



Department
of Health

Government Response to Consultation on Special Category Mechanism and other support in England

October 2017

Title:

Infected blood: Government Response to Consultation on Special Category Mechanism and other support in England

Author:

Infected Blood Scheme Reform Policy

Document Purpose:

Consultation response

Publication date:

28 September 2017

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 schemes (the Macfarlane Trust, the Eileen Trust and the Caxton Foundation), MFET Ltd and Skipton Fund Ltd).

GPs

Nurses

Doctors

Royal Colleges

Social care providers

General public

Contact details:

Infected Blood Scheme Reform Policy

EPHPP

Department of Health,

Room 164

Richmond House

79 Whitehall

London SW1A 2NS

infectedbloodreform@dh.gsi.gov.uk

You may re-use the text of this document (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit www.nationalarchives.gov.uk/doc/open-government-licence/

© Crown copyright

Published to gov.uk, in PDF format only.

www.gov.uk/dh

Infected blood: Government Response to Consultation on Special Category Mechanism and other support in England

Prepared by

The Department of Health, England

Contents

Executive Summary	4
Introduction	5
Chapter One: what we did - how we ran the consultation exercise, who responded and how we analysed their responses	6
Building on the 2016 consultation	6
Information on consultation respondents	7
Analysing the responses	8
Chapter Two: analysis of responses.....	9
Question 1: Do you agree that we should add type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) to the current hepatitis C stage 2 conditions? Applicants would apply under the existing stage 2 process.....	9
Question 2: Do you agree with our proposal for how the SCM will assess whether an applicant is having a substantial and long-term adverse impact on their ability to go about their routine daily lives as set out in Annex B?	10
Question 3: We consider that the proposed payments make the best use of the available funding, allowing more hepatitis C stage 1 beneficiaries to benefit from increased annual payments while preserving the discretionary fund as far as possible. Do you agree?.....	11
Question 4: So that we can design the reformed discretionary scheme to meet the needs of beneficiaries in a way that is fair to all groups, which of the elements described in paragraph 2.36 would you find most useful in the new discretionary scheme.	15
Question 5: In light of our Equality Analysis published alongside this consultation, are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?	16
Chapter Three: introduction of payment uplifts, the Special Category Mechanism and other reforms	18
Chapter Four: transition to a reformed scheme.....	24
Annex A: The Special Category Mechanism (SCM)	27
Annex B: what does this mean for me?	38

Executive Summary

- i. The consultation on Infected Blood Support: special category mechanism ran from 6 March 2017 until 17 April 2017 and received just over 250 responses.
- ii. This document provides a breakdown of the consultation responses and an explanation of the reforms that will be introduced to the scheme.
- iii. The Government has listened to those responses and made improvements to the proposals contained within the consultation.

Special Category Mechanism

- iv. From November 2017, we're introducing the SCM to enable people with a stage 1 infection that's having a substantial and long-term negative impact on their daily lives to apply for the higher annual payments received by those with HIV or stage 2 hepatitis C infection.
- v. Following points raised in the consultation, we have made the application process as accessible as possible and will reimburse any reasonable costs of providing medical evidence.

Stage 2 Criteria

- vi. Type 2 or 3 cryoglobulinemia accompanied by MPGN is a complication of hepatitis C infection that requires dialysis and has a significant negative impact on life expectancy.
- vii. From November 2017, we'll add it to the current list of conditions that qualifies for hepatitis C stage 2 payments. We'll also backdate payments to April 2017.

Annual Payments

- viii. The Government has listened to the concerns raised by those who, under the 2017 consultation, were no longer going to be receiving annual payment uplifts in April 2018. In recognition of this we have identified additional funding so that the annual payment uplifts for all those infected, as announced in 2016, can be introduced from April 2018.

Discretionary Support

- ix. In recognition of the concerns raised in the consultation responses, we are increasing funding for discretionary support and harmonising the way it's allocated in a new fair, transparent and flexible system under the new administrator.
- x. The purpose of discretionary support is to provide additional, time-limited financial and non-financial support to you and your family. This is to address immediate infection-related needs that have a direct effect on your independence but are not otherwise being met.

Introduction

- 0.1 Since 1988, successive governments have 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 £450 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. In July 2016 the government issued its response to the January 2016 consultation: *Infected blood: Reform of financial and other support*, making £125 million of additional funding available until 2021 to support scheme beneficiaries.
- 0.3 Since then the Department of Health has been working to develop the proposed special appeals mechanism, now called the Special Category Mechanism (SCM). The SCM seeks to ensure that when the reformed Infected Blood Payment Scheme comes into effect and transfers to NHSBSA in November 2017, it reflects the impact of this tragedy on individuals fairly.
- 0.4 Responding to beneficiaries' call for more clarity about this new process we launched a consultation on the detail of the SCM, with proposals for ensuring the scheme remains within budget, on 6 March 2017¹. While we sought the views of the beneficiaries of the current schemes and their immediate family members in particular, the consultation was open to all to respond from across the UK. The consultation closed on 17 April 2017.
- 0.5 The government has listened carefully to the responses to its consultation. There were 253 formal responses to the consultation document, 12 Parliamentary Questions tabled, and many individual letters to Ministers and the Department of Health. In drawing up 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 fair and transparent in 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.
- 0.6 This document presents our analysis of the responses, our final plans for the new 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;

¹ The consultation document, equality analysis and impact assessment can be found here: <https://www.gov.uk/government/consultations/infected-blood-support-special-category-mechanism>

- Chapter Three describes the main elements of the reformed system taking account of what we have heard from respondents;
- Chapter Four explains the transition arrangements which will be put in place in 2017/18 and beyond; and
- Annex A includes the update SCM application form and Annex B illustrates what the reformed scheme will mean for individuals.

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 06 March to 17 April 2017 and contained 5 questions.

We received 253 consultation responses, of which 94% came from respondents who are eligible for the English scheme, 1% for the Scottish scheme, 2% for the Welsh scheme and 1% for the Northern Irish scheme². The majority of respondents were registered with one of the current payments schemes (88%) and of those who declared their group, 72% were infected with hepatitis C and 24% with HIV. 18% of respondents were immediate family members of an infected individual.

Building on the 2016 consultation

- 1.1 The infected blood payment scheme system has evolved in an *ad hoc* and incremental manner since it was set up. The five schemes³ were established on an infection-specific basis, at different times, 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 Department's January 2016 consultation outlined initial proposals for a reformed scheme. Since then we have rolled out the new and increased payments promised for the financial year 2016/17. For the first time, almost 2,500 beneficiaries with chronic hepatitis C infection (stage 1 infection) will have been eligible to receive an annual payment of £3,500. Those with advanced hepatitis C (stage 2) and HIV will have received an uplift in their

² 2% of respondents either did not know or chose not to answer this question.

³ 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.

annual payment to £15,500 and we introduced a new £10,000 payment for bereaved partners and spouses. We also signalled the intention to move to a single scheme administrator enabling more efficient and consistent delivery of the scheme.

- 1.4 The March 2017 consultation outlined the Department's aims to consolidate our commitment to ensuring the new scheme is fair and makes the best use of available funding. We proposed expanding the criteria for the current hepatitis C stage 2 payments by adding a condition, augmented our proposals for the SCM offering higher annual payments for hepatitis stage 1 beneficiaries and developed our proposals for a new single discretionary scheme. In addition we announced the appointment of the NHS Business Services Authority (NHSBSA) as the administrator for the new Infected Blood Payment Scheme.
- 1.5 When the consultation was launched on 6 March, letters were sent to all 2,910 individuals who were registered with 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. The Department of Health also engaged with several Members of Parliament who raised various issues on behalf of their constituents over the past year.

