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# **Infected Blood Payment Scheme (NI)**

## **Consultation on enhanced support for hepatitis C stage 1**

# **Department of Health (NI) Response**

## **August 2022**

**Title:** Infected Blood Payment Scheme (Northern Ireland) - consultation on enhanced support for hepatitis C stage 1 – Department of Health (NI) response

**Author:** Infected Blood Inquiry Team, Department of Health NI

**Document Purpose:** Targeted consultation – Departmental response

**Issue date:** 3 August 2022

**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

**In March 2021, Health Minister Robin Swann announced plans to introduce enhanced financial support for eligible hepatitis C (HCV) stage 1 beneficiaries on the NI Infected Blood Payment 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 experience ongoing physical or mental health symptoms related to multisystem complications arising from a history of HCV infection or its treatment.

This support was not previously available on the NI Scheme and in order to achieve greater parity across the UK, Minister Swann committed to the introduction of enhanced support payments for eligible HCV stage 1 beneficiaries, at the same rates paid in England, to be backdated to 1 April 2019. This was subject to an assessment process being developed, which Minister Swann committed to taking forward in consultation with key stakeholders.

A targeted consultation process took place from 6 December 2021 to 5 January 2022 to support the development of an eligibility assessment process 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. To support the consultation exercise, a working group was set up with membership including scheme beneficiaries, those 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 consultation response report is available on the Department of Health NI website at: [www.health-ni.gov.uk/publications/infected-blood-payment-scheme-ni-surveys-and-consultations](http://www.health-ni.gov.uk/publications/infected-blood-payment-scheme-ni-surveys-and-consultations). Further background is available on the Department’s website at: [www.health-ni.gov.uk/consultations/infected-blood-payment-scheme-ni-consultation-enhanced-support-hepatitis-c-stage-1](http://www.health-ni.gov.uk/consultations/infected-blood-payment-scheme-ni-consultation-enhanced-support-hepatitis-c-stage-1).

## Department of Health (NI) response

**The new HCV stage 1 (enhanced) payment is intended to provide additional help with living costs to improve quality of life for HCV (stage 1) scheme beneficiaries who experience ongoing physical or mental health symptoms related to multisystem complications arising from a history of HCV infection or its treatment.**

To apply to receive these payments, the applicant must consider their HCV infection and / or its treatment to have a substantial and long-term adverse impact on their health and wellbeing, affecting their ability to carry out routine daily activities.

In developing a process to determine eligibility, the challenge was how to achieve an objective assessment of the impact of HCV infection on those stage 1 beneficiaries, while balancing that with the subjective nature of individuals' personal experience of living with the consequences of HCV and meeting the principles of managing public money.

## Considerations

In deciding on the most appropriate assessment model for the NI Scheme, a number of factors were taken into consideration including feedback from the consultation.

The consultation process sought feedback from key stakeholders including those infected and / or affected and medical professionals. While the total of 61 responses was low, the feedback was helpful in building a picture of the various viewpoints on the issues raised.

Detailed analysis was carried out to compare the enhanced HCV support models in place in the schemes in England, Scotland and Wales and consideration of the advantages and disadvantages of those systems identified through feedback received in surveys and other correspondence.

It was also important to be mindful of the criteria for stage 2 payments on the Scheme, given that the stage 1 (enhanced) payment will be the same annual rate. To be eligible to receive the stage 2 annual payment, the beneficiary must have one of a number of conditions: cirrhosis, primary liver cancer, B-cell non-Hodgkin's lymphoma; or received a liver transplant / on the waiting list or Renal Disease due to Membranoproliferative Glomerulonephritis (MPGN). A comprehensive 16-page application form requires detailed information on medical history and a declaration by the stage 2 applicant's treating medical professional.

A further consideration was the purpose of the NI Scheme, which is to provide **ex-gratia financial support** for individuals and their families who have been infected / affected by HIV, HCV, or both, following treatment with NHS-supplied blood or blood products. The Scheme **does not provide compensation** for past harms. This is an entirely separate matter under consideration by Sir Robert Francis in his independent review and may be considered by the Infected Blood Inquiry, led by Sir Brian Langstaff.

To meet the principles of managing and allocating taxpayer's money responsibly in the public interest, the new model needed to be underpinned by a robust business case which highlighted any potential risks and provided evidence for how funding should be spent now and in future years. This was particularly pertinent in light of the October 2021 Renewable Heat Incentive (RHI) Inquiry Response Report.

