



Department of
Health

An Roinn Sláinte

Männystrie O Poustie

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Northern Ireland Infected Blood Payment Scheme

Beneficiary Survey

October 2020

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Introduction

The Infected Blood Payment Scheme for Northern Ireland is a payment 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, tissue or blood products.

The Scheme offers various types of financial support, including:

- one off ex gratia payments in relation to HIV, chronic & advanced Hepatitis C;
- one off ex gratia payments in relation to widows, widowers and partners of deceased beneficiaries;
- monthly or quarterly support payments for infected beneficiaries;
- annual winter fuel payment;
- discretionary one off grant support;
- discretionary income top-up support (means-tested) for non-infected beneficiaries.

The Scheme was established in November 2017 and is administered by the Business Services Organisation (BSO) on behalf of the Department of Health NI. The Scheme provided the same levels of support as the England Infected Blood Support Scheme (EIBSS) in most aspects until April 2019 when, following representations made by the Chair of the UK Infected Blood Inquiry about severe hardships experienced by people who have been infected or otherwise affected, EIBSS payment rates to infected beneficiaries significantly increased.

In January 2020, the Minister of Health in Northern Ireland, Robin Swann announced that the Department of Health in Northern Ireland (DoH NI) would carry out a three phase review of the Scheme. The purpose of the review was to address the disparity that arose as an unintended consequence of the uplift in England in 2019 and also to address a range of issues which remained unresolved as a result of Northern Ireland being without an Executive and Health Minister from 2017 until 2020.

Phase one commenced in January 2020 and concluded in March 2020 and addressed the immediate disparity with England on annual financial support, which had occurred in the 2019/20 financial year. Phase two commenced in April 2020 and will continue throughout 2021 looking at all other aspects of support provided on the Scheme. Phase three will address any recommendations made by the ongoing UK Infected Blood Inquiry, chaired by Sir Brian Langstaff.

As a first step in Phase 2, in August 2020 Minister Swann introduced a permanent uplift in annual financial support to infected beneficiaries, increasing payments to the same levels as rates paid in England. The Minister gave a commitment to involve stakeholders in the review of the Scheme and in August 2020 commissioned a survey seeking the views of all existing beneficiaries on the range of support available on the Scheme. In September 2020 a questionnaire was issued to all 101 beneficiaries of the Scheme and a total of 56 questionnaires were returned giving a response rate of 55.4%.

The results of the survey are set out below and will be taken into consideration in any potential further reform of the Scheme as phase two of DoH NI's review continues.

Acknowledgments

The Department of Health NI thanks the Business Services Organisation (BSO) for issuing the questionnaires and collecting the responses on the Department's behalf; colleagues at the Belfast Health and Social Care Trust, including those in the Psychology Department, for their input in developing the questionnaire and to all beneficiaries of the Scheme who returned responses.

Survey findings

A questionnaire was sent to 101 beneficiaries of the Northern Ireland Infected Blood Payment Scheme and a total of 56 questionnaires were returned - a response rate of 55.4%. **It is important to recognise the relatively small number of responses and caution should be exercised when drawing conclusions from the findings.**

Section One: Financial support for the bereaved

Respondents were asked if they were aware that a £10,000 bereavement payment is available to spouses of those who have passed away as a result of receiving NHS-supplied infected blood. There were 49 valid responses to the question; around half (24 respondents) indicated that it was not applicable to them, 15 respondents were not aware, and 10 respondents were aware and had received the payment.

Comments from respondents

14 respondents provided comments on how they felt financial support to the bereaved could be improved, covering themes such as:

- Eligibility;
- Awareness;
- Amount, and;
- Lifelong support.

The Survey feedback suggested that there needs to be better promotion of the £10,000 bereavement payment raise awareness. A number of respondents suggested that it should be available to the next of kin, such as a sibling, for those who are not married or do not have a partner. Some suggested that the amount is not enough to cover funeral costs.

Observations by DoH

Improving promotion of the bereavement payment will be addressed as DoH work to improve communications as part of phase 2 of the ongoing review of the NI Scheme. Other issues raised will be considered and kept under review. The ongoing review of NI Scheme is considering annual financial support for non-infected bereaved.

