Department of
Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Infected Blood Payment Scheme (NI)

# Consultation on enhanced support for hepatitis C stage 1 – Report

May 2022

# Contents

**Introduction** ........ 3

**Consultation questionnaire findings** ........ 4

**Section One: Rationale for enhanced support** ........ 4

**Section Two: Type of assessment** ........ 5

**Section Three: Self-assessment** ........ 7

**Section Four: Clinical assessment with medical evidence** ........ 12

**Section Five: Equality impact analysis** ........ 16

**Section Six: Rural needs impact analysis** ........ 16

**Section Seven: Acknowledgments** ........ 16

## Introduction

On 25 March 2021, the Northern Ireland Health Minister Robin Swann announced 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 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 was subject to a process for assessment being developed, which Minister Swann committed to taking forward in consultation with stakeholders.

This Department of Health issued a consultation document on 6 December 2021 to seek views from relevant stakeholders on how eligibility for enhanced financial support for hepatitis C stage 1 should be assessed. The consultation closed on 5 January 2022 and the following is a report of the findings.

## Consultation questionnaire findings

As part of a consultation on enhanced support for hepatitis C stage 1, a questionnaire was issued to relevant stakeholders to complete. A total of 61 questionnaires were received. It is important to recognise the relatively small number of responses and caution should be exercised when drawing conclusions from the findings.

Over half of responses were from those who described their status as *a hepatitis C stage 1 scheme beneficiary* (33 responses).

| A hepatitis C stage 1 scheme beneficiary | A hepatitis C stage 2 scheme beneficiary | A non-infected scheme beneficiary | A family member of a scheme beneficiary | Other status categories |
|---|---|---|---|---|
| *33 responses* | *6 responses* | *9 responses* | *7 responses* | *6 responses* |

## Section One: Rationale for enhanced support

Respondents were asked to consider the proposed rationale for introducing enhanced support for hepatitis C (stage 1), with the majority of responses (93%) indicating agreement.

61 responses

**Comments**

49 respondents provided comments on the rationale for enhanced support covering themes such as:

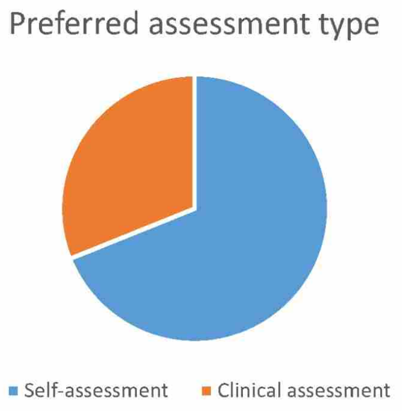
- Physical impact - various impacts among stage 1s e.g. fatigue, breathlessness, physical pain, nausea, liver damage;
- Important to continue to recognise the difference between stage 1 & 2;
- Psychological / mental health impact e.g. depression / anxiety / stress / low self-esteem / isolation / loneliness / brain fog;
- Financial impact e.g. impact on career, inability to work, high levels of sickness absence, reduced income;
- Impact on family / marriage / friends; stigma / keeping illness private;
- Achieves greater parity across the UK.

**Department of Health observations:**

There was a general consensus that some beneficiaries at stage 1 suffer to a greater extent than others in the same payment category and therefore the additional support is justified to help those experiencing a greater impact. It was noted that many respondents viewed the support provided on the Scheme as a form of compensation; it is important to be aware that the Infected Blood Payment Scheme NI provides ex-gratia financial support to assist with day to day living based on the residual impact of hepatitis C or its treatment in the present day. Compensation for past impact cannot be taken into consideration and is an entirely separate matter.

## Section Two: Type of assessment

Concerning how applications for enhanced support would be assessed, respondents were asked to indicate their preference for self-assessment (no input from medical practitioner) or clinical assessment (with medical evidence from healthcare practitioner). Around two-thirds of responses indicated self-assessment as their preferred option (42 responses, 69%) with the remaining third opting for clinical assessment (19 responses, 31%).