Information on consultation respondents

- 1.6 253 respondents replied to the consultation which closed on 17 April.
- 1.7 Across the UK, we received responses as follows:

Which scheme are you registered with?	No.	%
England	239	94%
Scotland	2	1%
Wales	4	2%
Northern Ireland	2	1%
I don't know	1	0%
Other/Not answered	6	2%

- 1.8 Additionally we received feedback during the consultation period from the Royal College of Physicians and the Hepatitis C Coalition⁴. Both organisations were supportive of our proposals and offered their endorsement.
- 1.9 We asked two questions to give us an understanding of the demographics of those who responded.
- 1.10 Firstly, we asked respondents about the nature of their infection. Most respondents indicated which group they belonged to:

⁴ The Hepatitis C Coalition is a group of leading clinicians, patient organisations and other interest parties with an interest in hepatitis C and the improvement of treatment and services.

Which of the following statements best describes your status?	No.	%
I have hepatitis C stage 1*	84	33%
I have hepatitis C stage 2*	49	19%
I am co-infected with HIV and hepatitis stage 1*	40	16%
I am co-infected with HIV and hepatitis stage 2*	10	4%
I am HIV positive but I am not infected with hepatitis C*	11	4%
I am immediate family (a widow, partner, dependant child) of someone infected with hepatitis C, HIV or both*	46	18%
Other/Not answered	23	9%

* from infected NHS supplied blood/blood products

- 1.11 Secondly, we asked whether respondents were registered with one of the current payment schemes. It should be noted that some individuals can be registered with more than one scheme. The breakdown is set out below:

Are you registered with one of the current payment schemes?	No.
The Macfarlane Trust (HIV charity)	71
The Eileen Trust (HIV charity)	1
The Caxton Foundation (Hep C charity)	98
The Skipton Fund (Hep C company)	197
MFET Ltd. (Hep C company)	39
None of the 5 schemes	8
N/A or Prefer not to say/Not answered	31

- 1.12 The current 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 are for beneficiaries infected in England. Wales, Northern Ireland and Scotland are responsible for the schemes in their respective countries. NHSBSA will act for beneficiaries infected in England.

Analysing the responses

- 1.13 The responses to the consultation provided a rich source of information on the views of the beneficiaries of the scheme and other interested parties. A small team was established to read and analyse the responses and to identify key themes (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 build a better understanding of both the quantitative and qualitative aspects of the responses.

Chapter Two: analysis of responses

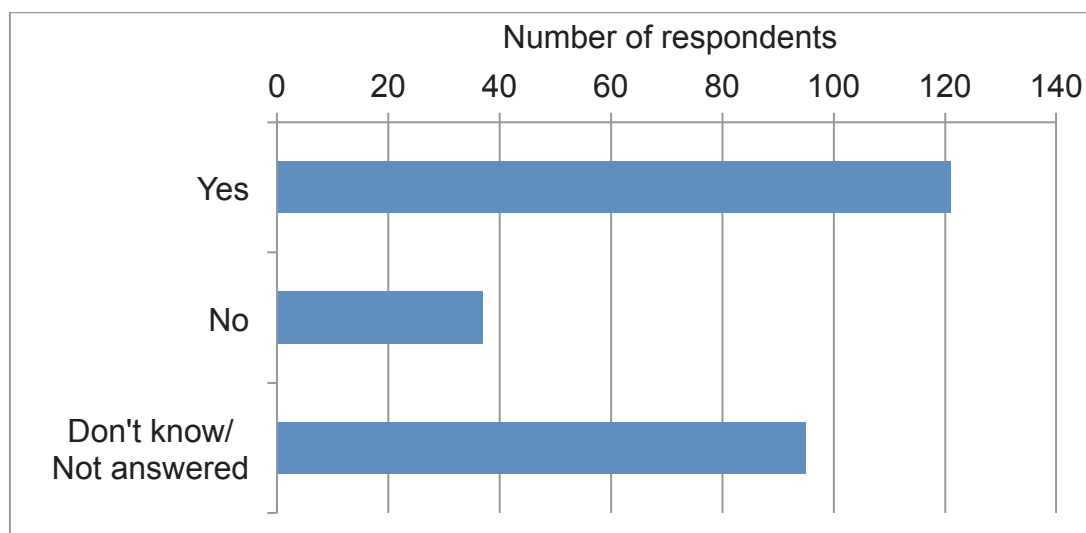
Summary

Our consultation questionnaire contained 5 questions about scheme reform and asked respondents to explain their answer. Given the diversity of affected groups impacted by infected blood 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 5 consultation questions and our analysis of the responses to these questions.

Question 1: Do you agree that we should add type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) to the current hepatitis C stage 2 conditions? Applicants would apply under the existing stage 2 process.

- 2.1 Type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) MPGN is a known complication of hepatitis C infection and those suffering from it require dialysis. A Department of Health reference group advised that MPGN has a comparable or even greater negative impact on life expectancy when compared with cirrhotic liver disease or its complications. We therefore propose to add MPGN to the current stage 2 indicators from November 2017. The chart below sets out the responses:

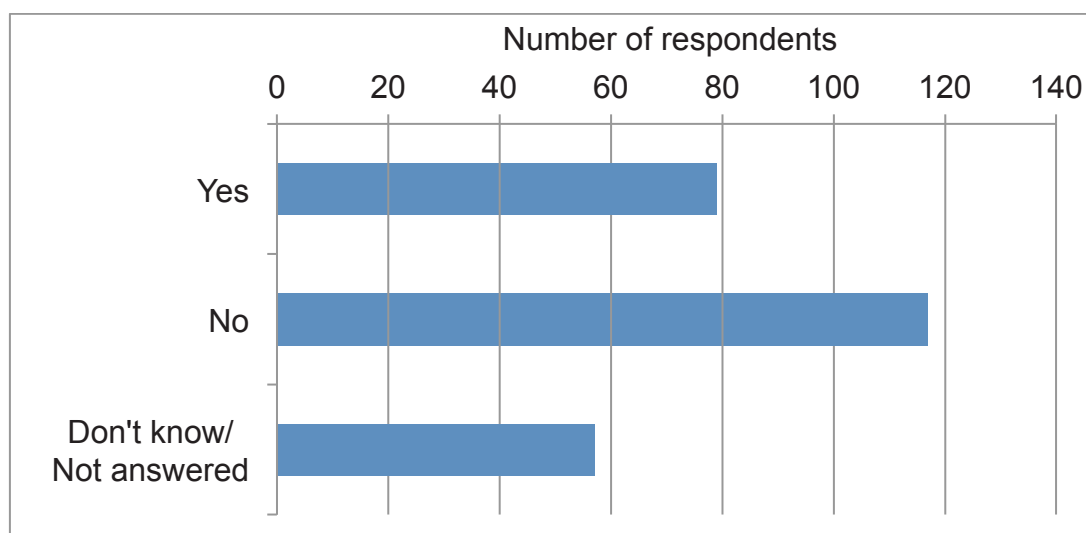


- 2.2 48% of respondents agreed that type 2 or 3 cryoglobulinemia accompanied by MPGN should be added to the current hepatitis C Stage 2 conditions. Of those who provided comments, many correspondents recognised this as a hepatitis C related condition and agreed that it should be added to the Stage 2 conditions.
- 2.3 35% of respondents indicated that they did not know. The most common reason for this response was that many respondents felt that they were not fully qualified or well-informed enough to answer the question.