Section Two: Income top-ups

Income top-ups are a discretionary monthly payment to increase household income to help with general living costs.

Around half of respondents were aware that income top-ups are available.

Three-fifths of respondents (33) indicated that they did not receive income top-ups and seven respondents did not provide a valid response to the question.

Of those who had received the top-up (16 respondents), similar numbers indicated they were satisfied as dissatisfied.



Comments from respondents

Nine respondents provided comments detailing the reasons for their dissatisfaction covering themes such as:

- Eligibility;
- Awareness;
- Amount;
- Process.

The general consensus among respondents was that income top-ups should not be means tested. Some respondents were not aware that bereaved spouses were entitled to income top-ups.

Observations by DoH

Income top-ups are being phased out as payment rates for infected beneficiaries have been significantly increased.

Section Three: Winter fuel payment

Almost all respondents were aware they could apply for a winter fuel payment.

Of those that have received the winter fuel payment (53 respondents), over two-thirds (37 respondents) were satisfied that the amount met their needs.



53 respondents

Comments from respondents

10 respondents provided comments on the winter fuel payment covering themes such as:

- Eligibility;
- Awareness;
- Amount.

Some feedback suggested that the winter fuel payment is not enough to cover the costs of fuel and that it should be higher for those who live alone or should vary depending on medical conditions.

Observations by DoH

DoH will keep the winter fuel payment under review.

Section Four: Discretionary support (one off grants)

Around a third (20 of the 56 respondents) were aware that discretionary financial support is available, with eight respondents indicating they had received such support.

Comments from respondents

Five respondents provided comments on discretionary support covering themes such as:

- Awareness;
- Decision-making process.

Some respondents said they were not aware that discretionary support was available or if they did, were not clear on how to apply. It was suggested that decisions should be made by independent assessment, rather than civil servants in the DoH NI.

Observations by DoH

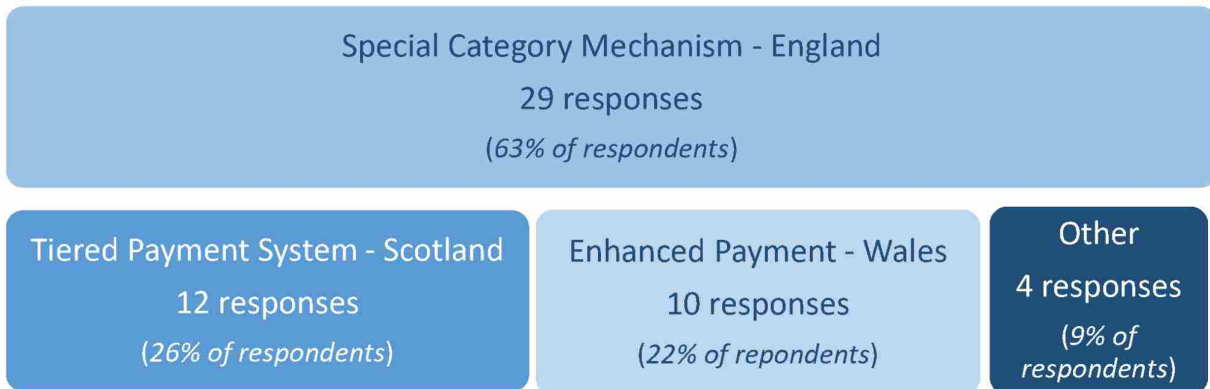
Developing an NI policy for discretionary support is part of the ongoing review of the Scheme. DoH NI will liaise with the BSO to ensure that communication is issued to all beneficiaries making sure they are aware of this support and how to apply.

Section Five: Enhanced support for Hepatitis Stage 1 beneficiaries

Around eight in 10 respondents reported being in favour of enhanced support for Hepatitis Stage 1 beneficiaries being introduced in Northern Ireland; the remaining respondents indicated they were not sure.

Respondents were presented with a brief outline of the models 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.



Comments from respondents

Eight respondents provided comments covering themes such as:

- Eligibility criteria;
- Medical assessment;
- Further consultation.