**Comments**

54 respondents provided comments on why they chose their preferred option.

In favour of self-assessment (no healthcare practitioner involvement):

- Quicker and easier for applicants to understand;
- Applicant best placed to understand their own condition and extent of daily impact;
- Fatigue / trauma at recalling past experience / stress of further assessment / been through enough / already provided evidence to Inquiry;
- Mistrust in healthcare practitioners (HCP) due to past experience;
- Some may not have sought professional support for mental health symptoms;
- Reduced burden on medics / no one healthcare practitioner knows enough about the impact;
- Belief that self-assessment would achieve greater UK 4 nations parity;
- Greater expense / time required for clinical assessment.

In favour of clinical assessment (with medical evidence from a healthcare practitioner):

- Evidence of impact (physical or mental health) readily available in patient's medical records;
- Those eligible will be severely impacted and therefore under the care of an appropriate healthcare professional (HCP);
- To ensure applications are honest and fair;
- To ensure consistent approach with other financial support on the NI Scheme;
- To ensure greater consistency across applications i.e. self-assessing the severity of physical and / or mental health symptoms and the impact on quality of life likely to be more subjective;
- HCP has experience, qualifications and skill to advise if condition is likely to be caused by HCV;
- Mitigate risk of potential fraud / abuse of system;
- Management of public money / ensure public funding targeted at those who need it.

**Department of Health observations:**

A significant number of respondents commented that only they as individuals could assess the extent to which the symptoms they experience as a result of hepatitis C and/or treatment affect their daily life. Some respondents indicated a lack of faith or trust in healthcare practitioners (HCP) due to having been infected through NHS treatment, whilst others believed that there isn't a sufficient understanding among HCPs about the range of conditions associated with HCV.

However, those in favour of some form of clinical based assessment commented that HCPs have the necessary qualifications, skills and experience to assess whether a patient's symptoms are the result of HCV and whether they are eligible and this should be a straightforward process as the medical evidence is available in medical notes to support applications. It was noted that around a third of stage 1 beneficiaries (10 out of 33 responses, 30%) who responded to the consultation indicated a preference for clinical assessment, with comments suggesting that this would make the system fairer and more robust, reducing the risk of fraud and ensuring public funding is allocated to those who need it most.

As some respondents noted, supporting medical evidence is required when joining the NI Scheme, when moving to stage 2 or when applying for discretionary grants, so to seek supporting information from a HCP in applying for enhanced S1 would maintain consistency with other aspects of the scheme.

DoH (NI) considers that in a clinical assessment scenario, the potential impact on healthcare practitioners would be low, and for GPs minimal, given the small numbers who may be eligible to receive the additional support. DoH (NI) notes that NI Scheme manager has an administrative role in managing the Scheme on behalf of the Department and is not medically qualified to determine if the applicant falls within the description set out in the agreed rationale.

DoH (NI) will consider how to achieve a straightforward system which ensures a balance of involving the applicant in the assessment of their condition and its impact on quality of life, with possible supporting additional input from the treating HCP on the causal link to HCV, to ensure resources are deployed responsibly in the public interest.