- 2.4 A smaller number of respondents (15%) said that they did not agree with this proposal. The most common reason for this was concern that money would be reallocated from other payments or types of support to fund this proposal.

Question 2: Do you agree with our proposal for how the SCM will assess whether an applicant is having a substantial and long-term adverse impact on their ability to go about their routine daily lives as set out in Annex B?

- 2.5 Question 2 asked beneficiaries whether they agreed with the proposal for how the SCM would assess an application for increased annual payments. This proposed SCM gives any stage 1 beneficiary the opportunity to apply for increased annual payments equivalent to those with HIV or stage 2 disease, if they consider the adverse impact of their hepatitis C infection (or its treatment) is having a substantial and long-term impact on their ability to carry out routine day-to-day activities.
- 2.6 The SCM was initially proposed to enable stage 1 beneficiaries who were experiencing an equivalent impact on their health as those with a hepatitis C stage 2 condition to apply for the same payments as those with hepatitis C stage 2. In developing the criteria and process, we listened to beneficiaries' expectations, consulted with our Reference Group, and took into account the government's obligations under the Equality Act 2010. As a result, we propose to broaden eligibility for a higher payment in order to benefit a wider group of stage 1 individuals than initially envisaged.



- 2.7 40% of definitive responses indicated that they agreed with our proposal. Comments from these respondents expressed concern about the distribution and source of funding for the SCM. Respondents also commented that assessments for SCM applications should be carried out by specialist medical professionals.
- 2.8 46% indicated that they did not agree with the SCM proposal for how beneficiaries would be assessed and a smaller number of respondents (19%) said they did not know. The most common reasons for both were:

- Assessments should not be conducted in order for applicants to prove eligibility for further payments, rather, anyone infected with Hepatitis C at stage 1 should receive the same increased payments automatically
- The process to introduce the SCM would be expensive and time consuming for the scheme to administer. Respondents felt that it would be more efficient and effective to introduce increased annual payments.
- Assessments will be difficult to conduct and assess fairly, given that beneficiaries have other health ailments that occur which are not directly caused by hepatitis C infection alone or may be difficult to provide medical evidence for
- Concern regarding the way in which the SCM is being funded, in particular by not proceeding with proposed uplifts to annual payments from 2018/19 onwards

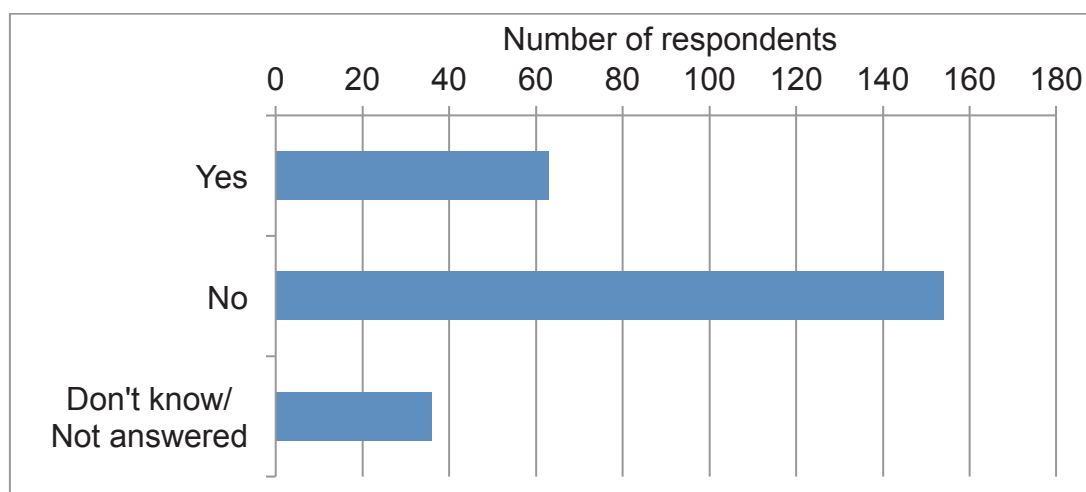
Question 3: We consider that the proposed payments make the best use of the available funding, allowing more hepatitis C stage 1 beneficiaries to benefit from increased annual payments while preserving the discretionary fund as far as possible. Do you agree?

Annual payment figures will be increased with CPI in 2017/18 and subsequent years.

- The basic annual payment for those with hepatitis C stage 1 infection is £3,535.
- Those with hepatitis C stage 2 disease will receive an annual payment of £15,655.
- Those infected with HIV will receive an annual payment of £15,655.
- Those with hepatitis C stage 1 who are successful under the SCM will receive an annual payment of £15,655 (equivalent to the annual payment for those with HIV or hepatitis C stage 2).
- Those co-infected with HIV and hepatitis C stage 1 will receive an annual payment of £18,685.
- Those co-infected with HIV who have hepatitis C stage 2 or have hepatitis C stage 1 and who successfully apply under the SCM will receive an annual payment of £30,805.
- All annual payments include a £500 winter fuel payment.
- The £50,000 lump sum remains reserved to those who develop a hepatitis C stage 2 condition. It is not paid to stage 1 beneficiaries who receive higher annual payments as a result of the SCM.

Note - As set out in March 2017 consultation

2.9 We sought views on whether the introduction of the SCM and the associated proposals regarding the £50,000 lump sum payment, annual payments increasing in line with CPI and the retention of a discretionary fund make best use of the available funding.



2.10 26% of respondents who answered this question thought that the proposals made best use of available funding. When analysing the comments of those who responded no or don't know, 10% of those expressed their support for the proposals although they had some concerns about the overall level of funding available. A further 16% of those who responded no or don't know were supportive of the SCM if annual payments increased in line with proposals set out in the government's response to the January 2016 consultation that were as follows

	2016/17	2018/19
hepatitis C stage 1	£3,500	£4,500
Severe hepatitis C (stage 2) or HIV	£15,500	£18,500
HIV and hepatitis C stage 1,	£18,500	£22,500
HIV and hepatitis C stage 2	£30,500	£36,500

2.11 Of those who provided comments expressing concern over the proposals, the most common themes were:

- More money should be made available overall in order to fund the scheme and provide additional support for beneficiaries and their families.
- Funding for the scheme should be guaranteed beyond the current spending review period.
- Those infected with HIV and/or those who are co-infected would be most impacted by the proposals.
- The discretionary fund should be maintained as it is valued by many beneficiaries (although a small minority of respondents commented that the discretionary fund should be removed).
- Concerns regarding the inconsistencies in support provided across the UK.
- No significant comments were made in relation to the £50,000 lump sum remaining reserved for those who develop HCV stage 2 criteria.

Question 4: So that we can design the reformed discretionary scheme to meet the needs of beneficiaries in a way that is fair to all groups, which of the elements described in paragraph 2.36 would you find most useful in the new discretionary scheme.

The types of support the reformed discretionary scheme may provide in the future are:

- Discretionary payments for travel and accommodation relating to ill health;
- Payment of prescription pre-payment certificates;
- Means tested grants for dealing with unexpected/immediate problems and acute events or health problems which are difficult or impossible to plan for and where support is not available elsewhere. This may include support with mobility, shelter, home adaptations and repairs and respite;
- Regularly reviewed means tested income top-ups;
- Winter fuel payments for bereaved family members;
- Funeral related expenses for bereaved family members;
- Means tested supplementary support for orphaned dependants and the children of primary beneficiaries who are under 21 and in full time education;
- A range of non-financial support and signposting including:
 - i. NHS, Social Care and wider Welfare System referrals
 - ii. Financial management advice and support
 - iii. Career and education advice and coaching
 - iv. Counselling and emotional support

Note - As set out in March 2017 consultation

2.12 In question 4, we sought views on reform of the discretionary element of the scheme. Respondents were invited to provide comments on what discretionary support they would most value from the new scheme in and why.