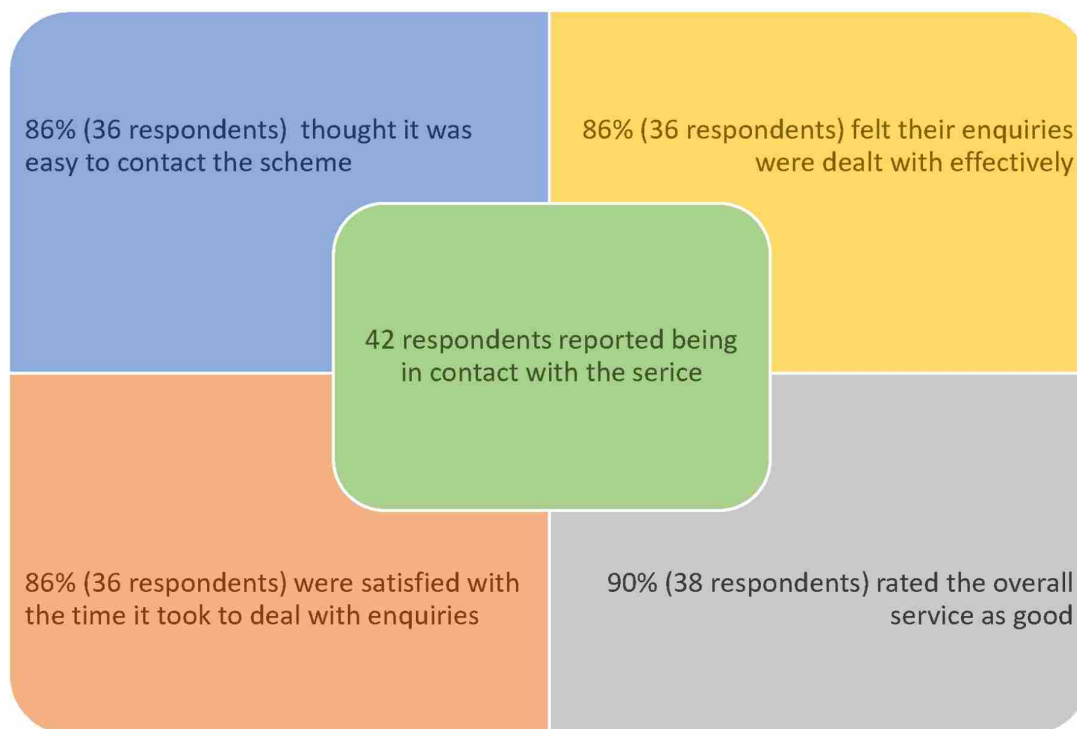
Those who commented suggested that there was a need for some form of additional payment to recognise the impact of Hepatitis C stage 1 on some sufferers – in particular the unpredictable nature of liver damage and other health problems associated with chronic (stage 1) Hepatitis C. Other respondents also suggested that the clinical distinction between stage 1 and stage 2 Hepatitis C 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 pros and cons of the various models in England, Scotland and Wales.

Observations by DoH

Enhanced support for Hepatitis C stage 1 is being considered as part of ongoing review of the Scheme and will require further and wider consultation on the detail with expert clinical advice to determine if it is feasible and, if so, the best model to adopt in NI.

Section Six: Customer service

Three-quarters of respondents (42) had been in contact with the Northern Ireland Infected Blood Payment Scheme.



Comments from respondents

Six respondents provided additional comments on the different aspects of customer service covering themes such as:

- Resourcing;
- Timeliness;
- Impact of COVID-19.

Some comments praised the speed at which BSO act on decisions taken by the Department in relation to the Scheme and the general support provided by BSO. Comments suggested that scheme administration needs to be better resourced as there is currently only one member of staff in BSO responsible for the day to day administration of the scheme.

Observations by DoH

DoH NI will liaise with BSO to seek to address the issues raised.

Section Seven: Communication

Of the 56 respondents, 40 reported that they had not used the BSO website. Of those that had used the website, around three-quarters (11 out of 15 respondents) found it useful.

