



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

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Infected Blood Payment Scheme (NI)

Consultation on enhanced support for hepatitis C stage 1

December 2021

Date of issue: 6 December 2021

Responses to be returned by: 5 January 2022

Title: Infected Blood Payment Scheme (Northern Ireland) - consultation on enhanced support for hepatitis C stage 1

Author: Infected Blood Inquiry Team, Department of Health NI

Document Purpose: Targeted consultation

Issue date: 6 December 2021

Target audience:

- All beneficiaries of the Infected Blood Payment Scheme (NI)
- Patients infected by Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with NHS-supplied blood or blood products
- Family members of people infected by HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products
- Spouses and partners bereaved as a result of infection with HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products
- Haemophilia Groups
- HSC Trust Medical Directors (to be circulated to relevant clinical specialists working with hepatitis C patients, including NI Liver Trust and NI Regional Hepatitis B&C Managed Clinical Network)
- GPs (to be distributed through BMA)
- NI Mental Health Champion

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Introduction

On 25 March 2021, the Northern Ireland Health Minister Robin Swann announced¹ plans to introduce enhanced financial support for eligible hepatitis C stage 1 beneficiaries on the NI Infected Blood Payment Scheme (NI Scheme).

This additional financial support, which is known as the ‘Special Category Mechanism’ (SCM) in England, ‘enhanced hep C +’ in Wales and ‘severely impacted category’ in Scotland, is intended to benefit hepatitis C stage 1 beneficiaries who consider their infection or its treatment to have a substantial and long-term adverse impact on their ability to carry out routine daily activities.

The NI Scheme does not currently provide this enhanced support and in order to achieve greater parity across the UK in payments to this category, Minister Swann has committed to the introduction of enhanced support payments for eligible hepatitis C stage 1 beneficiaries, in line with the same rates paid in England and once implemented, these payments will be backdated to 1 April 2019.

This is subject to a process for assessment being developed, which Minister Swann has committed to taking forward in consultation with stakeholders.

This document sets out the background, proposals and a timeline for implementing this new financial provision. It also includes a questionnaire at **annex D**.

The Department would welcome your views on how eligibility for enhanced financial support for hepatitis C stage 1 should be assessed.

¹ www.niassembly.gov.uk/globalassets/documents/official-reports/written-ministerial-statements/2020-2021/bv137_wms_dh_250321_2.pdf

Background

Since autumn 2017 each of the four UK countries has had its own infected blood financial support scheme to provide support for individuals and their families, who have been infected with, or otherwise affected by HIV, hepatitis C, or both, following treatment with NHS-supplied blood or blood products.

These replaced the UK-wide Alliance House Organisations (AHOs) - the Macfarlane Trust, the Eileen Trust, the Skipton Fund, MFET and the Caxton Foundation

However, since 2017 the four UK schemes have developed and as a result diverged in different ways, including in the levels of support and eligibility criteria for the various types of support provided on the schemes.

The then Northern Ireland Health Minister Michelle O'Neill decided to use the English model when establishing the NI Scheme and announced this in the NI Assembly in December 2016².

Northern Ireland continued to have parity with the England Infected Blood Support Scheme (EIBSS) in most respects until the UK Government announced on 30 April 2019 significant increases to its annual payments, which resulted in an unintended disparity with Northern Ireland.

The Special Category Mechanism (SCM), additional financial support for those with hepatitis C stage 1, was introduced in England in September 2017 when there was no functioning Northern Ireland Executive.

² [Michelle O'Neill announces improved financial support for people affected by contaminated blood | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/news/michelle-oneill-announces-improved-financial-support-for-people-affected-by-contaminated-blood)

New Decade New Approach

A commitment was included in the January 2020 document 'New Decade New Approach', an all-Party political agreement which restored the NI Executive after a three year absence. The commitment was as follows:

"The Executive will bring about parity in financial support to victims of contaminated blood in Northern Ireland with those in England".

However, there was no consensus as to what parity between the Northern Ireland and England schemes meant in practice as the schemes are complex and there were differences across all four UK schemes in terms of both the financial support provided and eligibility for that support.

A further consideration was the preservation of devolved authority in this matter.

Review of Infected Blood Payment Scheme (NI)

In January 2020³, the newly appointed NI Health Minister Robin Swann stated his intention to take forward a three phase approach to reviewing the NI Scheme.

Phase 1 addressed the immediate difference that had occurred in 2019-20 between the rates paid to Northern Ireland scheme beneficiaries when compared with those in England and in addition included £5,000 special payments to non-infected bereaved spouses and partners who were registered on the NI Scheme⁴. The funding available at that time was one-off and not recurrent annually.

³ www.health-ni.gov.uk/news/infected-blood-payments-announced-by-swann

⁴ www.health-ni.gov.uk/news/health-minister-announces-additional-infected-blood-payments

As a first step in phase 2 of the Review, on 31 July 2020 the Health Minister issued a formal Ministerial Direction instructing a permanent uplift to payments to infected beneficiaries in Northern Ireland in line with the rates paid in England. The uplift was announced on 30 August 2020⁵ with payments backdated to April 2020 and rising annually in line with the Consumer Price Index (CPI) rate. This decision represented a commitment of an additional £1.1m annually by DoH (NI). As a result of this increase in annual support, means-tested income top-up payments to infected beneficiaries discontinued from 1 September 2020.

Infected Blood Payment Scheme (NI) Survey

In early 2020, Minister Swann met with groups representing infected and affected people in Northern Ireland and undertook to ensure their views would be taken into account in the ongoing review of financial support.

During autumn 2020, a survey of all Scheme beneficiaries was conducted, seeking feedback on areas such as annual support for infected and bereaved beneficiaries, discretionary support, enhanced support for hepatitis C stage 1 beneficiaries and psychological support.

The findings of the survey, which had a response rate of 55.4%, were published on 1 March 2021.⁶

Approximately 80% of respondents reported being in favour of enhanced support for hepatitis C stage 1 beneficiaries being introduced in Northern Ireland. Respondents who commented suggested that there was a need for some form of additional payment to recognise the impact of hepatitis C on some stage 1 sufferers – in particular the unpredictable nature of liver damage and other health problems associated with chronic (stage 1) hepatitis C.

