- and post-consultation evidence from other sources, and reviewed the consultation proposals in line with respondents' views and other evidence.

There will be a single scheme administrator combining the functions of the existing schemes into a simple scheme going forward. The new administrator will become operational in the financial year 2017/18 and the current bodies will operate until then. The elements of the reformed scheme during the spending review period until the end of March 2021 will be:

- New annual payments of £3,500 for those infected with hepatitis C stage 1 with effect from this year (2016/17) and without the need for individual assessments. This will rise to £4,500 in 2018/19.
- The continuation of annual payments for those infected with severe hepatitis C (stage 2) or HIV of £15,500 from this year (an increase from the current £14,749), rising to £18,500 in 2018/19.
- For those co-infected with HIV and hepatitis C stage 1, annual payments will be £18,500 in 2016/17 and 2017/18, rising to £22,500 in 2018/19.
- For those co-infected with HIV and hepatitis C stage 2, annual payments will be £30,500 in 2016/17 and 2017/18, rising to £36,500 in 2018/19.
- Annual payments will be linked to the consumer price index (CPI) and include the £500 winter fuel payment as a standard payment without the need to apply for it.
- The continuation of the £50k lump sum payment for those infected with hepatitis C stage 1 who progress to stage 2.
- From 2017/18, and when the new scheme administrator is in place, there will be a new special appeals mechanism for those at hepatitis C stage 1 who consider that the impact of their infection may mean they could qualify for stage 2 annual payments and the £50k lump sum payment. This replaces our initial proposal for individual health assessments.
- New hepatitis C entrants to the scheme will continue to receive a one-off £20,000 lump sum payment. New HIV entrants' lump sums will also remain as now.
- The continuation of a discretionary scheme for infected and affected, as well as 'softer' support with an increased budget from 2018/19.
- A one-off lump sum payment of £10,000 to all those who were the partner or spouse of a primary beneficiary when they passed away and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse. This will apply to those already bereaved and newly bereaved from 2016/17 and beyond.
- All payments will continue to be ex-gratia, which means they are funded voluntarily by government. These payments will also continue to be additional to any other income a

beneficiary may receive, and are disregarded for the purposes of calculating income tax and eligibility for other state benefits.
- In addition, all annual payments will continue to be linked to the consumer price index (CPI) from next year.

Based on the responses, we have decided not to introduce new individual assessments and we will not provide accelerated access to hepatitis C treatment through the reformed scheme.

All elements of the above reform package apply to the current spending review period of 2016/17 to 2020/21, towards the end of which a review of the scheme will be undertaken.

The key themes emerging from the consultation

3.1 The government is committed to creating an accessible and equitable system of care and support that focuses on the welfare of infected individuals, a system that is 'light touch' and with services sensitive to beneficiaries' needs. The challenge is to establish a reformed scheme that is fair, takes account of medical advances and makes best use of available funding appropriately and equitably over the remainder of the 5-year Spending Review period, towards the end of which a review of the scheme will be undertaken. This review will particularly take account of the numbers being treated for hepatitis C and the implications for the future operation of the scheme.

3.2 The following key themes arose from our analysis of consultation responses in Chapter Two:

- Preference for a simplified scheme administrator governed by fairness, equal treatment, transparency, accountability and with qualified and caring staff;
- A fair and light touch approach to annual payments that recognises individuals' infection without the need for any individual health assessments;
- The request for a system that recognises the impact the infection has had on peoples' health through a variety of means - lump sum payments on entry, regular annual payments and through discretionary support targeted at those most in need including those bereaved;
- That treatment should be available but the costs should be carried by the NHS and not paid for with funding intended to help beneficiaries.

3.3 We have listened carefully to the consultation responses, analysed pre- and post-consultation evidence from other sources, and reviewed the consultation proposals in line with respondents' views and evidence and according to our commitment for an equitable system of support that recognises those most at need and that is within the available funding envelope for this spending review period to 2020/21.

Changes to the scheme administrator role

3.4 There was a clear preference by those who responded to our consultation in favour of a single, simple support scheme going forward (see our analysis of question 1). As such, we are now looking to set up a single body to carry forward the current schemes' functions and administer the new annual payment scheme, existing annual payments, discretionary scheme, applications and appeals system fairly and consistently. From 2017/18, the single scheme administrator will provide a quality service to all beneficiaries

based on strong and transparent governance arrangements – outwith the Department of Health but with clear accountability to the Department. This transition to a new scheme should not impact on beneficiaries of the current schemes or new beneficiaries coming forward in the future.