## Summary of NI model for HCV stage 1 (enhanced)

There are three criteria to be met to determine if a HCV stage 1 beneficiary is eligible for enhanced financial support:

- i. beneficiary experiences severe physical and/ or mental health symptoms which have an adverse impact on their quality of life;
- ii. symptoms prevent them from being able to carry out routine day-to-day activities, such as leaving home, using public transport, shopping, cooking or gardening;
- iii. symptoms are as a result of the residual impact of chronic HCV infection and/or its treatment.

The Health Minister Robin Swann has decided on a new NI model which is a hybrid of the systems in place in the other three UK schemes. It is designed to strike a balance between the subjective nature of individuals' personal experience of living with the consequences of HCV and the extent to which those symptoms impact on their everyday quality of life, with a more objective clinical assessment of the link to past chronic HCV infection as far as is possible, while meeting the principles of managing public money.

### **Name of new support**

The new payment category on the NI Scheme will be referred to as **HCV stage 1 (enhanced)**. This is to avoid any ambiguity over the distinction between stages 1 and 2. The application process will be entirely paper based and there will be no requirement for an in-person medical assessment.

### **Eligibility**

The NI Scheme will use the same list of conditions as the England Infected Blood Support Scheme (EIBSS) Special Category Mechanism (SCM) which was developed with support from an advisory group of clinical experts.

The purpose of applying this specific list of qualifying conditions is to assist with identifying HCV stage 1 beneficiaries who, as a direct result of HCV infection or treatment, suffer symptoms which have a significant adverse impact on their ability to carry out every day activities.

The EIBSS conditions to qualify for the SCM are those with pathogenetic data or other strong evidence of association with HCV, with the addition of mental health symptoms, persistent fatigue or other significant health and wellbeing impacts.

NI Scheme beneficiaries may be eligible to receive the HCV stage 1 (enhanced) payment if due to the impact of HCV and / or its treatment they:

- A.** have **autoimmune disease** due to or worsened by interferon treatment for hepatitis C (HCV), for example:
  - A1 Coombes positive haemolytic anaemia;
  - A2 Idiopathic fibrosing alveolitis of the lung;
  - A3 Rheumatoid arthritis.
- B.** have **sporadic porphyria cutanea tarda** causing photo sensitivity with blistering.
- C.** have **immune thrombocytopenic purpura**.
- D.** have **type 2 or 3 mixed cryoglobulinaemia** which is accompanied by:
  - D1 Cerebral Vasculitis;
  - D2 Dermal Vasculitis;
  - D3 Peripheral neuropathy with neuropathic pain.
- E.** are suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to HCV infection as a result of infected blood/ blood products, which affect the ability to perform daily tasks.

## Criterion E

Criterion E was included in order to address a concern raised by some consultation respondents who believed that a narrow list of qualifying medical conditions may be too restrictive. Whilst criteria A – D will have clinical evidence recorded on patient medical records to determine eligibility, criterion E remains more subjective.

Therefore stage 1 beneficiaries applying under criterion E will be required to provide a short description of the condition(s) / symptom(s) (physical or mental) which adversely impact daily life and which they believe to be plausibly related to past HCV infection and/or treatment.

For medical professionals, this may require a degree of professional judgement and in some instances may require seeking further evidence from other medical professionals treating the patient.

There will be a separate declaration which has been designed to safeguard public funds whilst supporting clinical staff with a pragmatic approach to the subjective element in this criteria.

### **Self-assessment section**

The NI Scheme will follow the precedent set by the Scottish Infected Blood Support Scheme (SIBSS) and Wales Infected Blood Support Scheme (WIBSS) whereby the applicant will be requested to self-assess their condition and its daily impact.

Applicants will be required to indicate on the application form if they suffer from one of the conditions listed (as detailed above), which are known to be caused by or directly linked to HCV, or if they suffer from significant mental health problems, persistent fatigue and/or other health and wellbeing effects due to HCV infection as a result of infected blood/ blood products, which impact on their ability to perform daily tasks.

Applicants will be required to indicate on the application form at what point following their infection with HCV the symptoms causing the additional difficulties began.

Guidance notes are included in the application form to assist applicants, including illustrative examples of what might merit eligibility for the enhanced support.

### **Medical professional section**

There are numerous conditions associated with HCV and it can be difficult to establish with 100% certainty whether a condition is directly attributable to HCV or due to other risk factors or comorbidities. In order to appropriately safeguard public funding as well as provide a greater degree of consistency and reduce the likelihood of fraudulent applications, a supporting declaration by a medical professional will be required to determine so far as is possible a link to HCV infection and / or treatment.