⁵ [New Infected Blood Payments introduced | Department of Health \(health-ni.gov.uk\)](#)

⁶ [Infected Blood Payment Scheme NI - Survey Report | Department of Health \(health-ni.gov.uk\)](#)

Other respondents suggested that the clinical distinction between stage 1 and stage 2 hepatitis C beneficiaries must continue to be recognised and reflected by maintaining a differential in payment rates for stages 1 and 2.

Some comments suggested that any system for enhanced support needed to be simple and fair and should include medical assessment so that it is not open to fraud, while others felt that they did not have a sufficient understanding of the pros and cons of the various processes used in the schemes in England, Scotland and Wales in order to identify a preference.

To assist in responding to this consultation exercise, the Department has developed a brief guidance document, comparing the enhanced financial support available on the schemes in England, Scotland and Wales and this is included at **annex B** of this consultation document.

Bereaved spouses and partners

On 1 March 2021 Minister Swann introduced annual financial support for bereaved spouses and partners on the NI Scheme⁷.

This followed consideration of the findings of the survey and comparison with the other UK schemes.

The payments announced were set at 75% of the rate the beneficiary's infected spouse or partner was in receipt of at the time of death, or would have been in receipt of had they been registered on the Scheme.

As a result of this newly introduced annual financial support, income top-ups for bereaved spouses and partners ceased from April 2021.

A third phase of reform of the scheme will be required to address recommendations from the UK-wide Infected Blood Inquiry, which is expected to deliver its report in 2022 at the earliest.

⁷ www.health-ni.gov.uk/news/infected-blood-bereaved-have-not-been-forgotten-swann

4-nations work to achieve greater parity

Since the increase in rates to those infected with hepatitis C and/or HIV was announced in England in April 2019 and in addition to the ongoing Review of the NI Scheme, regular engagement continued with the Health Departments in England, Scotland and Wales, along with the UK Cabinet Office (as sponsor to the Infected Blood Inquiry), to discuss how to achieve greater parity across the four UK schemes.

On 10 July 2019, in the absence of a Health Minister in Northern Ireland, the Department of Health NI Permanent Secretary Richard Pengelly, took part in a 4-nations ministerial level meeting in which the following three fundamental principles were agreed:

- i. The integrity of schemes developed under devolution should be respected, in recognition that the four schemes have evolved to address the needs of their respective beneficiary communities, in dialogue with those communities;*
- ii. All four nations are committed to achieving parity of support, while recognising that what is meant by the term parity will need refinement and goes above and beyond financial support alone; and*
- iii. As we progress in improving our schemes and achieving parity of support, we are clear that no beneficiary of any country's scheme will be made worse off, both in terms of financial and other types of support.*

Following the four nations' ministerial level meeting in July 2019, the case for central funding was raised by Jackie Doyle Price (then Under Secretary of State for Mental Health, Inequalities and Suicide Prevention in the Department of Health and Social Care in England) in a letter to David Lidington (then UK Cabinet Office Minister).

In his response, copied to HM Treasury, David Lidington agreed with the fundamental principle was that no beneficiary should be made worse off by changes to another UK scheme.

Progress was hampered by the Covid-19 pandemic, however policy officials continued to work on analysis and costings on how greater parity could be achieved.

On 11 March 2021 Minister Swann attended a meeting with the Secretary of State for Health and other UK Health Ministers, where there was agreement in principle that there should be greater parity of approach to financial support across the four schemes and that no beneficiary should lose out financially from the different approaches taken in each UK country.

Following this meeting, engagement and negotiation continued at pace with officials in Cabinet Office and the other UK Health Departments and a supporting updated costings exercise was carried out ahead of confirmation of funding from DHSC.

As a result the former Paymaster General Penny Mordaunt MP announced on 25 March 2021 plans to bring the UK schemes into broader parity⁸.

Minister Swann made a written statement to the Northern Ireland Assembly on 25 March 2021⁹ announcing the following changes to the NI Scheme:

⁸ [Written statements - Written questions, answers and statements - UK Parliament](#)

⁹ www.niassembly.gov.uk/globalassets/documents/official-reports/written-ministerial-statements/2020-2021/bv137_wms_dh_250321_2.pdf

- **financial support to bereaved spouses/partners** - all four UK countries to align with the Scottish Infected Blood Support Scheme (SIBSS), which pays 100% of the infected rate for the first year and 75% thereafter. The NI Scheme already provided 75% payments, further to the Minister's announcement on 1 March 2021. The NI Scheme has subsequently paid arrears to all eligible scheme beneficiaries to meet the requirement to pay 100% of infected rate for the first year on the scheme;
 - **lump sum payment to a hepatitis C stage 1 beneficiary** – to increase from £20,000 to £50,000, with the additional £20,000 payable if a stage 1 beneficiary moves to stage 2. The total lump sum payable for hepatitis C beneficiaries remains at £70,000. This policy is in line with the position in Scotland and all eligible beneficiaries registered with the NI Scheme have subsequently received this additional payment in arrears backdated to 1 April 2017;
 - **lump sum payment to a HIV beneficiary** – to increase from the previous range of payments up to maximum of £80.5k (depending on circumstances) to an automatic £80.5k, backdated to 1 April 2017. All eligible beneficiaries registered with the NI Scheme have subsequently received appropriate additional payments in arrears subject to the lump sum amount previously received;
 - **£10,000 bereavement lump sum** – this has been provided since the NI Scheme was established in 2017, but the UK parity agreement means it will now be payable to the Estate of the deceased in cases where there is no living spouse or partner, in line with the position in England and Wales. This will be backdated to 1 April 2017, meaning all eligible beneficiaries currently registered on the NI Scheme have received the appropriate payment in arrears;
 - **enhanced support for hepatitis C stage 1** – known as the 'Special Category Mechanism' (SCM) in England, 'enhanced hep C +' in Wales and
-

‘severely impacted category’ in Scotland. The NI Scheme does not yet have SCM / equivalent provision and in order to achieve greater parity across the UK in payments to this category of beneficiary, Minister Swann committed to the introduction of enhanced support payments for eligible hepatitis C stage 1 beneficiaries, in line with rates paid in England and backdated to 1 April 2019, subject to a process being developed in consultation with stakeholders.