Annual payments

Hepatitis C stage 1 annual payments

3.5 One of the biggest sources of criticism in the current schemes is that people with hepatitis C stage 1 do not currently receive annual payments. Nearly 75% of beneficiaries fall into this category and we sought to address this in our consultation proposals through the introduction of a new annual payment and individual assessments to determine the amount of that annual payment.

3.6 However, we have heard that the majority of respondents did not like the proposal for individual assessments (see analysis of question 2). Many respondents considered that they should not have to prove that they are ill to receive an annual payment when medical evidence of their illness exists. We have listened to respondents' views and decided not to proceed with the individual assessment. Instead, starting this financial year, we will offer a new fixed rate annual payment to all those at hepatitis C stage 1, thereby extending annual financial support to all infected individuals; something not previously offered.

3.7 Nearly 2,500 hepatitis C stage 1 beneficiaries will benefit from this new annual payment in recognition of their chronic infection. During 2016/17 and 2017/18, annual payments will be £3,000 plus £500 for winter fuel payment (that is £3,500) and will be backdated to April 2016 for existing beneficiaries. From April 2018/19 onwards, annual payments will rise to £4,500 per year (inclusive of winter fuel payment). Over the lifetime of this spending review period, this change will ensure each hepatitis C stage 1 sufferer currently registered will receive £20,500 in annual payments.

Hepatitis C stage 2 annual payments and for those infected with HIV

3.8 At present, those infected with hepatitis C stage 2 or HIV receive an annual payment of £14,749. With effect from the current financial year, and backdated to April 2016 for existing beneficiaries, this amount will be increased to £15,000 plus £500 for winter fuel payment for 2016/17 and 2017/18 (£15,500 in total). From 2018/19, these annual payments will increase to £18,500 per year (inclusive of winter fuel payment). Over the lifetime of this spending review period, this change will ensure each hepatitis C stage 2 or HIV sufferer currently registered will receive £86,500 in annual payments.

Annual payments for those co-infected with hepatitis C and HIV

3.9 Regarding all those co-infected, we want to be clear that two annual payments will be made as follows:

- For those who are co-infected with HIV and hepatitis C stage 1, annual payments with effect from this year will be £18,500 (that is £15,000 plus £3,000 plus £500 for winter fuel payment) rising to £22,500 (that is £18,000 plus £4,000 plus £500) from 2018/19.

- For those who are co-infected with HIV and hepatitis C stage 2, annual payments with effect from this year will be £30,500 (that is two times £15,000 plus £500 for winter fuel payment) rising to £36,500 (that is two times £18,000 plus £500) from 2018/19.

3.10 This means that over the lifetime of this spending review period, this change will ensure those currently registered co-infected with hepatitis C stage 1 or 2 will receive £104,500 or £170,500 in annual payments respectively.

Annual payments - summary

3.11 As set out above, all annual payments will include the £500 winter fuel payment with effect from this year. This removes the need to apply separately for winter fuel payments from the discretionary schemes, which we appreciate has added unnecessary burden to beneficiaries. It also frees up the equivalent budget in the discretionary scheme (described below) for additional support for those most in need.

3.12 We also confirm that all annual payments will continue to be linked to the consumer price index (CPI) and thus would increase in line with a positive index from 2017/18 onwards. Should the CPI decrease, we will not adjust payments downwards.

3.13 In summary, annual payments will increase as set out in the below table, include the annual winter fuel payment, and will continue to be disregarded for the purposes of calculating income tax and eligibility for other state benefits. In addition, all annual payments will continue to be linked to the consumer price index (CPI) from next year." Please see also Annex A which shows how the proposed changes may affect different groups of beneficiaries.

Annual payments	**Current amount per year**	**New annual amount in 2016/17 and 2017/18***	**Annual payment from 2018/19***	**Over course of this spending review period 2016/17 to 2020/21***
Hepatitis C, stage 1	£0	£3,500	£4,500	£20,500
Hepatitis C, stage 2	£14,749	£15,500	£18,500	£86,500
HIV	£14,749	£15,500	£18,500	£86,500
Co-infected with HIV and hepatitis C stage 1	£14,749	£18,500	£22,500	£104,500
Co-infected with HIV and hepatitis C stage 2	£29,498	£30,500	£36,500	£170,500

*Figures exclude CPI increases.

Progression from hepatitis C stage 1 to stage 2

3.14 Under the current scheme, those who progress from hepatitis C stage 1 to stage 2 receive a lump sum payment of £50,000. When we asked whether we should retain this payment (question 4), 53% of overall respondents and 58% of those who identified themselves as having hepatitis C (the group most affected by our proposal) considered that the payment should be retained. We have thus decided to retain the £50,000 one-off payment for those progressing to hepatitis C stage 2. This reflects our desire to support those whose health is most affected.