2.13 In response to the types of support listed in the consultation document:

- 20% of respondents were supportive of payments for travel and accommodation relating to ill health
- 22% of respondents were supportive of payment of prescription pre-payment certificates
- 24% of respondents were supportive of payments in support of bereaved family members
- 21% of respondents were supportive of means tested income top-ups and grants for dealing with unexpected/immediate problems where support is not available elsewhere
- 21% of respondents were supportive of non-financial support
- 5% of respondents said that there should be no means tested elements of support

This question on types of support provided a free text box for respondents to make further comments, therefore, more than one option may have been chosen by individuals.

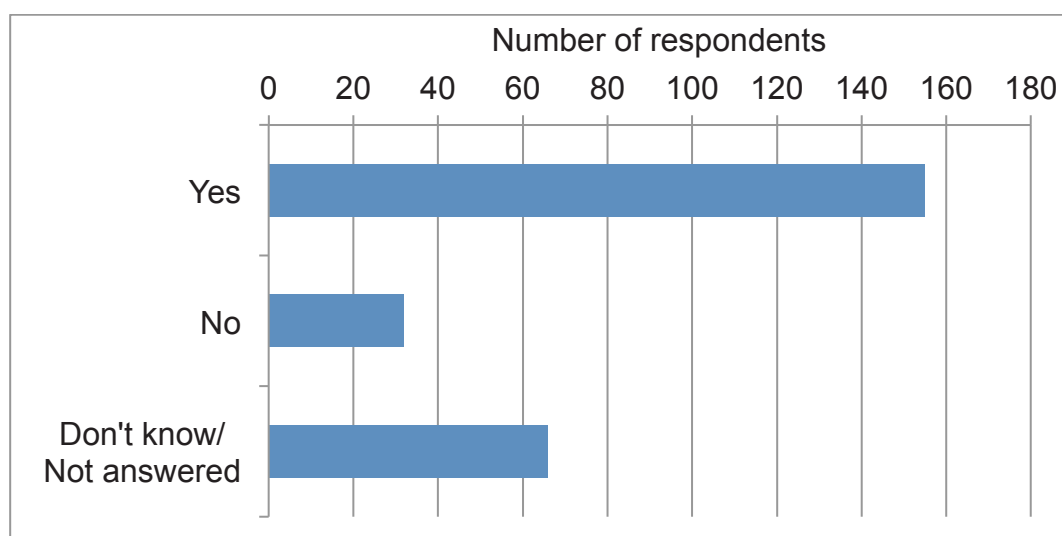
2.14 Further points that emerged in the comments were:

- Recognition of the mental health effects that many beneficiaries suffer from and ensuring due consideration of this in any non-financial support arrangements
- Some considered 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
- Understanding the particular experience and knowledge possessed by the existing schemes and the need to ensure that is maintained through the transfer to the new scheme

2.15 Some respondents said that they did not feel well placed to respond as they were only able to give a view on what types of discretionary support would be most beneficial for themselves

Question 5: In light of our Equality Analysis published alongside this consultation, are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals?

2.16 Finally, our last question asked about the impact of our proposals on any particular group of individuals. 241 (95%) respondents answered this question.



2.17 65% of respondents answered yes. The most common concerns were:

- Those who are co-infected, infected with HIV or infected with hepatitis C at stage 2 would not receive the higher annual payment

that was anticipated which does not reflect the more serious nature of their conditions.

- Those infected with hepatitis C at stage 1 should receive an annual payment at the same level as other beneficiaries due to the considerable effect infection at stage 1 can have on an individual
- There is no guaranteed provision for bereaved spouses who are particularly vulnerable after dedicating much of their lives to caring for their partners
- There is no provision for support for bereaved children or parents
- All beneficiaries should receive the same level of annual payment and that categorisation of infections should be removed.

Conclusion

2.18 From this analysis it is clear that a significant proportion of respondents are supportive of our proposals, although some remain concerned about specific elements. Our analysis of the comments that these respondents provided suggest that there is, in principle, support for the proposals to introduce the SCM and to maintain the discretionary scheme, although concerns about the overall level of funding remained.

2.19 The Department of Health remains committed to the principle of a fair scheme that ensures all those affected by this tragedy are supported and it is on this basis that we have decided to proceed with the proposals set out in the consultation. The Department does acknowledge the concerns of respondents and the need to provide further information and clarity about elements of our proposals which are set out in the next chapter.

Chapter Three: introduction of payment uplifts, the Special Category Mechanism and other reforms

Summary

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.

This Chapter sets out our improved plans for reform, specifically the introduction of payment uplifts from 2018/19 previously announced in 2016, introduction of the Special Category Mechanism and a new programme of discretionary support, as well as detail regarding other proposals in the consultation:

- The continuation of annual payments for those infected with severe hepatitis C (stage 2) or HIV of £15,655 in 2017/18 rising to £18,500 from 2018/19.
- The continuation of annual payments for those with hepatitis at stage 1 of £3,535 rising to £4,500 in 2018/19.
- A new Special Category Mechanism (SCM) for those with hepatitis C infection at stage 1 in November 2017
- Those with hepatitis C stage 1 who are successful under the SCM will the higher annual payment 2017/18, this will rise to £18,500 from 2018/19 (equivalent to the annual payment for those with HIV or hepatitis C stage 2).
- Annual payments for those co-infected with HIV and hepatitis C stage 1, annual payments will be £18,685 in 2017/18, rising to £22,500 in 2018/19.
- For those co-infected with HIV and hepatitis C stage 2, annual payments will be £30,805 in 2017/18, rising to £36,500 from 2018/19.
- All annual payments include the winter fuel payment
- Addition of type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis, MPGN), to the current hepatitis C stage 2 conditions
- The introduction of a single programme of discretionary support for all - infected and bereaved
- An increase in the overall level of funding for discretionary support in 2018/19

All aspects of the reformed scheme will be run by NHS Business Service Authority (NHSBSA).

- 3.1 The government is committed to creating an accessible and fair system of support that focuses on the welfare and long-term independence of infected individuals. The challenge is to establish a reformed scheme that will be run by NHSBSA, which is fair to all, 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 to 2020/21.

- 3.2 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 a system of support that recognises those most at need. That is why we have identified additional funding so that uplifts to annual payments can be introduced from 2018/19. All payments will continue to be tax free and disregarded if applying for welfare state benefits.

Type 2 or 3 cryoglobulinemia accompanied by MPGN

- 3.3 From November 2017 type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN) will be added to the current list of conditions that would qualify a beneficiary for hepatitis C stage 2 payments. The majority of respondents agreed with this proposal and while a number of respondents felt they did not have the knowledge or expertise to give a view, experts that we have consulted with have advised of the seriousness of the effects of this condition. MPGN is a known complication of hepatitis C infection and has a comparable or even greater negative impact on life expectancy when compared to cirrhotic liver disease or its complications.
- 3.4 This would mean that hepatitis C stage 1 beneficiaries who have been diagnosed with MPGN (or any of the existing stage 2 conditions) would be able to apply for the higher annual payment of £15,655 in 2017/18 (rising to £18,500 from 2018/19) and the £50,000 lump sum payment through the existing stage 2 process. In order to maintain the consultation proposal to add MPGN to the list of hepatitis C stage 2 conditions in April 2017, all payments will be backdated to April.
- 3.5 As was stated in the consultation, we will continue to keep scientific literature under review for possible inclusion of other hepatitis C related complications to the stage 2 criteria based on life expectancy.