The UK health ministers agreed to pay the same annual rates to infected beneficiaries as the England Infected Blood Support Scheme (EIBSS), however the Northern Ireland Health Minister had already increased rates to EIBSS levels in August 2020¹⁰.

The Schemes in the other Devolved Administrations (DAs) have been similarly adapted to achieve greater parity in terms of financial support to those infected and/or affected across the UK.

The introduction of enhanced support will not result in any detrimental effect on the financial support already provided to beneficiaries on the NI Scheme – in other words, no one will lose out financially as a result of this change.

Ministers also agreed that any future changes to their infected blood financial support schemes would be subject to consultation across the four administrations to mitigate the risks of future disparities.

¹⁰ www.health-ni.gov.uk/news/swann-announces-increased-payments-infected-blood

Purpose of the consultation

What is the objective?

The aim of the new policy for enhanced support will be to benefit hepatitis C stage 1 scheme beneficiaries who consider their infection, or its treatment, to have a substantial and long-term adverse impact on their ability to carry out routine daily activities.

The purpose of this consultation exercise is to support the development of an eligibility assessment process for hepatitis C stage 1 enhanced support that is fair and reasonable in the interests of achieving greater parity of financial support across the UK, whilst demonstrating proper accountability for public money.

The introduction of enhanced support for hepatitis C stage 1 will be a significant new element of the Infected Blood Payment Scheme NI and we must consider measures to ensure that the scheme, overall, remains within the allocated budget while distributing available funds in the fairest possible way.

Please note that any changes to the NI Scheme as a result of this consultation exercise will **not affect the general application process** for applying to receive support from the Scheme. This consultation relates only to the process for assessing **applications for enhanced support for hepatitis C stage 1.**

What is being proposed?

The Department wishes to consult with NI Scheme beneficiaries and other interested stakeholders on developing policy options for an eligibility assessment process for enhanced support for hepatitis C stage 1.

The UK Health Ministers have already agreed that the four schemes will provide the same level of payment – equivalent to the annual payment received by hepatitis C stage 2 beneficiaries (that is, advanced liver disease such as cirrhosis and its complications) or those infected with HIV.

As with other annual payments on the Scheme, the new enhanced payment will increase annually in line with the Consumer Price Index (CPI).

What is not included in the proposals?

Lump sums for those in receipt of enhanced support

Paying an enhanced support stage 1 beneficiary the same lump sum as a stage 2 beneficiary is not included within the terms agreed by the UK health ministers in the parity agreement of March 2021.

The NI Health Minister Robin Swann has already agreed with the other UK health ministers that all four UK Schemes will make **annual payments** for enhanced financial support for hepatitis C stage 1 at the same level as payments for stage 2 and HIV, which is currently £28,680 (2021/22 rate).

The additional lump sum payment to stage 2 hepatitis C beneficiaries was introduced in 2011 following expert advice which concluded that the needs of those with advanced liver disease from hepatitis C merit higher levels of financial support.

Stage 2 beneficiaries are eligible to receive the additional lump sum in recognition of the fact that development of stage 2 disease sadly not only reduces the quality of life but also substantially and negatively impacts on life expectancy.

Successful stage 1 enhanced support applicants would therefore **not** be eligible to receive the equivalent additional lump sum that is currently paid to stage 2 beneficiaries (£20,000). This lump sum will remain available only to those with **clinically diagnosed advanced hepatitis C (stage 2 beneficiaries on the Scheme)**. This is also the case in England, Scotland and Wales, under their respective enhanced support systems.

Should a successful enhanced support stage 1 beneficiary unfortunately go on to develop one of the stage 2 indicators they would qualify for the additional £20,000 through the existing stage 2 process.

Deceased beneficiaries / estates

It is not within the terms of the parity agreement to make bereaved payments at the enhanced rate in circumstances where a stage 1 infected spouse or partner died before assessment for enhanced support could be carried out; the stage 1 rate would apply in these cases.

Under the terms of the UK parity agreement announced in March 2021, bereaved spouses and partners are entitled to receive annual payments at 100% of the rate that their late spouse received, or indeed would have been entitled to had they been on the scheme, for the first year of financial support, followed by 75% of that rate in subsequent years.

Until 31 March 2022, these payments can be backdated to 1 April 2019 for new bereaved beneficiaries who successfully apply to the NI Scheme, provided that their spouse or partner died prior to 1 April 2019. However, from 1 April 2022 onwards, payments to bereaved spouses and partners will be backdated to the beginning of the financial year in which the application is made or the date of death, whichever is latest.

The Department recognises that there may be some bereaved beneficiaries who believe that their late spouse or partner may have been entitled to receive the enhanced payment in respect of their hepatitis C (stage 1) had this support been available when they were alive and had they been registered on the Scheme. In these circumstances, the assumption might be made that the bereaved spouse or partner should therefore receive an annual payment based on the enhanced (stage 2) rate that they believe their late partner should have received.

However, in such circumstances, it would simply not be possible to carry out any

form of assessment in the present day to determine whether a deceased person would have been eligible to receive enhanced stage 1 support.

Hepatitis stage 2 payments

Scheme beneficiaries who have been diagnosed with cirrhosis, primary liver cancer, B-cell non-Hodgkin's Lymphoma, have had or are on the waiting list to receive a liver transplant, or have renal disease due to Membranoproliferative Glomerulonephritis (MPGN), should already be receiving **hepatitis C stage 2 annual payments** and so would **not be eligible for enhanced stage 1 support.**

Working group

To support the consultation exercise, a working group has been set up whose membership includes scheme beneficiary representatives, both infected and affected, clinical expertise and representatives of the relevant haemophilia organisations, as well as officials from the Business Services Organisation (BSO) and Department of Health NI (DoH NI).

The purpose of the group is to provide advice and insight to support the Department of Health in developing policy options for enhanced support and to provide assistance in understanding the impact of the reforms on the communities affected by them. See **annex C** of this consultation document for working group membership and Terms of Reference.

What information is required?

The Department would like to hear your views on a process for eligibility assessment; a questionnaire is included at **annex D**. After responses to the consultation have been received, options will be developed for a decision by the NI Health Minister.