3.15 We recognise that there can be a wide spectrum of ill-health associated with chronic hepatitis C infection, some of which may be prolonged and severe, and also that the older treatments for hepatitis C infection can occasionally have a long-term health impact. While there was a clear message from the responses against individual assessments (see question 2), some cases may only be determined on an individual basis. We have therefore decided to introduce a special appeals mechanism for people currently at stage 1 to apply for a higher level of payment, equivalent to the stage 2 payments. This special appeals mechanism will be introduced in 2017/18.

3.16 Expert advice is now being sought on the criteria and process for this mechanism. Our criteria will be transparent and give clear, easy to understand guidance to those who may be eligible. Applications to this special appeals mechanism will of course be voluntary.

3.17 In summary, those infected with hepatitis C who progress from hepatitis C stage 1 to stage 2 will receive a £50,000 one-off payment on top of their new annual payments. In 2017/18, we are also introducing a new appeals system for those at stage 1 who consider they could qualify for stage 2 support. This reflects respondents' preference and our desire for a reformed system that is responsive to beneficiaries' needs and health status. Please see Annex A for details on how this might affect existing beneficiaries.

Lump sum payments for new entrants

3.18 When we asked whether we should retain the lump-sum payment for new entrants to the scheme, the majority of respondents (72%) thought that the reformed scheme should continue to provide a £20k payment for those entering the scheme (see question 3).

3.19 We understand the importance of such a payment to all those newly joining the scheme. We have thus decided to honour the current entry payments going forward.

Discretionary support

3.20 We heard that the majority of respondents appreciate the availability of discretionary support in addition to receiving regular payments and that this support should go beyond the provision of travel and accommodation costs for those infected (question 9). We have thus decided to enhance the discretionary scheme, including with continued non-financial support.

3.21 The current discretionary arrangements will continue as they stand in 2016/17. From 2017/18, the current schemes will be replaced with a new discretionary scheme with a set of criteria that applies to infected and affected as consistently and as practicable as possible.

3.22 This new system of discretionary support will be equitable, transparent and consistent for all beneficiaries. It will have robust criteria and provide help to those who need it most, and in a way that does not see them "beg cap in hand" – a message we have consistently heard. It will be more streamlined, easy to access, and have a consistent and transparent application process with criteria embedded that take account of individuals' needs. Payments from the new enhanced discretionary scheme will continue

to be disregarded for the purposes of calculating income tax and eligibility for state benefits, and will include not only financial but other holistic advisory support that many people have told us they so value under the current arrangements.

3.23 As we design the new enhanced discretionary support scheme, due consideration will be given to those currently relying on discretionary payments and to the elements of the existing schemes current beneficiaries find so valuable. The enhanced scheme will continue to include elements of financial and non-financial support.

3.24 The enhanced discretionary scheme will have an increased budget from 2018/19. As the winter fuel payment of £500, which until now required beneficiaries to make separate applications to the discretionary schemes, will now be included in the annual payments all beneficiaries receive, this policy change further increases the amount available through the new discretionary scheme for supporting those most at need.

One-off support to the bereaved

3.25 The consultation sought views on support for bereaved partners/spouses such as a lump sum payment and/or support from a discretionary scheme (questions 5 and 6). The vast majority of those who responded considered that there should be a choice of support (70%). We have also received letters describing the positive effect discretionary support has on families and we have heard from Members of Parliament who have expressed concerns on behalf of their bereaved constituents.

3.26 Therefore, all those who are bereaved will continue to have access to support from the existing discretionary scheme and of course the enhanced discretionary scheme going forward. In addition, there will be a new one-off lump sum payment of £10,000 to all those who were the partner or spouse of a primary beneficiary when they passed away and where infection with HIV and/or hepatitis C contributed to the death of their partner/spouse. This will apply to those already bereaved and newly bereaved in 2016/17 and during the spending review period. As mentioned above, this group will also continue to have access to the discretionary scheme in addition to the new £10,000 payment.

Elements we decided not to progress

Individual assessments

3.27 The consultation proposed that those with hepatitis C stage 1 would receive new annual payments on the basis of an individual assessment of the impact of infection on their health (question 2). The rationale for our proposal was that we wanted to provide most financial support to those who are most ill as a result of their infection.