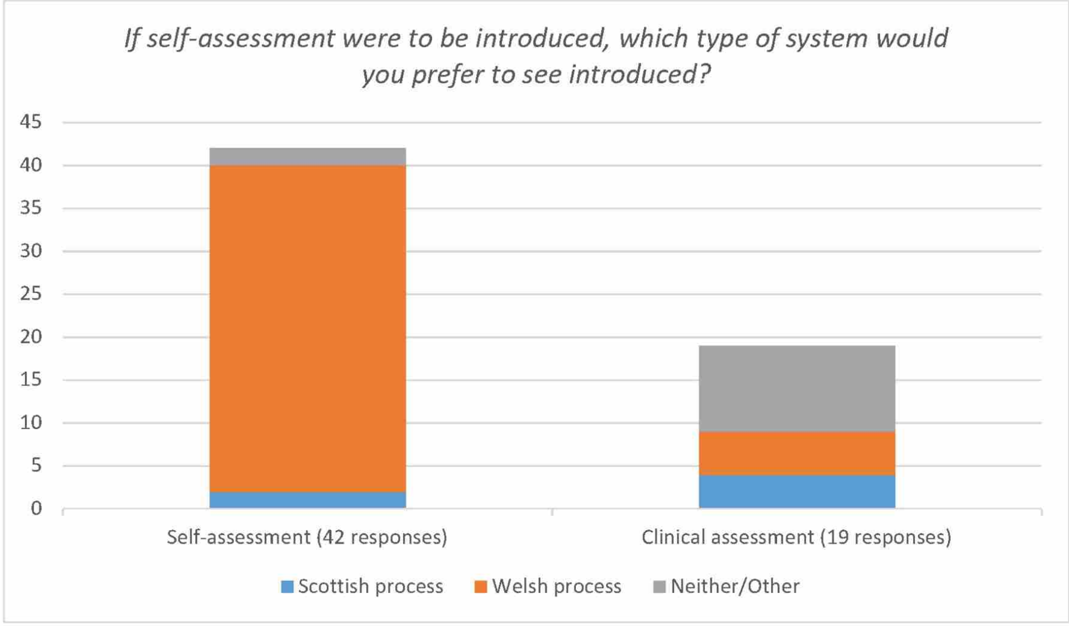
## Section Three: Self-assessment

All respondents were asked about their views on a potential self-assessment process, regardless of whether this was their stated preference. Where appropriate, responses have been split, detailing the views of both groups.

In addition to the additional supporting paper providing detailed background on the schemes in the rest of the UK, the consultation questionnaire included a brief description of the self-assessment processes in Scotland and Wales. Respondents were asked to indicate their preferred approach, with the majority opting for the Welsh process (43 responses).

61 responses

There was a difference in preferred approach when considering those who opted for self-assessment and those who opted for clinical assessment; the majority of those who opted for self-assessment chose the Welsh process (38 out of 42 responses) while those that had opted for clinical assessment were more likely to choose the *Neither/Other* option (10 out of the 19 responses).



**Comments**

45 respondents provided comments on their reasons for preferred process.

Scottish:

- Provision of evidence / examples will cut down on potential for fraud;
- Providing no evidence / examples doesn't make sense;
- This is a fairer process.

Welsh:

- Less traumatic / stressful process;
- More straightforward process / less bureaucracy / faster / simpler / fairer;
- Less invasive / intrusive.

Neither:

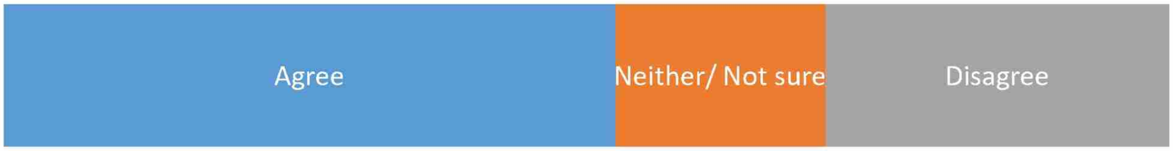
- Clinical evidence should be required to support application / avoid fraudulent claims;
- Would like public apology and compensation;
- English approach is fairer;
- Both systems (Scottish and Welsh) have shortfalls and imbalance in terms of physical/mental aspects.

**Department of Health observations:**

The preferred choice of self-assessment model was the Welsh system, with the main reason being that it would be easier and less stressful for applicants. Some respondents commented that adopting the Welsh model would achieve greater parity, however to take this theory to its logical conclusion would suggest that equally, adopting the England or Scotland model would achieve greater parity as all of the other three UK schemes have different methods to determine eligibility for the higher stage 1 support. DoH (NI) will consider how to achieve a system for assessment of eligibility which is as straightforward as possible for applicants whilst sufficiently safeguarding public funds.