Developing a process for assessment of eligibility

Rationale for enhanced support for hepatitis C stage 1

Enhanced financial support is intended to provide additional help with living costs for **chronic hepatitis C (stage 1) scheme beneficiaries** where hepatitis C virus (HCV) infection or its treatment continues to have a substantial, long-term adverse impact on their quality of life affecting everyday health and wellbeing. Enhanced support may be available to help those who suffer a significant impact on daily life due to ongoing physical health symptoms related to the multisystem complications arising from a history of HCV infection or its treatment.

In addition it is recognised that chronic HCV has for some people had a considerable impact on quality of life due to psychological factors. Mental health disorders associated with chronic HCV and its treatment include depression, anxiety, low self-worth or post-traumatic stress disorder and for some people the impact on their mental health has had financial consequences, such as reduced earnings due to inability to work, having to work reduced hours or having to change role or even career. For others it has led to the breakdown of relationships or made it difficult to leave home or socialise with other people.

Enhanced support may be available to help stage 1 beneficiaries with additional living expenses in cases where the mental health impact prevents them from being able to carry out routine day-to-day activities, such as leaving home, using public transport, shopping, cooking or gardening.

NI Health Minister Robin Swann has committed as part of UK parity agreement to introduce enhanced support for hepatitis C stage 1 at the same rates as England which will be backdated to 1 April 2019 once implemented. This consultation will help provide evidence to support the Minister's decision on the most appropriate process for assessment of eligibility.

Assessment options

The Department seeks views from consultees on assessment options. There are two ways assessment is carried out on the other UK schemes:

- a) **Clinical assessment;**
- b) **Self-assessment.**

(a) Clinical assessment

A clinical assessment process would consider those with chronic hepatitis C (stage 1 beneficiaries) who have been diagnosed with one or more of a number of hepatitis C related conditions (which would be agreed with professional advice from clinicians) that would cause people with these conditions to experience a substantial and long-term adverse impact on their daily lives.

The application process would include input from the applicant's medical practitioner, based on the information provided by the applicant and evidence from the applicant's medical notes where appropriate. The medical practitioner would not be making a decision on eligibility for enhanced support; eligibility assessment and decision would be taken by the BSO or independent assessment panel in the case of a two stage assessment.

The medical practitioner would most likely be the applicant's hospital hepatitis consultant or a viral hepatitis nurse or other relevant consultants (for example, rheumatologist or mental health expert). In exceptional cases, where the applicant is not under the care of a hospital consultant or viral hepatitis nurse, the medical practitioner may be their GP.

The medical practitioner would be required to make a judgement as to whether the problem experienced is substantial and long-term, and whether it is related to the applicant's hepatitis C infection or its treatment. For example, someone who experiences problems most days of each week or indeed daily and has done so for 12 months or more, and whose medical practitioner confirms this is the case and is a direct consequence of their hepatitis C

infection or treatment, would be likely to have their application accepted.

The England Infected Blood Support Scheme (EIBSS) uses a clinical assessment process. More background is included at **annex B** of this consultation document. This consultation process seeks views on what level of medical input there should be to the application process.

(b) Self-assessment

A self-assessment process would enable hepatitis C stage 1 beneficiaries to apply for the additional financial support if they consider their hepatitis C infection or its treatment to have a substantial and long-term adverse impact on their physical or mental health, and/or that fatigue due to hepatitis C infection or its treatment has a substantial and long-term adverse impact on their daily lives.

With this type of process, applicants may need to provide examples of their symptoms and describe how severe these are and how often these symptoms impact on their ability to carry out day to day activities.

Medical evidence or a declaration from a medical practitioner would usually not be required in a self-assessment process. The schemes in both Scotland and Wales use different forms of self-assessment. More background is included at **annex B** of this consultation document.

Appeal

In either type of assessment, where an application is not successful, applicants would have the opportunity to appeal the decision.

The questionnaire at **annex D** seeks feedback from stakeholders on the preferred process for assessment of eligibility and this will be used to support policy options and advice to the Northern Ireland Health Minister.

Impact assessments

Draft templates have been completed for:

- Equality Screening, Disability Duties and Human Rights Assessment;
- Rural Impact Assessment Screening.

No significant impacts have been identified at this stage and therefore it is proposed that full impact assessments are not required

The draft templates are included at **appendices 1 and 2** in **annex D** (consultation questionnaire) and questions 5 and 6 of the questionnaire seek responses on the draft templates.

If necessary, the templates will be amended and updated to reflect the outcome of the consultation process, before the final versions are published on the Department's website.

Proposed* timescale

Target	Action	Target date
1	Seek nominees for working group - letters to Haemophilia Groups and scheme beneficiaries.	05-Jul-21
2	Expressions of interest for working group to be received by DoH.	16-Jul-21
3	Finalise membership of working group, notify members of group and seek availability for first meeting.	10-Sep-21
4	Submission to Minister with draft consultation document, questionnaire, WG ToR and action plan in advance of first meeting of working group.	24-Sep-21
5	First meeting with working group to agree ToR, discuss approach, agree timetable & discuss/agree draft consultation document.	29-Oct-21
6	Share amended consultation document with working group.	05-Nov-21
7	Meeting of working group to discuss and agree final version for issue.	12-Nov-21
8	Issue consultation document to Scheme beneficiaries, haemophilia groups and other agreed stakeholders.	06-Dec-21
9	Deadline for responses to consultation questionnaire to be received by DoH.	05-Jan-22
10	DoH analyse responses to consultation and produce report.	28-Jan-22
11	Submission to Minister with consultation response report for information 'to note'.	31-Jan-22
12	Share consultation report with WG for consideration (once noted by Minister).	04-Feb-22
13	Meeting of working group to discuss consultation report and agree policy options.	18-Feb-22
14	Submission to Minister with policy options and recommendation.	28-Feb-22
15	Inform working group of Minister's decision	04-Mar-22
16	Inform other stakeholders of Minister's decision	07-Mar-22
17	New policy put into operation; arrears paid & new payments set up. Invoices to DHSC.	31-Mar-22
18	Evaluation and feedback	30-Apr-22

****Timescale subject to change***

Responding to the Consultation

This consultation will run for 4 weeks, from 6 December 2021 to 5 January 2022. We welcome responses from beneficiaries and other interested parties.