3.28 We appreciate that the majority of respondents was not in favour of introducing individual assessments. Respondents considered they should not have to prove that they deserve annual payments – and we understand that. We also received additional advice from experts who considered that a fair and meaningful assessment based on evidence-based criteria covering clinical and other relevant information would be difficult to deliver without a face-to-face assessment that could be potentially onerous.

3.29 Thus, we decided not proceed with the proposal for introducing individual assessments. Instead, as described above, we will introduce a new flat rate annual payment for those with hepatitis C stage 1s from 2016/17 and the special appeals mechanism for those who consider they may qualify for stage 2 annual and lump sum payments (from 2017/18). This will help ensure that the reformed system is responsive to the most severely affected as a result of their infection.

Accelerated access to hepatitis C treatment

3.30 Finally, the consultation sought views on whether the scheme should provide enhanced access to the new hepatitis C drug treatment being rolled out by the NHS (questions 7 and 8). Over 70% of respondents felt that access to hepatitis C treatment should be part of the reformed scheme; however, of those who commented, 38% said that treatment should be provided by the NHS and not this scheme, and some argued that providing treatment through the scheme would amount to beneficiaries paying for their treatment.

3.31 Since launching the consultation in January, the NHS expects to increase the number of patients treated with new therapies to 10,000 in 2016/17, with numbers increasing to up to 15,000 per year in the following years.

3.32 In line with the consultation responses, and on account of the need for fairness towards all those in need of this NHS treatment, access to hepatitis C treatment for scheme beneficiaries will be provided by the NHS on the basis of clinical need in line with NICE guidelines. We have decided not to use funding available for the scheme to provide enhanced access to the new treatments. However, we will ensure the new scheme administrator works with the NHS to ensure that beneficiaries are signposted to, and made aware of, treatment services and the treatments available. We will also review how many beneficiaries are being treated and/or have already completed their treatment.

The Public Sector Equality Duty and the 'Family Test'

3.33 As we analysed the consultation responses and considered our proposals for scheme reform, we reflected on how our proposals affect the groups protected under the government's Equality Act 2010 and through the application of the 'Family Test'. This analysis is published as a separate document alongside this consultation response (*Equality Analysis – The Public Sector Equality Duty and Family Test: Consultation on Reform of Financial and Other Support*). We would advise you read this document alongside this response document.

Summary

3.34 We have listened carefully to the consultation responses and reviewed our initial consultation proposals in line with respondents' views and other evidence. Our package of reform described in this document, alongside the equality analysis, addresses the themes from the consultation responses set out in Chapter Two – an equitable new system of support that recognises those most at need and, importantly, is within the available funding envelope.

Chapter Four: Transition to a reformed scheme

Summary

This chapter summarises the changes that will happen this financial year and from 2017/18 when the reformed scheme comes into existence. Payments will be formally effective from next year. This year's payments will be backdated to April 2016 or to the date of joining the scheme if later.

As the four UK countries implement scheme reform for their jurisdictions, we also affirm our commitment to work with the governments in Scotland, Northern Ireland and Wales to ensure that transition is effected as smoothly as possible, communicated effectively and is fully transparent to all scheme beneficiaries affected by the changes.

4.1 This chapter sets out the arrangement for scheme reform during this spending review period (2016/17 to 2020/21).

Arrangements in 2016/17

4.2 The following arrangements will apply this financial year (in 2016/17):

- The current five schemes will continue to operate for the remainder of this financial year, covering both annual and discretionary payments to UK beneficiaries. Arrangements for the new single scheme administrator will be progressed with a view to it becoming operational in 2017/18.
- New hepatitis C stage 1 and increased annual payments for those infected with hepatitis C stage 2 or HIV of £3.5k and £15.5k respectively will be phased in and backdated to April 2016 where appropriate.
- Those progressing to hepatitis C stage 2 will receive the £50k lump sum and an increase in their annual payment from stage 1 to 2 (£3.5k to £15.5k). The specials appeal mechanism is part of the reformed scheme and will not be available this year.
- The one-off lump sum payment of £10,000 to all those who were the partner or spouse of a primary beneficiary when they passed away, and where infection with HIV and/or hepatitis C contributed to their death, will be available. This will apply to those already bereaved and newly bereaved partners/spouses and will be in addition to the support those qualifying already receive from the existing schemes.

Additional arrangements from 2017/18

4.3 The following additional arrangements will apply from 2017/18:

- The new single scheme administrator will become operational.
- The specials appeal mechanism for those at hepatitis C stage 1 who consider they may qualify for stage 2 support will be introduced in 2017/18.
- The new discretionary scheme will be available.
- Annual payments will be adjusted in line with a positive consumer price index (CPI).