Special Category Mechanism

- 3.6 In our consultation we stated our intention to recognise the adverse impact hepatitis C infection at stage 1 (or its treatment) can have on an individual's ability to carry out routine day-to-day activities by introducing a Special Category Mechanism. This would enable stage 1 beneficiaries to apply for increased annual payments equivalent to those with HIV or stage 2 disease. Many respondents (40%) agreed with our proposal and the greater fairness it would offer to those stage 1 beneficiaries who experience substantial and long-term adverse impact to their health.
- 3.7 As a result, the SCM will be introduced and operated by the new scheme administrator, the NHSBSA, from November 2017. As proposed the SCM will be a wholly voluntary and largely paper-based application process. However,

we have listened to the concerns some respondents had about the length and complexity of the application form and the risk that this could discourage some beneficiaries from applying. Therefore we have made the application form more user-friendly and accessible. The updated application form can be found at Annex A.

- 3.8 We have also listened to concerns respondents had regarding the need for a medical expert to assist with the application process. As we outlined in the consultation, the expectation is that the required medical evidence to support the application will be provided by a hospital consultant or viral hepatitis nurse as they are likely to have a detailed understanding of the individual's condition. However we understand that in some cases a GP will be best placed to provide this evidence, such as when the individual is not in regular contact with a consultant or hepatitis nurse. The commitment to reimburse any reasonable cost incurred in obtaining medical evidence remains.
- 3.9 We have also listened to calls to ensure that applications are considered by those with relevant experience and expertise. In recognition of this we have prioritised this in our discussions with the new scheme administrator. In addition, appeals will be heard by an independent group of experts.
- 3.10 Applications for the SCM will open on 1 November 2017. Any application received within 8 weeks of this date, if successful, will be eligible for higher payments backdated to 2 October 2017. This will ensure applicants do not lose any value in their annual payments whilst the new scheme administrator processes the anticipated high level of applications. After this period all payments linked to successful application for the SCM will be backdated to the date on which the application is received by the scheme administrator.
- 3.11 Beneficiaries who are unsuccessful in applying for higher annual payments via the SCM (with or without an initial appeal) will be limited from reapplying for a period of 6 months (beginning from the date the application was originally received by the scheme administrator), with the expectation that new evidence will need to be provided in order for such cases to be considered.

Discretionary support

- 3.12 Although a small number of respondents thought that funding for the discretionary support should be redirected toward annual payments many more made clear that discretionary support remains an important and valued component of the support that beneficiaries and their families receive. In response, we therefore will be increasing the amount of overall discretionary funding available.
- 3.13 However, we want to ensure a new discretionary scheme continues to provide a valuable form of support for all beneficiaries and their families. As we move to a new discretionary scheme that, for the first time, harmonises the fragmented nature of the existing support arrangements it is important to

clearly state the purpose of the discretionary payments:

- 3.14 *'The purpose of discretionary support is to provide additional, time-limited financial (and non-financial) support to beneficiaries and their families in order to address immediate needs. Such needs are considered as those that have a direct effect on an individual's independence, have been brought about as a result of their infection or its treatment and are otherwise unable to be met.'*
- 3.15 This purpose statement is broadly underpinned by the principles that were set out in the consultation, serving as a guide to the scheme administrator in how it operates the scheme, assesses eligibility and allocates support and generally engages with individuals. The principles the new scheme will follow are:
- Fairness – The scheme will treat each applicant fairly and equitably, basing its decisions on individuals' needs and financial hardship within the overall affordability of the scheme.
 - Transparency – The scheme will be open in its decision making process, with an appeals process available for all applicants
 - Flexibility – The scheme will be responsive to the needs and circumstances of individuals, ensuring a person centred approach and will be responsive to the changing nature of needs over time.
- 3.16 Respondents were broadly in favour of the types of discretionary support proposed in the consultation. We have listened to this and will ensure the following elements are incorporated within the new discretionary support system:
- Discretionary payments for travel and accommodation relating to ill health;
 - Payment of prescription pre-payment certificates;
 - Means tested grants for dealing with unexpected/immediate problems and acute events or health problems which are difficult or impossible to plan for and where support is not available elsewhere. This may include support with mobility, shelter, home adaptations and repairs and respite;
 - Regularly reviewed means tested income top-ups
 - Winter fuel payments for bereaved family members
 - Funeral related expenses for bereaved family members
 - Means tested supplementary support for orphaned dependants and the children of primary beneficiaries who are under 21 and in full time education
 - A range of non-financial support and signposting including:
 - i. NHS, Social Care and wider Welfare System referrals
 - ii. Financial management advice and support
 - iii. Career and education advice and coaching
 - iv. Counselling and emotional support

- 3.17 In providing this support the aim is to strengthen financial independence in order that individuals are not wholly reliant on long-term discretionary financial support. Key to this will be the non-financial practical elements incorporated into the scheme's remit. As well as signposting to relevant organisations and agencies, financial advice and support in navigating wider welfare system processes, the support will include access to counselling and employment and training advice services. Respondents have told us of the considerable strain their infection and its treatment has had on their mental health and the value that counselling and other support services can have in alleviating this. Similarly, many respondents have spoken of their desire to increase their financial independence. Where beneficiaries feel able to develop their skills and find employment, the scheme will support them in doing so by providing access to careers support and coaching services.
- 3.18 Grants to provide support for those affected by an unexpected event or an acute need will continue to be available. These means tested payments will be made to assist with immediate short-term needs that present a serious risk to the health and safety of the individual or their family. Support for longer-term needs may also be provided, for example where an individual requires a home adaption or mobility assistance.
- 3.19 To ensure discretionary support in the new, single, scheme is balanced, consistent and fair to all beneficiaries, the scheme administrator will conduct a review of all regular on-going payments such as income top ups. A decision on eligibility will be made on the basis of overall income and individual need. On-going support will continue to be considered and provided through means tested income top ups, however, such payments are likely to be at a lower level than existing payments and will be reappraised on an annual basis to ensure a model with greater consistency and sustainability. Where payments may be discontinued or reduced, the move will be phased in over a period of time in order to avoid an immediate reduction in payments received.
- 3.20 We have listened to respondents' particular concerns about support available for bereaved spouses or partners. Reviews of regular ongoing payments to the bereaved will recognise the impact that the loss of a partner will have had in both the immediate and longer term and will afford bereaved individuals more time to adjust to their new situation and to move toward financial independence in a maintainable and responsible way. As proposed in the consultation, we will include winter fuel payments to the types of support available for the bereaved, in addition to all other types of discretionary support. Furthermore, we will include funeral related expenses to the types of support available to the bereaved through the new discretionary scheme. The one-off £10,000 payment to bereaved partners and spouses will also continue to be available. Combined these changes will ensure bereaved spouses or partners continue to be supported.
- 3.21 Together these changes help to ensure sustainability by providing a maintainable level of support for recipients and by encouraging individuals to consider their longer term as well as immediate needs.