Respondents are encouraged to submit their responses via the online questionnaire at <https://www.health-ni.gov.uk/consultations/infected-blood-payment-scheme-ni-consultation-enhanced-support-hepatitis-c-stage-1>

However, responses may also be submitted by email or post.

- You can request a hard copy from and email your responses to: ibit@health-ni.gov.uk or;
- You can complete the questionnaire in writing and post your response to:
Infected Blood Team Consultation Response
Health Protection Branch
Room C4.8, Castle Buildings
Stormont
Belfast
BT4 3SQ.

Please ensure we receive your response by **23.59hrs on 5 January 2022**.

The Department cannot respond specifically to individual consultation responses and any received after the closing date may not be considered in the final analysis of responses.

What happens next?

Following the close of the consultation on **5 January 2022**, all responses and feedback will be collated for review by the Department of Health and a summary report will be produced, to be shared with respondents and subsequently published on the Department's website.

Privacy, Confidentiality & Access to Consultation Responses

For this consultation, we may publish all responses except for those where the respondent indicates that they are an individual acting in a private capacity (e.g. a member of the public). All responses from organisations and individuals responding in a professional capacity will be published. We will remove email addresses and telephone numbers from these responses, but apart from this, we will publish them in full. For more information about what we do with personal data please see our consultation privacy notice.

This document can be viewed at:

<https://www.healthni.gov.uk/sites/default/files/consultations/health/doh-privacy-notice-consultation-on-infected-blood.pdf>. It can also be provided separately by email / post on request from ibit@health-ni.gov.uk

Your response and all other responses to this consultation may also be disclosed on request in accordance with the Freedom of Information Act 2000 (FOIA) and the Environmental Information Regulations 2004 (EIR); however all disclosures will be in line with the requirements of the Data Protection Act 2018 (DPA) and the UK General Data Protection Regulation (UK GDPR) (EU) 2016/679.

If you want the information that you provide to be treated as confidential it would be helpful if you could explain to us why you regard the information you have provided as confidential, so that this may be considered if the Department should receive a request for the information under the FOIA or EIR.

Data Controller Name: DoH(NI)
Address: Castle Buildings, Stormont,
BELFAST, BT4 3SG
Email: OrgChgDir@health-ni.gov.uk
Telephone: 02890520533

Data Protection Officer Name:
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Telephone: 02890522353
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Being transparent and providing accessible information to individuals about how we may use personal data is a key element of the Data Protection Act (DPA) and the UK General Data Protection Regulation (UK GDPR). The Department of Health (DoH) is committed to building trust and confidence in our ability to process your personal information and protect your privacy.

Annex A - NI Survey findings

The survey¹¹ carried out in 2020 found that approximately 80% of respondents reported being in favour of enhanced support for hepatitis C stage 1 beneficiaries being introduced in NI; the remaining respondents indicated they were not sure. Respondents were presented with a brief outline of the processes in place in England, Scotland and Wales and were asked to indicate which approach they would like to see introduced in Northern Ireland. Respondents were able to select more than one approach and were also able to suggest an alternative approach.

Ten respondents did not provide an answer to the question; of the 46 respondents that did and considering all the responses given, 'Special Category Mechanism – England' was the most common response provided:

- Special Category Mechanism - England 29 responses (*63% of respondents*)
- Tiered Payment System - Scotland 12 responses (*26% of respondents*)
- Enhanced Payment - Wales 10 responses (*22% of respondents*)
- Other 4 responses (*9% of respondents*)¹²

Those who commented suggested that there was a need for some form of additional payment to recognise the impact of chronic (stage 1) hepatitis C on some sufferers – in particular the unpredictable nature of liver damage and other health problems associated with chronic (stage 1) hepatitis C.

Other respondents suggested that the clinical distinction between stage 1 and stage 2 hepatitis C beneficiaries must continue to be recognised and reflected by maintaining a differential in payment rates for stages 1 and 2. Comments suggested that the system needed to be simple and fair and should include medical assessment so that it is not open to fraud. Some commented that they did not have a sufficient understanding of the various processes in England, Scotland and Wales.

¹¹ [Infected Blood Payment Scheme NI - Survey Report | Department of Health \(health-ni.gov.uk\)](#)

¹² *Note: percentages do not total 100% because some respondents selected more than one option without indicating a preference; therefore those responses were given equal weighting.*

Annex B - UK comparison

In order to help inform your responses to the consultation, this document sets out a summary of the enhanced support systems available on the schemes in England, Scotland and Wales, including background, eligibility criteria, assessment process, payment, uptake, advantages / disadvantages and links to further information.

It is recommended that you read this document before responding to this questionnaire.

This document can be viewed at:

<https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-annex-b-uk-comparison.pdf> .

It can also be provided separately by email / post on request from ibit@health-ni.gov.uk

Annex C - Working Group

To support the consultation exercise, a working group has been set up whose membership includes scheme beneficiary representatives, both infected and affected, clinical expertise and representatives of the relevant haemophilia organisations, as well as officials from the Business Services Organisation (BSO) and Department of Health NI (DoH NI).

The purpose of the group is to provide advice and insight to support the Department of Health in developing policy options for enhanced support and to provide assistance in understanding the impact of the reforms on the communities affected by them.

This document can be viewed at:

<https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-annex-c-working-group-enhanced-support.pdf>

It can also be provided separately by email / post on request from ibit@health-ni.gov.uk

Annex D - Consultation Response Questionnaire

Infected Blood Payment Scheme (Northern Ireland) - consultation on enhanced support for hepatitis C stage 1

Please ensure you have read the consultation document before completing this questionnaire.

We would be grateful if you would complete this questionnaire online if possible at:

<https://www.health-ni.gov.uk/consultations/infected-blood-payment-scheme-ni-consultation-enhanced-support-hepatitis-c-stage-1>

Alternatively, you can download the questionnaire via the link above, complete it in writing and email it to: ibit@health-ni.gov.uk

Or, you can complete the questionnaire in writing and post to:

Infected Blood Team Consultation Response
Health Protection Branch
Room C4.8, Castle Buildings
Stormont
Belfast
BT4 3SQ

All responses must be received by by 23.59 on 5 January 2022

About you

Please see page 23 of the consultation document for information on privacy.