Additional arrangements from 2018/19 and for the remainder of this spending review period to 2020/21

4.4 The following additional arrangements will apply from 2018/19:

- Annual payments for those at hepatitis C stage 1 will go up from £3.5k to £4.5k; and annual payments for those at hepatitis C stage 2 or HIV will go up from £15.5 to £18.5k (amounts will be adjusted in line with a positive CPI).
- We will look to enhance the financial provision for the discretionary scheme.
- Towards the end of the Spending Review period (2020/21), there will be a review of the workings of the reformed scheme to inform the next government. This review will particularly take account of the numbers being treated for Hepatitis C and the implications for the future operation of the scheme.

Outline proposals for the single scheme administrator

4.5 We are now working towards setting up a single body to carry forward the current schemes' functions and administer the elements of the reform described in this document. From 2017/18, the single scheme administrator will provide a quality service to all beneficiaries based on strong and transparent governance arrangements – outwith the Department of Health but with clear accountability to the Department.

Consideration of UK wide elements

4.6 The reformed scheme set out this document will apply in England only. The Scottish government has already published its policy for scheme reform in Scotland. It will be for ministers in Wales and Northern Ireland to decide how to provide for the beneficiaries within their jurisdictions.

4.7 The Department of Health is working with its colleagues in the Devolved Administrations and the current scheme administrators to ensure that any country specific arrangements for this financial year can be affected promptly. We will also work together to ensure that country specific arrangements for 2016/17 and beyond transition smoothly.

4.8 We are committed to ensuring that:

- 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.

- Changes will be clearly communicated to all existing beneficiaries in advance of the changes, who would also be directed to access other support, for example advice on benefits and managing their finances.

Data Transfer

4.9 Under the existing schemes, beneficiaries already provide certain personal information (name, address, HIV/hepatitis C status, bank details, etc.) to the relevant five organisations. When the single scheme administrator is introduced to replace these schemes, we will look to transfer a registrant's details from the existing schemes to the reformed scheme so that payments can be made efficiently. The exact mechanism for this will be determined as we are progressing with the implementation of the new administrator. However, this will be done sensitively and in accordance with data protection legislation. Of course, everyone will be notified in writing in advance and consent will be sought from everyone affected.

4.10 All personal information will be transferred and stored securely in compliance with the Data Protection Act 1998.

Next steps

4.11 We are now working towards setting up a single body to carry forward the current schemes' functions and administer the elements of the reform described in this document.

4.12 The current scheme administrators will continue to operate in their current form until the new scheme administrator is operational. We are working with the current scheme administrators to ensure that beneficiaries receive their payments for 2016/17 promptly and without delay, and that any changes will be clearly communicated to all existing beneficiaries.

4.13 As mentioned above, we are also working towards designing the new enhanced discretionary support scheme, and on the criteria and process for the new special appeals mechanism. All of these elements will be clear, transparent, easy to understand and applied fairly and consistently.

Annex A: Flow charts – what do the changes mean for me?

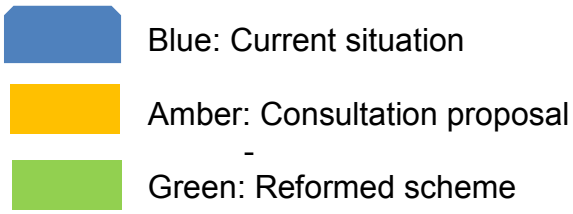
Summary

The below flow charts are intended to illustrate how the proposed changes in the consultation and the reformed scheme described in Chapters Two and Three, respectively, affect current and future scheme beneficiaries during this spending review period to 2020/21.

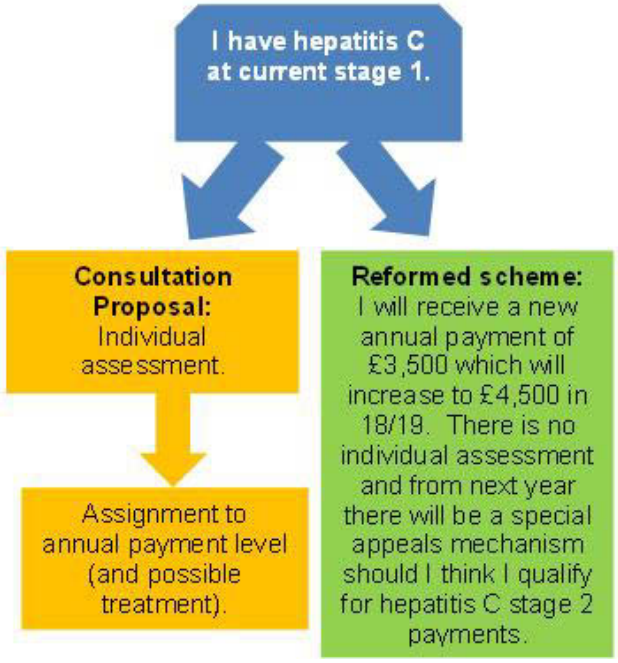
Note that all annual payments include the winter fuel allowance and will be CPI linked from 2017/18. All payments will continue to be ex-gratia, which means they are funded voluntarily by government. Payments will continue to be additional to any other income a beneficiary may receive, and are disregarded for the purposes of calculating income tax and eligibility for other state benefits. In addition, all annual payments will continue to be linked to the consumer price index (CPI) from next year.