Payments schedule

- 3.22 Respondents were supportive of the expansion of the hepatitis stage 2 criteria, the greater fairness in how different groups of beneficiaries are treated with the introduction of the SCM and the value to respondents of keeping the discretionary scheme. In order to ensure the scheme remained within its funding envelope until April 2021, the consultation set out annual payments that would remain at current levels until the end of the Spending Review period, but would increase in line with Consumer Price Inflation (CPI) to compensate for any loss in value of this payment. In addition the £50k lump sum will remain only for those who progress to stage 2.
- 3.23 However, we heard and understood the disappointment of respondents who had anticipated receiving higher annual payments from 2018/2019. The proposal as set out in the government's response to the 2016 consultation will still be introduced and beneficiaries will receive the higher annual payments from 2018/19.
- 3.24 We believe that these plans are a fair and reasonable distribution of the available funding, ensuring that all those affected by this tragedy are supported to meet their needs.
- 3.25 In summary, annual payments as set out in the below table, include the annual winter fuel payment and are not taken into account in applications to the welfare system and are tax-free. Please see also Annex B which shows how the proposed changes may affect existing beneficiaries.

Annual payments	Annual payments in 2017/18	Annual payments in 2018/19
hepatitis C stage 1 without SCM	£3,535	£4,500
hepatitis C, stage 1 with SCM	£15,655	£18,500
hepatitis C, stage 2	£15,655	£18,500
HIV	£15,655	£18,500
Co-infected with HIV and hepatitis C stage 1	£18,685	£22,500
Co-infected with HIV and hepatitis C stage 2	£30,805	£36,500

The Public Sector Equality Duty and the 'Family Test'

- 3.26 As we analysed the consultation responses and considered our plans for scheme reform, we reflected on how they 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 – Infected blood: Consultation on Special Category Mechanism and financial and other support in England*).

Chapter Four: transition to a reformed scheme

Summary

This chapter summarises the changes that will happen through the year 2017/18 when the new scheme comes into effect, notable the move to the new single scheme administrator, the NHS Business Services Authority (NHSBSA)

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 to the end of this spending review period, 2020/21.

Changes taking effect in 2017/18

4.2 The following arrangements will apply in 2017/18:

- The new single scheme administrator, NHSBSA, will be operational from 1 November 2017.
- The SCM for those with hepatitis C stage 1 who consider they may qualify for higher annual payments will be open for applications from 1 November 2017.
- The new discretionary scheme will be operational from 1 November 2017.

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

4.3 From April 2018, all annual payments will be uplifted as outlined earlier in this document and from 2019/20 the annual payments will be increased in line with CPI.

4.4 Toward the end of the current Spending Review period (2020/21), there will be a review of the workings of the reformed scheme.

Move to the single scheme administrator – the NHSBSA

4.5 The transition to a new discretionary scheme will entail some key changes in the way the scheme is administered. For the first time all beneficiaries of any of the current five schemes will be receiving support from a single scheme administrator, the NHSBSA. This will allow for a more fair and consistent

scheme, that shares resources amongst all affected individuals and applies the same core principles to each case.

- 4.6 As far as possible, we will ensure that the transition is smooth and seamless. Beneficiaries already provide certain personal information to the organisations that operate the existing schemes. When the NHSBSA take over as the single scheme administrator, registrants' personal information and details will be transferred from the existing schemes to the new scheme, ensuring that payments are made in a timely fashion. This will be done in accordance with the Data Protection Act 1998 taking account of the sensitive and confidential nature of this information.
- 4.7 The launch of the new scheme will also be the start of a new relationship between the scheme administrator and beneficiaries. Equally important to the transfer of data and processing of payments will be the new scheme administrator's understanding of the conditions and personal circumstances of beneficiaries and their families. Beneficiaries and their families will be accustomed to engaging with dedicated schemes and will require reassurance and confidence that their needs are well understood. The Department of Health recognises the importance appropriately skilled staff and medical experts have in the effective administration of the scheme. We have therefore required the NHSBSA to ensure that the role of such staff and medical experts is maintained in the new scheme.
- 4.8 Finally, we are keen to ensure beneficiaries continue to have an open line of communication with the scheme administrator. The NHSBSA will maintain a service that will allow beneficiaries to speak with the scheme administrator directly in order to raise queries and requests. Additionally the new scheme administrator will be inviting participation from beneficiaries to provide feedback and comment on the operation of the new scheme. More details will be communicated by NHSBSA once they become the new scheme administrator.

Consideration of UK wide elements

- 4.9 The reformed scheme as set out this document will apply in England only. The Scottish and Welsh governments have already published their policy for scheme reform and new ministers in Northern Ireland will decide how to provide for the beneficiaries within their jurisdiction in due course.
- 4.10 The Department of Health is working with its colleagues in the Devolved Administrations and the current scheme administrators to ensure that existing payments are being made to beneficiaries across the UK.
- 4.11 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 impact on individuals.

Next steps

- 4.12 The current scheme administrators will continue to operate the existing five schemes until the new scheme and new scheme administrator are operational. We are working with the current scheme administrators to ensure that beneficiaries receive their payments through the remainder of the first half of 2017/2018 and without delay. From November 2017 payments to all beneficiaries will be received from the NHSBSA.
- 4.13 Further information regarding the new scheme administrator, contact information and any other changes will be communicated in due course ahead of the launch of the new scheme in November.

Annex A: The Special Category Mechanism (SCM)

This section includes guidance notes and the application form for the SCM process.

Guidance Notes

Please read these notes before completing the application form attached at the end of these notes.

Applicant's notes for completing the application form

Please complete the application form if you believe that your hepatitis C infection, or its treatment, complications, or a condition caused by the infection is affecting your ability to carry out everyday activities.

You will need to contact your hospital consultant or viral hepatitis nurse to complete the form, as your application will need their medical evidence to confirm the impact the infection is having. Together you will need to complete, sign, and date the form before sending it to us.

If you are not being seen by a hospital doctor or viral hepatitis nurse, please contact the scheme administrator who will be able to advise you about who could help you with this form.⁵

If you have to pay to obtain medical evidence at this stage, the scheme administrator will pay you back in full.

Please complete:

either Section A *or* Section B (whichever of the two is the most appropriate to your situation)

and Section C.

Section A – Evidence that you have a hepatitis C associated condition

Complete **Section A** of the form if you have *one of the diseases listed there*.

If the evidence confirms that you have one of the conditions listed at the start of Section A, you will be successful in your application.

You must:

- complete the first part of Section A; and
- sign and date the declaration at Section C.

Your hospital doctor (or viral hepatitis nurse) must:

- complete the second part of Section A and provide supporting medical evidence;
- provide an overall clinical assessment at Section C; and
- sign and date the declaration at the end of Section C.

⁵ Your GP may be an acceptable alternative, but we would prefer the evidence to come from the hospital service treating you.

Section B – Evidence that your hepatitis C is having a substantial and long- term adverse effect on your ability to carry out daily activities

If you do not have any of the diseases listed in Section A, please complete **Section B** with the help of your hospital doctor or viral hepatitis nurse.

You must

- complete the first part of Section B: and
- sign and date the declaration at Section

Your hospital doctor (or viral hepatitis nurse) must:

- complete the second part of Section A and provide supporting medical evidence;
- provide an overall clinical assessment at Section C; and
- sign and date the declaration at the end of Section C.

This section looks at whether your infection, or its treatment or complications, are causing mental health problems or tiredness that affect what you can do, day to day. The form asks for supporting statements about this from you and your doctor or nurse.

To be successful in your application, the evidence must need to show that any impact is substantial and long-term.

Your hospital doctor or viral hepatitis nurse will also be asked to assess how likely it is that any problems you have are caused by your infection (and not something else).

If you and those treating you do not agree over the evidence provided, then the evidence submitted will be reviewed by an independent panel of experts.