Which of the following best describes your status? Please tick **ONE** option below.

A hepatitis C stage 1 scheme beneficiary	
A hepatitis C stage 2 scheme beneficiary	
A hepatitis C stage 1 and HIV co-infected scheme beneficiary	
A hepatitis C stage 2 and HIV co-infected scheme beneficiary	
A HIV scheme beneficiary	
A non-infected scheme beneficiary e.g. bereaved spouse or partner	
A family member of a scheme beneficiary	
A health and social care professional	
Responding on behalf of an organisation (if yes please complete below)	
Other (please indicate)	

Hepatitis C stage 1 - Chronic hepatitis C infection which has not progressed to stage 2.

Hepatitis C stage 2 - Chronic hepatitis C infection where the infected person has or has had: (i) cirrhosis; (ii) primary liver cancer; (iii) B cell non-Hodgkin's Lymphoma; (iv) a liver transplant (or is on the waiting list to receive a liver transplant); (v) renal disease due to Membranoproliferative Glomerulonephritis (MPGN)

If you are responding **on behalf of an organisation** please include the details here:

Name	
Job title	
Organisation	
Address	
Telephone no.	
Email address	

Question 1: Rationale for enhanced support

The rationale for introducing enhanced support for hepatitis C (stage 1) – that is, chronic hepatitis C virus (HCV) which has not progressed to advanced HCV (stage 2) - is set out on page 17 of the consultation document. Please read the rationale (set out in the box below) and answer the question which follows.

*Enhanced financial support is intended to provide additional help with living costs for **chronic hepatitis C (stage 1)** scheme beneficiaries where HCV infection or its treatment continues to have a substantial, long-term adverse impact on their quality of life affecting everyday health and wellbeing, or if infection has worsened but is not covered by the stage 2 qualifying conditions. Enhanced support may be available to help those who suffer a significant impact on daily life due to ongoing physical health symptoms, or the legacy of past impacts of HCV (including conditions not related to the liver) or other complications arising due to HCV or treatment.*

It is recognised that chronic HCV has for some people had a considerable impact on quality of life due to psychological factors. Mental health disorders associated with chronic HCV include depression, anxiety, low self-worth or post-traumatic stress disorder and for some people the impact on their mental health has had financial consequences, such as reduced earnings due to inability to work, having to work reduced hours or having to change job role or even career. For others it has led to the breakdown of relationships or made it difficult to leave home or socialise with other people. Enhanced support may be available to help stage 1 beneficiaries with additional living expenses in cases where the mental health impact has prevented them from being able to carry out routine day-to-day activities, such as leaving home, using public transport, shopping, cooking or gardening.

Q 1.1 Do you agree or disagree with this rationale for enhanced support for those at hepatitis C stage 1? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us why:

Question 2: Type of assessment

We need to understand your views on how **applications for enhanced support** will be assessed. Please note that any changes to the NI Scheme as a result of this consultation exercise will **not affect the general application process** for applying to receive support from the Scheme.

It is recommended that you read annex B of the consultation document for further background before responding to this question.

In summary there are two options:

1. **Self-assessment** – you complete an application form with no medical input.
The infected blood support schemes in Scotland (SIBSS) and Wales (WIBSS) use a self-assessment application process.
 - *SIBSS - applicant self certifies, providing examples on the application form of how hepatitis C or its treatment has a significant impact on their ability to carry out routine daily activities;*
 - *WIBSS – applicant self-certifies, ticking a box to indicate that they suffer adverse mental health / wellbeing symptoms related to hepatitis C infection and these affect their ability to carry out day to day activities.*

2. **Clinical assessment** – you complete an application form with medical input from a doctor or other medical professional.
The England Infected Blood Support Scheme (EIBSS) Special Category Mechanism (SCM) uses an evidence-based certification process, which requires the applicant to complete an application form which includes a declaration from a medical practitioner (e.g. consultant, nurse). The medical practitioner must confirm that the applicant is suffering from the condition(s) listed. If the applicant states that they suffer from a mental health condition or chronic fatigue, the medical practitioner must confirm this. The medical practitioner is also required to provide an overall clinical opinion that their patient's hepatitis C infection or its treatment is having a substantial and long-term adverse impact on their ability to carry out daily activities.

Q 2.1 Do you agree that eligibility to receive enhanced support for hepatitis C stage 1 should be **self-assessed** by the applicant, without evidence from a medical practitioner? Or would you prefer an application process that requires **provision of medical evidence by a medical practitioner**? Please tick **ONE** option from the table below.

Self- assessment (no input from medical practitioner)		If you selected this option, please tell us why in the comments box below.
Clinical assessment with medical evidence from medical practitioner		If you selected this option, please tell us why in the comments box below.

Please tell us why you selected the option above:

Question 3: Self-assessment

It is recommended that you read annex B of the consultation document for further background before responding to this question.

In Scotland, applicants self-assess whether they are one of three categories: no noticeable day to day impact; moderately affected; severely affected. To qualify for the severely affected payment (equivalent of SCM in England), applicants must provide information showing examples of the impact hepatitis C has on their day to day life. Most applications are not subject to any additional checks, with the exception of applications to change status from 'moderately' to 'severely' affected, which requires a supporting clinician's letter.

In Wales, applicants are asked to tick a box indicating whether they are suffering from any mental health or well-being issues and if they believe these issues are related to their infection from contaminated blood or blood products. They are then asked if their symptoms affect their ability to carry out day-to-day activities. If applicants answer yes to all three questions, the application is accepted with no further assessment.

Q 3.1 Regardless of whether you selected a preference for a self-assessment or clinical assessment application process; if self-assessment is introduced, which type of system would you prefer to see introduced in Northern Ireland? Please tick **ONE** option below.

Scotland approach	
Wales approach	
Neither / other	

Please tell us why you selected the option above:

A self-assessment approach would rely on an individual's own judgement of the daily impact of hepatitis C and/or its treatment. There is scope for different beneficiaries to interpret the severity of symptoms (physical or mental) differently. In Scotland, guidance is provided with illustrative examples of what might represent inclusion in the 'severely affected' category, to help applicants make their assessment.