All beneficiaries continue to have access to the current discretionary schemes and will have access to the new discretionary scheme from 2017/18.

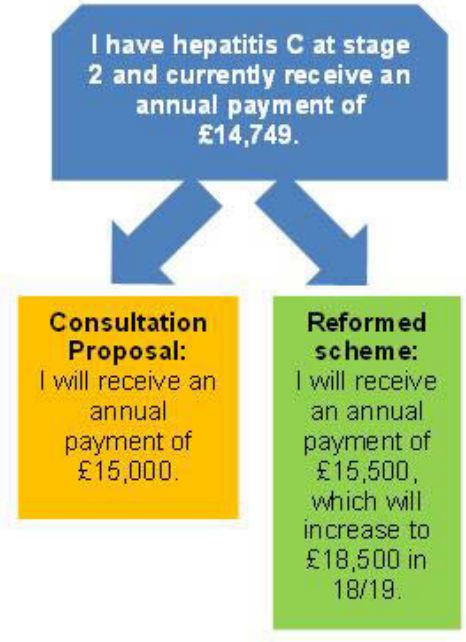
Legend:



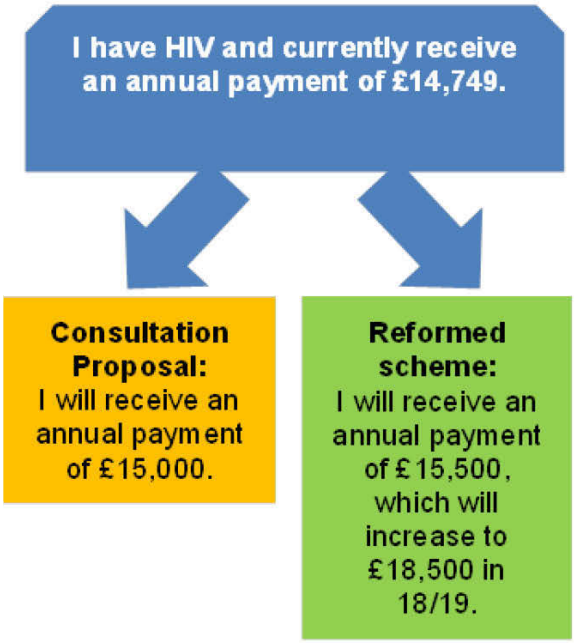
1. Current registrants with hepatitis C stage 1



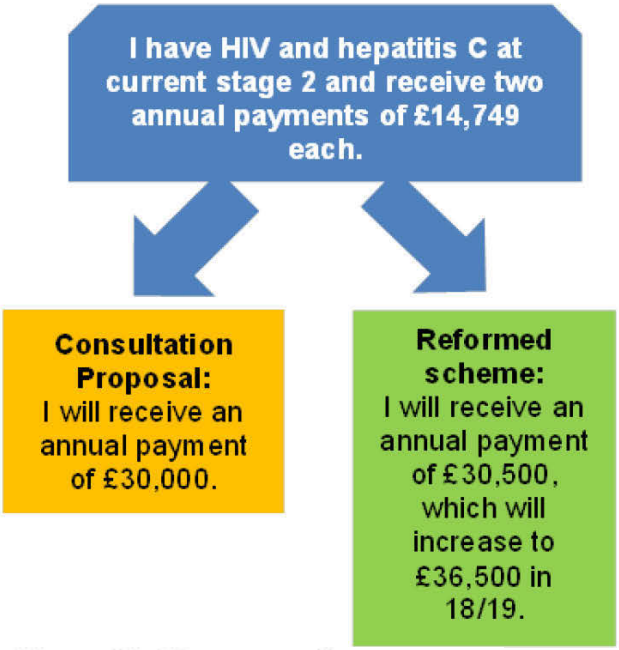
2. Current registrants with hepatitis C stage 2