Section C – Overall clinical opinion and declaration for both the Applicant and Medical Practitioner

By this stage, you and your hospital doctor/nurse need to have completed Section A or Section B of the form.

The first part of Section C asks your hospital doctor or nurse to provide an overall clinical assessment of your condition and its impact on your ability to carry out daily activities.

Evidence from your medical records is also requested.

After this are declarations for you and the doctor/nurse to complete and sign.

Please read everything carefully as a partially completed form may have to be returned to you and will delay the processing of your application.

Other important information for the applicant:

The evaluation made by your treating doctor/nurse is important. However, we recognise that it may not always be possible for them to provide factual evidence from your medical records. In such cases their clinical judgement may be enough to allow the scheme administrator to decide your case.

If your application is rejected, you will have the chance to appeal the decision. A panel of independent experts will look at your application and all accompanying evidence. However, the decision then made by the experts will be final and you will not be able to appeal against their decision. In such cases you will be eligible to reapply after a period of six months, taken from the date that your original application was received. It is expected that further applications will include additional evidence that was not provided in the original application.

If you disclose in this application form that you are in receipt of any state benefits, this will not affect your entitlement to any support you are applying for in this application.

Data Protection

Your personal information will only be used by the NHS Business Services Authority (NHSBSA) on behalf of the Department of Health, to check your eligibility for a payment and to administer your application. In the event that you appeal a decision, your information may be disclosed to a panel of experts. Your information will otherwise be held in the strictest confidence and will not be shared with any other organisations. All personal information will be transferred and stored securely in compliance with the Data Protection Act 1998.

By submitting this form to a medical professional, you consent that your medical details necessary to evidence your application will be supplied to the NHSBSA for the purpose of administering your application. If your application is deemed to be ineligible, the scheme will keep your application form on file for up to ten years so that it has a full historical record in the event that you lodge an appeal or if you reapply for a payment. If you have any questions regarding the use of your information, please contact the scheme administrator, by telephone on XXXXXX, by Email to xxxx@xxxx.org, or in writing to NHSBSA [address]⁶

Notes for hospital doctors or viral hepatitis nurses completing the application form

The ex gratia support scheme was set up by the Department of Health to help those infected with hepatitis C and/or HIV through NHS supplied blood or blood products before 1991.

Your patient has arranged to meet with you because they consider their chronic hepatitis C infection acquired through NHS supplied blood or blood products, or its treatment, or a specific causally linked hepatitis C associated condition (listed in

⁶ This information will be included in the final version of the form and guidance notes which will be available when NHSBSA start running the scheme in November.

Section A of the form), is having a substantial and long-term adverse effect on their ability to carry out day-to-day activities. They are seeking your help to provide evidence to support this so they can claim increased annual payments from the ex gratia support scheme as a stage 1 beneficiary

You are being asked to assist with this process because you will know the status of the applicant's health best and will have the evidence required. If your patient suffers from any of the below listed conditions, then they are eligible for higher annual payments as stage 2 beneficiaries and so this process does not apply to them:

- cirrhosis
- primary liver cancer
- liver transplant patient (or on the waiting list for one)
- B-cell non-Hodgkin's Lymphoma
- membranoproliferative glomerulonephritis (MP GN) caused by Type 2 or 3 cryoglobulinaemia.

If the applicant is in doubt about their eligibility for stage 2 payments, we advise they contact the scheme administrator immediately.

Your role is important in providing the evidence and/or endorsement of the impact hepatitis C is having on your patient.

- Section A of this application process asks the applicant if they have been diagnosed with one of the diseases listed.
- Section B is only applicable if the applicant has not been diagnosed with one of the diseases listed, and asks if the applicant has mental health problems or chronic fatigue as a result of their hepatitis C, which is impacting on their ability to carry out daily activities.

Please ensure your patient has completed the appropriate section and provide evidence of this and whether they have required treatment (e.g. anti-depressants or other therapies).

Please then provide an overall clinical assessment at Section C then sign the declaration.

We appreciate that some of what is being sought by way of evidence may be subjective and therefore difficult for you to provide and we accept that some answers may rely on asking you to exercise your professional judgement. You may wish to seek further evidence from other people treating your patient

If you have any questions or queries related to this process, we advise you contact the scheme administrator and speak with a member of staff from the scheme about this. Their telephone number is **XXXXXX**⁷. They will be able to provide you with further details and answer any questions you may have about this process.

⁷ This information will be included in the final version of the form and guidance notes which will be available when NHSBSA start running the scheme in November.

SPECIAL CATEGORY MECHANISM APPLICATION FORM

Please complete this application form if you meet **both** of the following criteria:

- You are registered with the NHS Business Services Authority (NHSBSA) infected blood payment scheme at Stage 1
- You have one of the specific hepatitis C associated conditions listed in Section A **OR** you consider your hepatitis C infection, or its treatment as having a substantial and long-term adverse impact on your ability to carry out daily activities.

This Special Category Mechanism process allows Stage 1 beneficiaries to apply for the higher annual payment, equivalent to HIV and hepatitis C Stage 2 annual payments.

Registrants of the scheme who are diagnosed with cirrhosis, primary liver cancer, have been offered or are in receipt of a liver transplant, B- cell non-Hodgkin's Lymphoma and Type 2 or 3 Cryoglobulinaemia (only accompanied by membranoproliferative glomerulonephritis (MPGN), will already be receiving hepatitis C Stage 2 annual payments. Please speak to the scheme administrator for further advice about this if you are unsure.

If you find you do not qualify, you may complete this application form.

To complete this application form, it is important that applicants in the first instance contact their hospital consultant or viral hepatitis nurse to discuss the application and the accompanying guidance notes. If the applicant is not under the care of a hospital doctor or viral hepatitis nurse, applicants are advised to contact the scheme administrator who will be able to advise further.

Please note that applicants must complete:

- **EITHER** Section A or Section B
- **AND** Section C

Section A – to be completed by the applicant

Q1. Do you have any of the following conditions? Please discuss with your hospital specialists (Tick all that apply)

If none of these apply, please go to Section B.

Condition		Please tick	Date of diagnosis
A	Autoimmune disease due to, or worsened by, interferon treatment for hepatitis C, for example:		
A1	• Coombes positive haemolytic anaemia		
A2	• Idiopathic fibrosing alveolitis of the lung		
A3	• Rheumatoid arthritis		
B	Sporadic porphyria cutanea tarda causing photo-sensitivity with blistering		
C	Immune Thrombocytopenic Purpura with anti-platelet antibodies		
D	Type 2 or 3 mixed Cryoglobulinaemia, which is accompanied by:		
D1	• Cerebral vasculitis		
D2	• Dermal vasculitis		
D3	• Peripheral neuropathy with neuropathic pain		

Section A – to be completed by the applicant's hospital doctor or viral hepatitis

Please provide confirmation that the applicant is suffering with the diagnosis or diagnoses ticked from the list above and include evidence from the applicant's medical records.

If you wish to add more information, please attach to the back of this application form.

Reminder: Not to be completed at this time

Note: If you have completed Section A please proceed straight to Section C.

Section B – to be completed by the applicant

Please provide information on how your infection, or its treatment and possible complications, affect your daily living. Section B has two questions which ask whether the impact of your hepatitis C or its treatment affects your ability to carry out daily activities because of a) mental health problems or b) chronic fatigue.

Please answer **at least one** of these questions.