Q 3.2 Regardless of whether your preference is for the Scottish or Welsh system or neither, do you agree or disagree that guidance should be produced to help ensure that self-assessments are completed in a consistent way so that the application process is as fair as possible? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us why you selected the option above:

In Scotland beneficiaries who receive the 'severely affected' (equivalent of stage 2) payment are required to re-assess the impact of their hepatitis C every three years.

Q 3.3 Regardless of whether your preference is for the Scottish or Welsh system or neither, do you agree or disagree that hepatitis C stage 1 beneficiaries in receipt of enhanced support should be subject to periodic reassessment? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us why you selected the option above:

If you selected 'agree' or 'strongly agree' please tell us how often you think this should be reassessed:

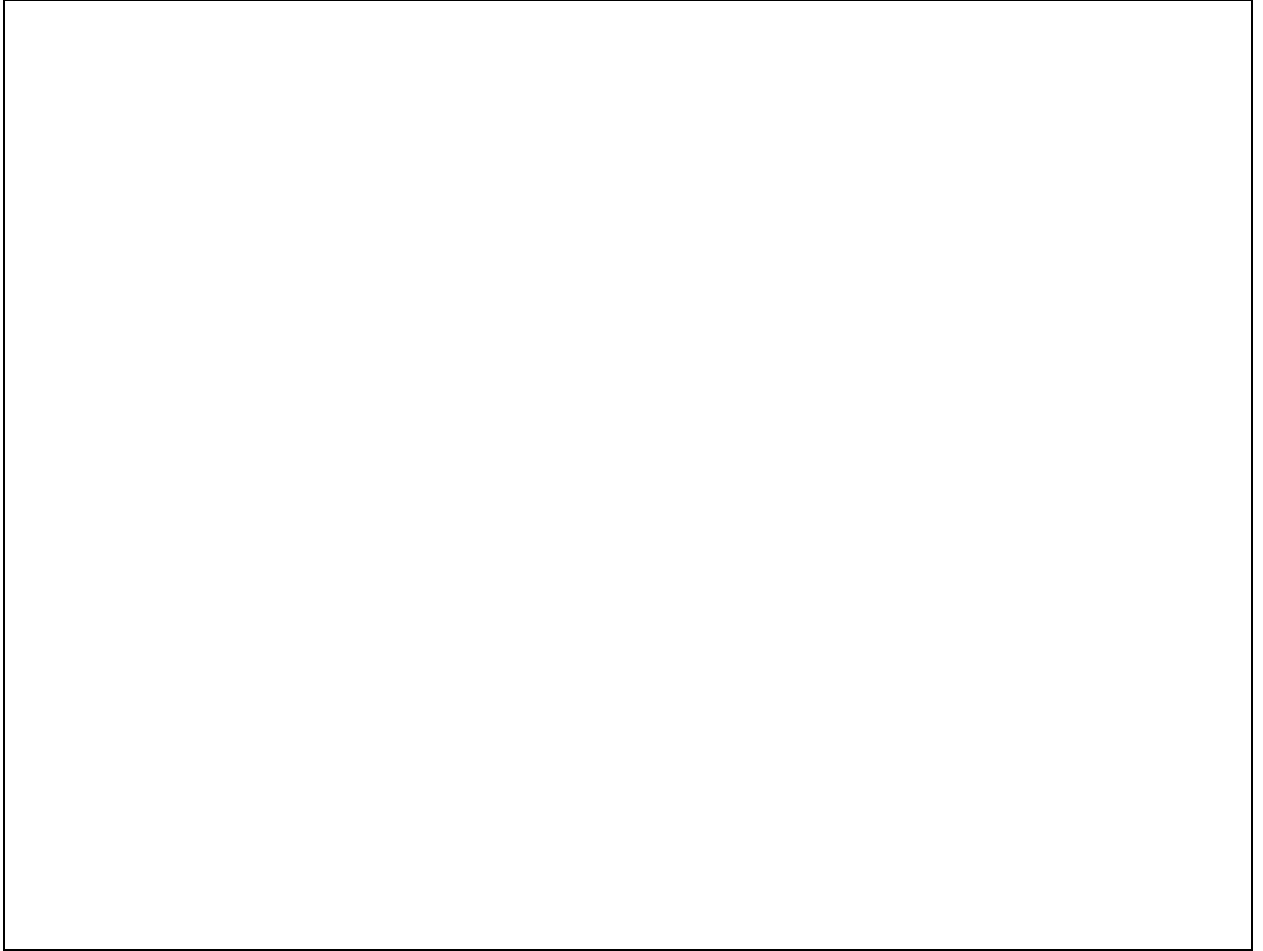
Question 4: Clinical assessment with medical evidence

It is recommended that you read annex B of the consultation document for further background before responding to this question.

Q 4.1 Regardless of whether you selected a preference for a self-assessment or clinical assessment application process, if an application process that requires medical evidence, from a medical practitioner (MP) is introduced, which of the following options do you think would be most appropriate? Please tick **ONE** option from the table below.

1 medical practitioner	Medical evidence required on application form from <u>one MP</u> e.g. consultant, viral hepatitis nurse, GP, psychologist or social worker. Eligibility assessment and decision taken by BSO.	
2 medical practitioners	Medical evidence required on application form from <u>two MPs</u> e.g. consultant, viral hepatitis nurse, GP, psychologist or social worker. Eligibility assessment and decision taken by BSO.	
Two stage medical assessment	Medical evidence required on application form from one MP, followed by an assessment and decision by two independent medical assessors (similar to English SCM system).	

Please tell us why you selected the option above:

A large, empty rectangular box with a thin black border, intended for the user to provide a written response to the question above. The box is currently blank.

Q 4.2 Do you agree or disagree that applications should be assessed against an agreed list of medical conditions? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us why you selected the option above:

The England Infected Blood Support Scheme (EIBSS) uses a list of qualifying conditions which are used as criteria to assess eligibility to receive enhanced support for hepatitis C stage 1. These are shown below. Please consider this list of qualifying conditions and answer the questions which follow.