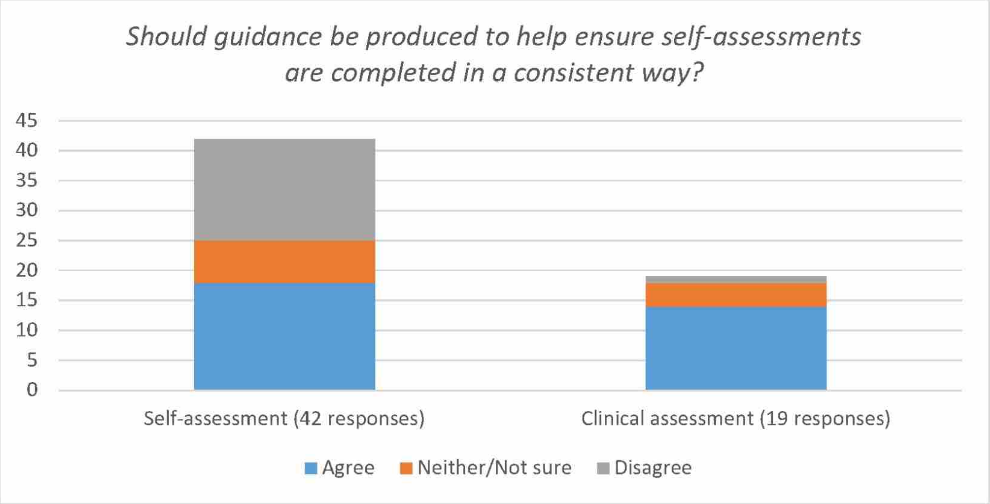
## Guidance

Respondents were asked whether they agreed or disagreed with the suggestion that guidance should be produced to help ensure self-assessments are completed in a consistent way so that the application process is as fair as possible. Overall around half of respondents agreed with the suggestion (32 responses, 52%), 18 respondents disagreed (30%) and 11 respondents (18%) indicated neither/not sure.



61 responses

As before, there was a difference in responses between those who preferred self–assessment and those who preferred clinical assessment.



**Comments**

44 respondents provided comments regarding their views on guidance.

Agree:

- Should help applicants understand criteria and how to complete the form / more user-friendly;
- Should speed up the process;
- Belief that it would reduce stress / anxiety;
- Likely to make applications more consistent / level playing field / fairer system;
- Would help make the system more accountable / less open to abuse or fraudulent claims.

Disagree:

- Belief that it could cause confusion / ambiguity;
- Could make the application process more difficult / time-consuming;
- Guidance may not cover the wide range of symptoms / conditions;
- Welsh system is clear and to the point / there is no guidance in Wales;
- People understand how to explain their condition, too many forms means recalling past trauma.

**Department of Health observations:**

Some respondents commented that adopting the Welsh model would achieve greater parity, however as noted in the observations earlier, to take this theory to its logical conclusion would suggest that equally, adopting the England or Scotland model would achieve greater parity as all of the other three UK schemes have different methods to determine eligibility for the higher stage 1 support. Guidance would be helpful in distinguishing between those conditions or symptoms relating to consequences of hepatitis C infection or its treatment and those that are more likely to be due to haemophilia / bleeding disorders or other factors. Guidance is provided on the Schemes in England and Scotland and is considered important to ensure greater consistency in how applications are completed and to help applicants with their assessment. If guidance is to be provided, this would be drafted in a way that is clear and concise and intended to help applicants. The aim would be to include the guidance as notes in the application form, avoiding the need for additional supporting material, to keep paperwork to a minimum and ensure the application process is as straightforward and stress-free as possible.