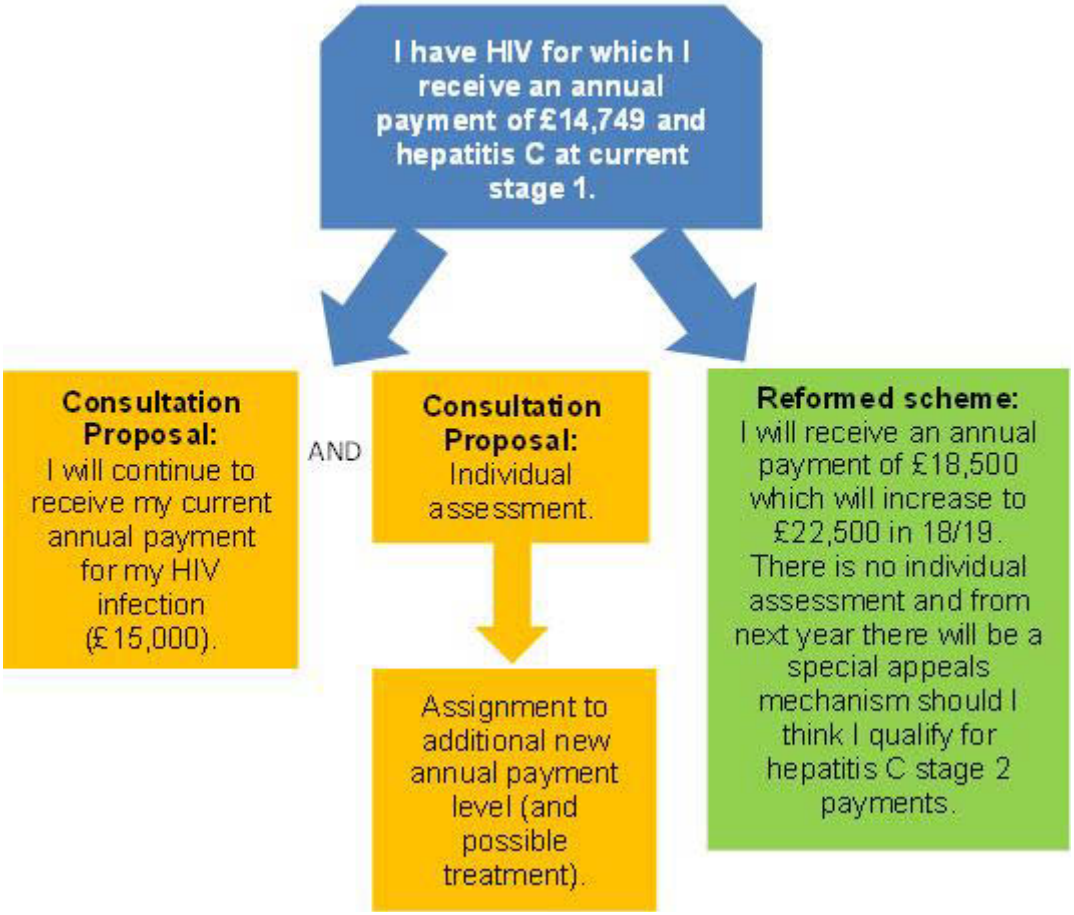
3. Current Registrants with HIV



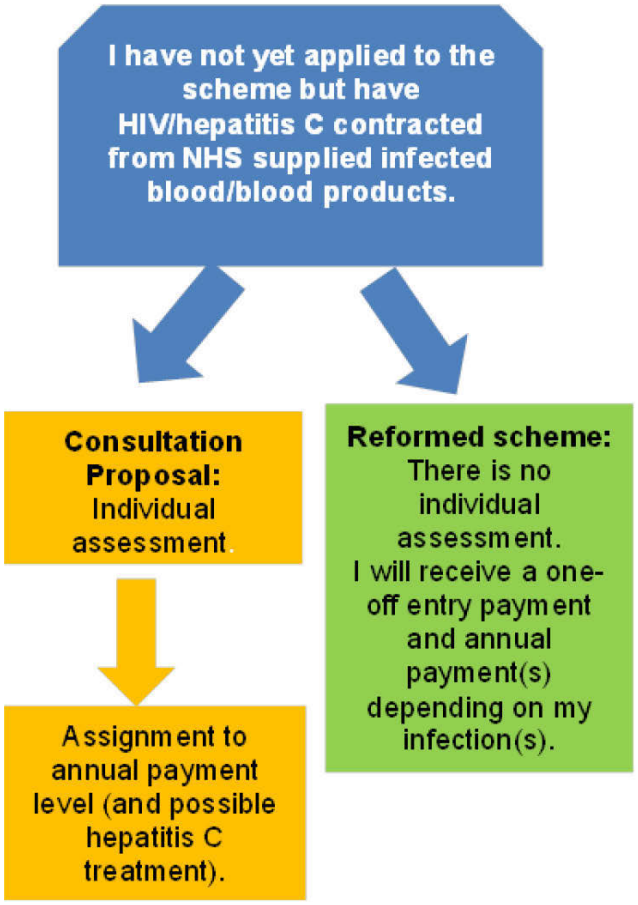
4. Current registrants with HIV and hepatitis C stage 2