The application form will include two separate medical professional declarations, depending on whether the beneficiary applies under criteria A – D or criterion E, where the medical professional declaration should be based on the information available and where there is no medical evidence to the contrary.



The declaration is a one-off requirement and supporting medical evidence will not be requested. GPs may claim for costs associated with the time taken to complete the form if they consider that this work is outside of the normal terms of the GP contract. Guidance notes are included in the application form.

## Application process

Written, online and e-mail versions of the application form will be available, to provide options for applicants.

The applicant will be required to complete sections 1 and 2 of the application form and must then pass the form on to a medical professional to complete section 3. Ideally the medical professional should be the clinician who is treating or has treated the applicant for the condition on the grounds of which they are applying for the enhanced support.

The form should then be sent directly by the medical professional to the Scheme Manager in the Business Services Organisation. The preferred option is for the application form to be sent electronically by scanning and e-mailing it from an official e-mail address. Alternatively, a hard copy of the application form with a hospital / GP practice stamp for verification may be sent by post.

The Scheme Manager is available to help with any queries. If the applicant is unable to secure completion of the declaration at section 3, they should return the form to the Scheme Manager who will provide advice. If an application is unsuccessful, there will be an opportunity to appeal the decision. The flowchart at **annex A** provides a summary of the application process pathways.

## Independent medical panel

Under the EIBSS Scheme, all SCM applications are referred for a second stage of assessment by an independent medical panel. In order to ensure applications are assessed as soon as possible, it has been decided that the NI Scheme will not include this stage of assessment.

However, in instances where the medical professional feels unable to support their patient's self-assessment, applicants may be able to have their application referred to the EIBSS independent panel of medical assessors for completion of the medical declaration based on the information provided on the application form.

### **Three Year Audit**

Once in receipt of HCV stage 1 (enhanced) payments, there will be no further re-assessment. However, the October 2021 RHI Inquiry Response Report stated that all government Departments must put in place systems to monitor schemes to ensure that implementation is working in practice especially when a third party is involved in implementing and/or administering the scheme or policy.

To meet this requirement, it has been agreed that an audit of all NI Scheme members will take place every three years.

This will be carried out by the BSO which administers the Scheme on behalf of the Department of Health (NI). Scheme beneficiaries **in all payment categories** will be required to sign a form to confirm whether there has been a change of circumstances including (in the case of HCV or HIV beneficiaries) whether their condition has deteriorated, improved or remains unchanged. There will be no requirement for medical professional verification.

Where a beneficiary notifies the NI Scheme that their condition has significantly improved, their annual payments may revert back to the standard stage 1 rate after a period of receiving the enhanced support, however there would be no question of basic stage 1 support ceasing.

If at any stage, a beneficiary has reason to believe they may no longer be entitled to receive the HCV stage 1 (enhanced) payment, they should inform the NI Scheme to ensure their annual payments revert to the standard stage 1 rate and that they are not overpaid.

The audit is a necessary means of ensuring records are up to date and accurate and that public funds are being allocated responsibly.

## HCV stage 1 (enhanced) payments

The Department of Health and Social Care (DHSC) in England agreed to fund payments to support the introduction of enhanced support for Hepatitis C stage 1 beneficiaries backdated to 1 April 2019, up to the current 2022/23 financial year.

Going forward, there is limited funding available across of all of health and social care in NI and it will not be possible to keep a permanent backdating policy in place. The NI Health Minister Robin Swann has therefore decided that a cut-off date of **30 June 2023** will be applied **for backdating** of any new eligible applications. Successful applications received after this date, will be paid from the date of the application.

## Summary

There must be some means of measuring how beneficiaries fit into the various payment categories on the NI Scheme and whilst mindful of the suffering and distress beneficiaries have experienced, the Department must meet its obligation to take all steps required in managing and deploying public resources responsibly in the public interest and ensuring any new scheme is underpinned by a robust evidence base that can stand up to scrutiny now and in future years.

The agreed model is designed to place the greatest degree of control possible in the hands of the applicant, providing them with the opportunity to describe the impact on their daily life as it is acknowledged that they are best placed to assess this themselves. The supporting medical professional declaration is intended to help so far as is possible to determine the link to HCV and / or treatment, to provide the necessary assurances in terms of responsible management of public money as well as consistency in how applications are processed.

The Department will take steps to formalise the new policy and work with the BSO to implement the new financial support. The BSO will continue to monitor the new support to ensure it is operating as intended in practice and will address any issues or concerns which arise.

## Infected Blood Payment Scheme NI HCV stage 1 (enhanced) support Application process

Annex A