Respondents were asked whether they agreed or disagreed with the suggestion that hepatitis C stage 1 beneficiaries in receipt of enhanced support should be subject to periodic reassessment. Over half (37 respondents) disagreed with this suggestion; the majority of those who had opted for self-assessment disagreed (33 out of 43 responses) whilst those who had opted for clinical assessment were more likely to agree (12 out of 19 responses).

| Overall | Self-assessment | Clinical assessment |
|---|---|---|
| 25% agree<br>*15 responses* | 7% agree<br>*3 responses* | 63% agree<br>*12 responses* |
| 15% neither<br>*9 responses* | 14% neither<br>*6 responses* | 16% neither<br>*3 responses* |
| 60% disagree<br>*37 responses* | 79% disagree<br>*33 responses* | 21% disagree<br>*4 responses* |

Of the 15 respondents that agreed with the suggestion concerning reassessment, 7 thought annual assessment would be appropriate with a further 5 respondents indicating between 2 and 5 years.

**Comments**
46 respondents provided comments regarding their views on reassessment:

Agree to reassessment:

- May be improvement or full recovery from symptoms (mental or physical) following treatment;
- Condition may deteriorate and beneficiary may be eligible for stage 2 (including lump sum);
- Would reduce potential for fraudulent claims / ensure system not open to abuse.

Disagree to reassessment:

- Belief that HCV is incurable / symptoms unlikely to ever improve;
- View that this is unnecessary / humiliating / stressful / embarrassing / fatigue at recalling past experience;
- Belief that this would be a form of UK disparity.

**Department of Health observations:**

It is important to distinguish between medical assessment (which is the responsibility of the treating clinician) and regular review to monitor whether a beneficiary continues to meet the eligibility criteria for enhanced financial support. DoH (NI) has observed that some respondents may have misinterpreted what reassessment meant; in this context it is intended to mean a paper-based review by the NI Scheme, perhaps every two or three years in the form of a simple form to be returned to BSO with no requirement for an 'in person review' or medical input. Such review is considered to be important in the context of responsible management of public money. In terms of UK parity, in Scotland reassessment is carried out by the beneficiary every three years.

HCV is curable and many beneficiaries who suffered liver damage during the period of chronic infection have been successfully treated and had the damage reversed by new effective anti-viral treatments, however it is acknowledged that some continue to experience symptoms as a result of residual damage of HCV in the present day and for many of those people their condition may be unlikely to improve. The Infected Blood Inquiry Hepatitis Expert Group concluded that people previously chronically infected with HCV but now PCR negative can continue to experience long-term health consequences from the consequences of viral damage to the liver or damage outside the liver ('extrahepatic manifestations'), long-term effects attributable directly to treatment and psychological impacts. However, many of the physical and mental health conditions associated with having a higher prevalence among those with HCV infection are also common among the general population.

DoH NI will consider how to achieve a system which will identify those who continue to be eligible for additional support in the long-term, due to ongoing symptoms which are a direct result of past HCV infection or its treatment, but to do so in an empathetic way that does not cause further stress for those beneficiaries.

## Section Four: Clinical assessment with medical evidence

All respondents were asked for their views on a potential clinical assessment process, regardless of whether this was their stated preference. Where appropriate, responses have been split, detailing the views of both groups.

*If an application process that requires medical evidence from a medical practitioner is introduced which of the following options do you think would be most appropriate?*

One medical practitioner
51 responses
(*84% of respondents*)

Two medical practitioners
7 responses
(*11% of repondents*)

Two stage medical assessment or no response given
3 responses
(*5% of respondents*)

The majority of those who had opted for self-assessment chose *one medical practitioner* however it should be noted that a number of respondents indicated that whilst they selected this option for this specific question, their preference remained self –assessment.

Of those who had opted for clinical assessment, the responses were more mixed with around half preferring *one medical practitioner* (10 out of 19 responses), around a third choosing *two medical practitioners* and the remainder opting for the *two stage medical assessment*.

**Comments**
49 respondents provided comments regarding their choice:

One medical practitioner:
- Belief that one HCP should be sufficient;
- Belief that the process would be less invasive / allow greater privacy;
- View that the process would be less stressful.

Two medical practitioners:
- View that this would make the process more reliable;
- Belief that this type of process would satisfy fairness and ensure equity;
- Symptoms may fall into more than one medical discipline e.g. medical / social / psychological.