Q3. Does your hepatitis C infection or its treatment make it difficult for you to carry out regular daily activities, such as leaving your home, using public transport or shopping for essentials, as a result of mental health problems (such as feeling depressed or anxious)?

Yes

☐

No

☐

Q3a. Please say how often this affects you? (Tick one box)

Occasionally

At least monthly

At least weekly

Most days of each week/daily

Please say how substantial the impact of the above is on your ability to carry out day-to-day activities. Please give clear descriptions of how you are affected and examples; and how long you have been experiencing this – if you wish to add more information, please attach to the back of this application form:

Reminder: Not to be completed at this time

Maximum word limit 500

Section B – to be completed by the applicant

Q4. Does your hepatitis C infection or its treatment make it difficult for you to carry out regular daily activities, such as walking more than 50 metres, climbing stairs, lifting objects from the ground or a work surface in the kitchen or physical tasks such as gardening as a result of feeling chronically fatigued?

Yes

☐

No

☐

Q4a. Please say how often this affects you? (Tick one box)

Occasionally

☐

At least monthly

☐

At least weekly

☐

Most days of each week/daily

☐

Please say how substantial the impact of the above is on your ability to carry out day-to-day activities. Please give clear descriptions of how you are affected and examples; and how long you have been experiencing this – if you wish to add more information, please attach to the back of this application form:

Reminder: Not to be completed at this time

Section B – to be completed by the applicant's hospital doctor or viral hepatitis nurse

Please confirm that, in your experience of the applicant, their hepatitis C infection (or its treatment or complications) is making it difficult for them to carry out regular daily activities **as a result of mental health problems**.

Please state a) which mental health problems, b) how long these mental health problems have been going on for, and c) their expected duration. If your patient has been receiving treatment for mental health problems (e.g. medication, counselling, other therapies), then please provide any evidence you have on this.

In your opinion, how likely is it that your patient's mental health problems are attributable to their hepatitis C infection (or its treatment or effects)?

(Tick one box)

1. Not likely – explained by other causes
2. Possible
3. Highly likely
4. Definite

If you wish to add more information, please attach to the back of this application form.

Reminder: Not to be completed at this time

Section B – to be completed by the applicant’s hospital doctor or viral hepatitis nurse

Please confirm that, in your experience of the applicant, their hepatitis C (or its treatment or complications) is making it difficult for them to carry out regular daily activities **as a result of chronic fatigue**.

Please state how long this chronic fatigue has been going on for, and its expected duration.

If your patient has been receiving treatment for fatigue (e.g. medication, counselling, other therapies), then please provide any evidence you have on this.

In your opinion, how likely is it that your patient’s fatigue is attributable to their hepatitis C infection (or its treatment or effects)? (Tick one box)

1. Not likely – explained by other causes
2. Possible
3. Highly likely
4. Definite

If you wish to add more information, please attach to the back of this application form

Reminder: Not to be completed at this time

Section C – to be completed by the hospital doctor or viral hepatitis nurse

Overall Clinical Opinion

Please confirm that, in your clinical judgement, it is likely that your patient's hepatitis C infection, (or its treatment or complications) is having a substantial and long-term adverse impact on their ability to carry out daily activities.

Please give an opinion on the following scale to say whether the difficulty in carrying out regular daily activities is likely to be attributable to the hepatitis C infection or its effects (tick one box)

1. Not likely – explained by other causes
2. Possible
3. Highly likely
4. Definite

If you wish to add more information, please attach to the back of this application form:

Clinical assessment

Reminder: Not to be completed at this time

Maximum word limit 500

Section C - Applicant Declaration

Declaration I confirm that the information given in this application form is, to the best of my knowledge and belief, correct and complete. I understand and consent to the sharing of information relating to my medical condition with assigned expert group members of the NHS Business Services Authority for the purposes of applying for increased annual payments and with the NHS Counter Fraud and Security Management Services for the purposes of verification of this claim and the investigation, prevention, detection and prosecution of fraud. I understand that if I knowingly give false information, support will be stopped and I may be asked to return any financial support given to me as a result of this application and that I may be liable for prosecution and civil recovery proceedings.

Name of Applicant		
Address		
Postcode		
		Preferred Contact Method
Telephone Number		
Mobile Number		
Email address		

Signed _____

Date _____

Section C - Medical Practitioner Declaration

Declaration: By signing this form I confirm that the information contained within Sections A and/or B and C of the form is true to the best of my knowledge and belief and that if I knowingly authorise false information this may result in disciplinary action and I may be liable for prosecution. I consent to the disclosure of information from this form to and by the NHS Business Services Authority and the NHS Counter Fraud and Security Management Service for the purpose of verification of this claim and for the investigation, prevention, detection and prosecution of fraud.

Signed _____ Date _____

Identity and Authority of the Medical Practitioner completing the relevant sections of the form

Name of Medical Practitioner	
Job Title	
Department	
Hospital	
When did you last see the applicant?	
Address	
Postcode	
Telephone Number	
Mobile Number	
Email address	

<i>If Section B was completed by a viral hepatitis nurse, this box should be signed by a hospital consultant hepatologist to verify the information and evidence provided by the nurse:</i>	
--	--

Hospital/GP Practice stamp:

--

FINAL STEPS

Please return this form and all required evidence to:

**The NHS Business
Services Authority
ADDRESS
EMAIL⁸**

All personal data acquired by the scheme administrator from this application form shall only be used for the purposes of this process and shall not be further processed or disclosed without the consent of the above signed applicant.

Please note:

- The declaration must be signed and dated by both the applicant (you) and the Medical Practitioner (hospital doctor or hepatitis nurse).
- Partially completed forms may be returned to you (unless the questions you omit are not relevant to you).
- Forms without a professional assessment (Section C) cannot be considered.
- Receipt of this form does not guarantee your application will be approved.
- If you do not provide appropriate evidence, or your application is not straightforward, then the scheme administrator can reject your application and you will be notified in writing.
- If the Scheme's administrator turns down your application, you will be able to appeal. A group of experts will then have the final say on your application and you will not be able to appeal their decision. But you will have the chance to reapply at a later date, or if you can provide evidence that your condition has worsened since last submitting this form.

⁸ This information will be included in the final version of the form and guidance notes which will be available when NHSBSA start running the scheme in November.

Annex B: what does this mean for me?

- hepatitis C at stage 1
 - you'll receive an annual payment of £3,535, rising to £4,500 in 2018/19, which will then increase in line with inflation
 - you can apply through the new SCM for a higher annual payment of £15,655 for 2017/18 and £18,500 from 2018/19
 - you can apply for a one-off £50,000 payment and higher annual payments through the existing stage 2 process if you go on to develop stage 2 disease
- hepatitis C at stage 2 or HIV
 - you'll receive an annual payment of £15,655 for 2017/18 and £18,500 from 2018/19, which will then increase in line with inflation
- hepatitis C at stage 1 and HIV
 - you'll receive an annual payment of £18,685 in 2017/18, rising to £22,500 in 2018/19, which will then increase in line with inflation
 - you can apply through the new SCM for a higher annual payment of £30,805 for 2017/18 and £36,500 from 2018/19
 - you can apply for a one-off £50,000 payment and higher annual payments through the existing stage 2 process if you go on to develop stage 2 disease
- hepatitis C at stage 2 and HIV
 - you'll receive an annual payment of £30,805 for 2017/18 and £36,500 from 2018/19, then increasing in line with inflation
- hepatitis C at stage 1 with MPGN
 - you can apply for a one-off £50,000 payment and higher annual payments through the existing stage 2 process, as MPGN will be listed as a stage 2 condition from November 2017