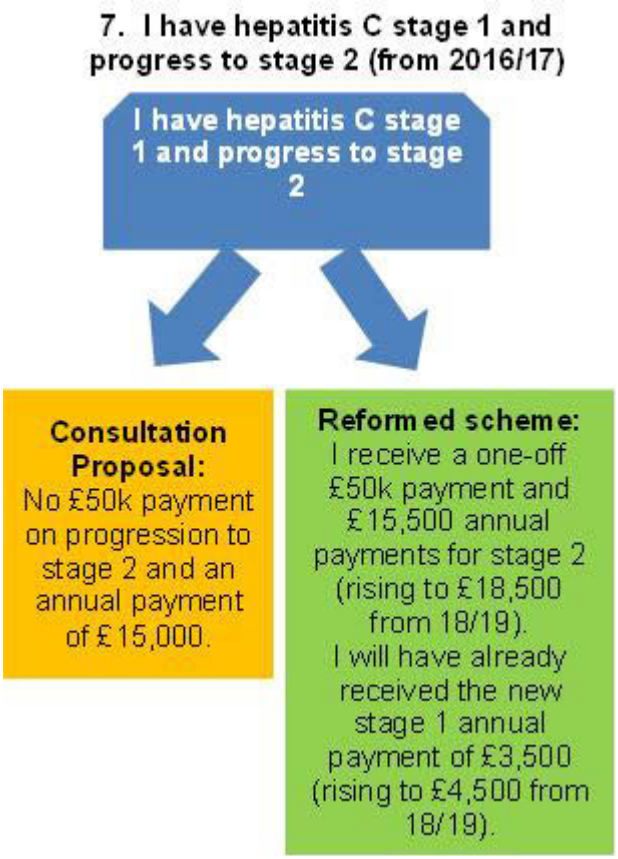
5. Current registrants with HIV and hepatitis C at stage 1



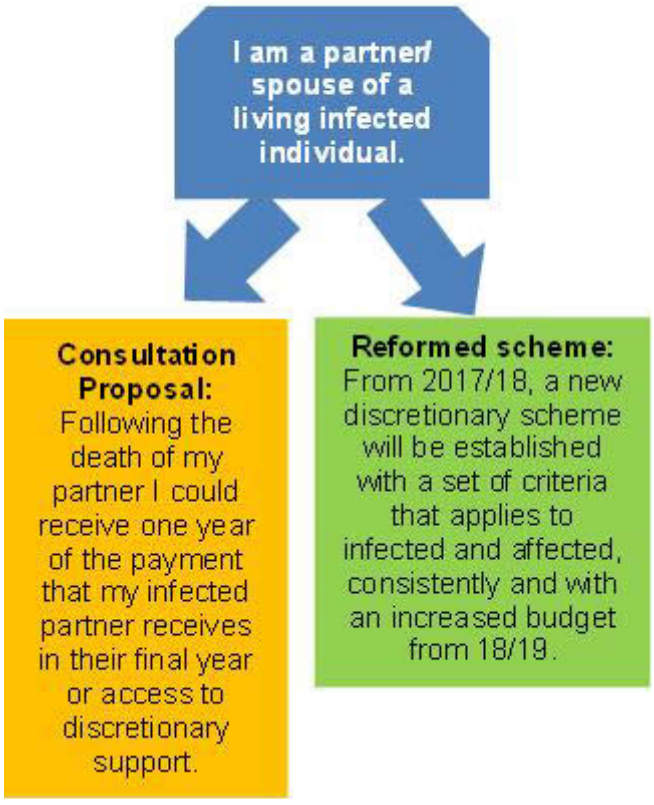
6. Future registrants of the scheme



7. I have hepatitis C stage 1 and progress to stage 2 (from 2016/17)



8. Partners/spouses of infected individuals



9. Bereaved partners/spouses