Three medical practitioners:
- Belief that this would ensure less potential for fraud.

**Department of Health observations:**
In addition to the responses received from the infected/affected community, a very small number of responses were received from clinicians. While the clinician responses strongly agreed with the rationale for providing enhanced support, there were opposing views on how eligibility should be assessed. One viewpoint indicated a strong preference for the Welsh system of a simple self-assessment with no type of medical input or reassessment, whilst another view was that robust clinical assessment with periodic reassessment is required as there is the potential for the patient to fully recover from HCV following successful treatment. DoH (NI) will consider how to ensure that the system for assessment of eligibility introduced for NI is as straightforward as possible for applicants and clinicians whilst providing an appropriate level of accountability in terms of managing public money.

## Qualifying medical conditions

Respondents were asked if they agreed or disagreed with the suggestion that applications should be assessed against an agreed list of medical conditions. Around half of respondents (29 responses) disagreed, with the remainder split between agreed (19 responses) and neither/not sure (13 responses).

61 responses

Two-thirds of those who had opted for self-assessment disagreed (28 out of 42 responses) whilst a similar proportion of those who had opted for clinical assessment agreed (13 out of 19 responses).

**Comments**

44 respondents provided comments regarding their view of an agreed list of medical conditions.

Agree to assessment against an agreed list of medical conditions:

- Belief this would be a more consistent approach;
- View that there is recognised clinical evidence readily available;
- Belief this would support / justify approval of application;
- Clinical assessment would help to determine severity of symptoms / clinician better able to understand conditions.

Disagree with assessment against an agreed list of medical conditions:

- Belief that people should be treated as individual;
- View that symptoms vary significantly among different people;
- Belief that a list would not be comprehensive enough to cover all symptoms;
- Belief that using a list of qualifying conditions would be out of step with UK parity.

**Department of Health observations:**

Research* has shown that there are numerous recognised conditions associated with HCV (many of which are highly prevalent in the general population), however there is an important distinction to be made between extrahepatic (non-liver) manifestations associated with HCV and those as a result of HCV (direct causation).

As the higher payment is to reflect the severity of impact of HCV / treatment, there also needs to be consideration of how the condition or symptoms impact on everyday life. Enhanced support is not a form of compensation or an automatic right due to infection alone; it is intended for those genuinely in need of additional financial support.

DoH (NI) will consider the issue of qualifying criteria taking into account the views from respondents and independent medical advice as well as clinical data from a range of sources.

* Expert Report to the Infected Blood Inquiry: Hepatitis

When asked to indicate if they agreed or disagreed with the suggestion that the NI scheme should use the same qualifying conditions as the England Infected Blood Support Scheme (EIBSS), around half of respondents disagreed (29 out of 61 responses), a quarter agreed (16 responses) and a quarter responded neither/not sure (16 responses).

As with previous questions, there were differences in responses between those who had opted for self-assessment (two-thirds of the 42 respondents disagreed) and those who had opted for clinical assessment (two-thirds of the 19 respondents agreed).

**Comments**

35 respondents provided comments regarding their views on whether the NI Scheme should use the same qualifying conditions as EIBSS. The reasons given in favour or against using the EIBSS list are similar to the reasons given in the previous section relating to whether or not there should be a list of qualifying conditions.

Agree:

- Would be more consistent / ensure everyone is assessed fairly;
- Clinical experts drew up the EIBSS list of conditions caused by HCV based on medical research;
- Applicants would not have the medical knowledge to determine if a condition was caused by HCV / only a qualified medical specialist would know;
- Would achieve greater parity with England.

Disagree:

- Belief that the list is too narrow and should be as broad as possible to include all possible health implications of HCV infection;
- EIBSS does not list mental health conditions;
- Victims have suffered enough without the indignation of having to fit into a pre-defined category;
- Would not achieve UK parity as Scotland and Wales do not use the same conditions as EIBSS.