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, if autoimmune with antiplatelet antibodies

D. Type 2 or 3 mixed cryoglobulinaemia, which is accompanied by:

- D1 Cerebral vasculitis;
- D2 Dermal vasculitis;
- D3 Peripheral neuropathy with neuropathic pain.

E. Affected in performing daily duties due to the infection or the treatment (if applicant has not been diagnosed with one of the conditions listed at A - D, they may be eligible for SCM if they suffer from mental health problems or chronic fatigue as a result of their hepatitis C, which is impacting on their ability to carry out daily activities).

The above conditions must be as a result of treatment with contaminated blood or blood products.

Symptoms must be so severe such that the patient is unable to work and struggles to carry out daily activities e.g. shopping, cooking and cleaning.

Occasional problems or where the medical practitioner considers it unlikely that the impact is substantial and long-term or related to the hepatitis C infection would be unlikely to be successful.

Q 4.3 Do you agree or disagree that the Infected Blood Payment Scheme NI should use the same qualifying conditions (above) as the EIBSS? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us if there are any other qualifying conditions you think should be included:

Please let us know if you think any of the above listed conditions should not be included:

The EIBSS medical assessor must believe that on the balance of probabilities, the reported symptoms are due to the hepatitis C virus and in reaching this conclusion, consideration must be given of the duration of symptoms alongside the duration of the hepatitis C.

The EIBSS medical assessor may therefore wish to see medical evidence from the GP and/ or other specialists to confirm that alternative causes for the symptoms have been checked and excluded.

*EIBSS recognises that some of the evidence sought may be subjective and difficult for a medical practitioner to provide and some answers may require **professional clinical judgment**.*

The EIBSS application form therefore provides the following guidance note for doctors or viral hepatitis nurses completing the application form:

We appreciate that some of what is being sought by way of evidence may be subjective and therefore difficult for you to provide and some answers may rely on asking you to exercise your professional judgment.

Q 4.4 In the absence of factual medical evidence of physical or mental health impact, do you agree or disagree that the medical practitioner should provide their input based on professional clinical judgement? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Please tell us why you selected the option above:

Question 5: Equality Impact Analysis

Q 5.1 An equality impact analysis template (appendix 1) proposes that a full screening is not needed for this consultation. Do you agree or disagree with this analysis? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

If 'disagree' or 'strongly disagree', are you aware of any evidence that would show our policy proposals would negatively impact any particular groups of individuals? If so, which groups?

Question 6: Rural Needs Analysis

Q 6.1 A rural needs impact analysis template (appendix 2) proposes that there are no issues specific to those living in rural areas. Do you agree or disagree with this analysis? Please tick **ONE** option below.

Strongly agree	<input type="checkbox"/>
Agree	<input type="checkbox"/>
Neither agree or disagree	<input type="checkbox"/>
Disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

If 'disagree' or 'strongly disagree', in what way do you think the policy proposal could have an impact on rural needs?

Equality Impact Analysis

This document can be viewed at:

<https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-app-1-equality-screening.pdf> .

It can also be provided separately by email / post on request from ibit@health-ni.gov.uk

Rural Needs Impact Analysis

This document can be viewed at:

<https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-app-2-rural-needs-impact-assessment.pdf> .

It can also be provided separately by email / post on request from ibit@health-ni.gov.uk

Checklist

Please use the checklist below to ensure you have responded to all the questions.

No.	Question	✓
Question 1: Rationale for enhanced support		
1.1	Do you agree or disagree with this rationale for enhanced support for those at hepatitis C stage 1?	
Question 2: Type of assessment		
2.1	Do you agree that eligibility to receive enhanced support for hepatitis C stage 1 should be self-assessed by the applicant, without evidence from a medical practitioner? Or would you prefer an application process that requires provision of medical evidence by a medical practitioner? (please tick ONE option from the table).	
Question 3: Self-assessment Level of medical input		
3.1	Regardless of whether you selected a preference for a self-assessment or clinical assessment application process; if self-assessment is introduced, which type of system would you prefer to see introduced in Northern Ireland?	
3.2	Regardless of whether your preference is for the Scottish or Welsh system or neither, do you agree or disagree that guidance should be produced to help ensure that self-assessments are completed in a consistent way so that the application process is as fair as possible?	
3.3	Regardless of whether your preference is for the Scottish or Welsh system or neither, do you agree or disagree that hepatitis C stage 1 beneficiaries in receipt of enhanced support should be subject to periodic reassessment?	
Question 4: Clinical-assessment with medical evidence		
4.1	Regardless of whether you selected a preference for a self-assessment or clinical assessment application process, if an application process that requires medical evidence, from a medical practitioner (MP) is introduced, which of the following options do you think would be most appropriate? Please tick ONE option from the table below.	
4.2	Do you agree or disagree that applications should be assessed against an agreed list of medical conditions? Please tick ONE option only from the table below.	
4.3	Do you agree or disagree that the Infected Blood Payment Scheme NI should use the same qualifying conditions (above) as the EIBSS?	
4.4	In the absence of factual medical evidence of physical or mental health impact, do you agree or disagree that the medical practitioner should provide their input based on professional clinical judgement?	
Question 5: Equality Impact Analysis		
5.1	An equality impact analysis template (appendix 1) proposes that a full screening is not needed for this consultation. Do you agree or disagree with this analysis?	
Question 6: Rural Needs Analysis		
6.1	A rural needs impact analysis template (appendix 2) proposes that there are no issues specific to those living in rural areas. Do you agree or disagree with this analysis?	

Conclusion

This consultation exercise is an essential part of the policy development process to introduce a system for enhanced financial support for hepatitis C stage 1 beneficiaries on the NI Infected Blood Payment Scheme that is fair and reasonable in the interests of achieving greater parity of financial support across the UK, whilst demonstrating proper accountability for public money.

It is important that we hear the views from anyone who is likely to be affected by this new provision.

The Department would encourage you to respond to the questionnaire by the deadline of **5 January 2022**, in order to ensure that your feedback is taken into consideration when the Minister makes a decision on a process for eligibility assessment.

The Department would like to thank all those who gave up their time to participate in the Working Group which assisted in developing this consultation document and questionnaire.

It is in working together that we are able to achieve the best result possible.

ENDS