**Department of Health observations:**

The SCM in England was designed to benefit those who have been diagnosed with one of a number of set hepatitis C related conditions, which experts advised would cause people with these conditions to experience a substantial and long-term adverse impact on their daily lives. It is also there to support those who can show that HCV infection or its treatment has a substantial and long-term adverse impact on their mental health, and/or that fatigue due to HCV has a substantial and long-term adverse impact on their daily lives. In developing the criteria and process, DHSC listened to beneficiaries' expectations about what the SCM should offer, consulted with a Reference Group and experts and took into account the government's obligations under the Equality Act 2010. DHSC England set up an advisory Reference Group of experts to help inform and shape their SCM policy. Members of this Group included scheme beneficiary representatives, clinical experts, relevant charities (the Hepatitis C Trust and the Haemophilia Society) and the Scheme administrators. DoH NI will consider whether it would be appropriate to adopt the EIBSS list of conditions as guidance or qualifying criteria in the assessment process for the NI Scheme.

## Professional clinical judgement

The same proportion of respondents agreed as disagreed with the suggestion that in the absence of factual medical evidence of physical or mental health impact, the healthcare practitioner should provide their input based on professional clinical judgement (24 responses each) with the remaining 13 responses indicating neither/not sure.

**Comments**
40 respondents provided comments regarding their views on a healthcare practitioner providing input based on professional clinical judgement.

Agree:
- Belief this would provide greater confidence in the process;
- View that this would make the process more reliable;
- Recognition of expertise / knowledge of conditions associated with HCV.

Disagree:
- Belief that that the patient should be listened to / believed / trusted;
- Many feel they have been through enough medical assessment;
- View that this would be in line with four nations parity as not all regions have guidance;
- Belief that if infected through contaminated blood/blood products, all should qualify.

**Department of Health observations:**
Many respondents agreed that if medical evidence was not available, the application process should be based on the HCP's judgement as they have extensive knowledge and experience of HCV and a good understanding of its impact on their patient's health and wellbeing. Some respondents said that this would make the application process fairer and more reliable and would help to safeguard the system to ensure those in need of the additional financial support receive it.

Many felt that if an applicant meets the criteria for enhanced support (as set out in the agreed rationale) he or she will be severely unwell and therefore already under the care of an appropriate HCP and therefore the supporting medical evidence will be readily available in the patient's notes to support the application, so it's unlikely that a professional judgement call would be necessary. Other respondents stated that in all cases there must be medical evidence to support a claim for enhanced support

Of the many respondents who did not agree with professional judgement being used, the main reason given was that the patient is best placed to understand their own condition and should be trusted to provide an honest assessment of how it impacts on daily life. Some believed it would be unfair because HCPs are not involved at all in the Scottish and Welsh Schemes.

Enhanced support is not a form of compensation for infection alone; it is intended for those genuinely in need of additional financial support. DoH (NI) will consider how to ensure that the system for assessment of eligibility is as straightforward as possible for applicants whilst sufficiently safeguarding public funding.

## Section Five: Equality impact analysis

*An equality impact analysis template proposes that a full screening is not needed for this consultation. Do you agree or disagree with this analysis?*

| Agree | Neither/Not sure | Disagree |
|---|---|---|
| 32 responses | 22 responses | 7 responses |
| (*52% of respondents*) | (*36% of respondents*) | (*11% of respondents*) |

## Section Six: Rural needs impact analysis

*A rural needs impact analysis template proposes that there are no issues specific to those living in rural areas. Do you agree or disagree with this analysis?*

| Agree | Neither/Not sure | Disagree |
|---|---|---|
| 30 responses | 19 responses | 12 responses |
| (*49% of respondents*) | (*31% of respondents*) | (*20% of respondents*) |

## Section Seven: Acknowledgments

The Department of Health NI thanks the members of the Working Group set up to shape this consultation document, which included representatives from the Business Services Organisation (BSO), independent clinical representation, Haemophilia NI, The Haemophilia Society, Families and Friends of Haemophilia NI and those infected and/or affected by contaminated blood. The Department also thanks all those who took the time to respond to the consultation.