Comments from respondents

13 respondents provided comments on the website and how communication could be improved. Comments suggested that there needs to be better promotion of the Scheme to raise awareness, including online and by post. A regular newsletter was suggested. There was also a suggestion that there needed to be greater transparency from DoH NI in relation to policy development.

Observations by DoH

As part of the ongoing review of the Scheme, one of the areas under consideration is how to improve communication and promotion of the Scheme, with more information on what support is available. This will include consideration of how the website can be improved and publication of hard copy materials such as posters and leaflets for those who do not use digital or online platforms.

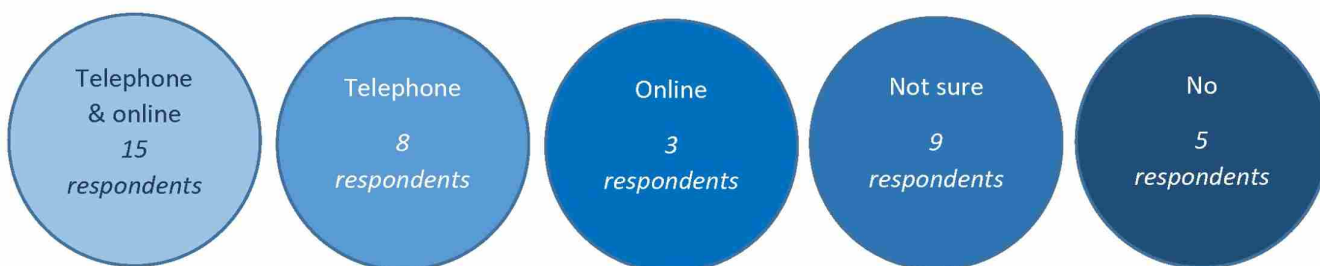
Section Eight: Psychological/mental health support

34 respondents were not aware that psychological support is available from the Belfast Health & Social Care Trust for patients and families affected by contaminated blood or the Infected Blood Inquiry, 10 respondents were aware but have not used the service and nine respondents indicated they are currently using the service. Of the nine who are currently using the service, six respondents indicated they were satisfied with the service.

COVID-19

A small number of respondents (eight) provided a response to having used the service during the COVID-19 pandemic with the responses indicating satisfaction (five respondents) or neither satisfied nor dissatisfied (three respondents) with any change in delivery.

When asked whether they would like the option of a continued telephone or online service, 40 respondents provided a response.



Other psychological services

Around three-quarters of respondents (40) had not used any other psychological services in relation to coping with their health condition, eight respondents had done so in the past and four respondents indicated they were currently using another psychological service. Of these twelve respondents, eight indicated they were satisfied with the service.

Support

Respondents were asked whether they or their family would wish to receive any form of psychological or mental health support in relation to infected blood, if they were not currently doing so; 49 respondents gave a valid response. Over half (26 respondents) indicated they would not wish to receive such support, a third (16 respondents) said they were not sure, with the remaining seven respondents indicating they would like some form of support for themselves or their family.

Twelve respondents identified factors that would be important to them in accessing support; from the list provided, a therapist with specialist knowledge of the Infected Blood Inquiry was the most common response given.

Factors deemed important in accessing support – respondents were able to select multiple responses



Comments from respondents

Respondents provided feedback on how awareness could be improved, why they have not used the service and their experiences of the service generally. Many of those who commented said that they weren't aware that a psychology service was available, with some suggesting that all those who have been infected and their family members should be made aware of this in writing.

33 respondents provided feedback on a number of issues relating to psychological/mental health support.

Some commented that it was important that the psychologist is aware of the issues specific to infected blood, but that the service needed to be made available in locations outside of Belfast, in particular the North West. Comments referenced the fact that the Infected Blood Inquiry psychosocial expert group had recommended that specialist psychological support should be available. Some commented that COVID-19 had increased anxiety and this had led to a reluctance to receive face to face counselling. Others indicated a preference for private counselling, not connected to the Belfast Health & Social Care Trust. There were some who felt that the service was only put in place in response to the Inquiry and should have been available earlier.

Observations by DoH

As part of the review of the Scheme, DoH NI will consider how best to ensure psychological support services are available beyond the Inquiry and whether these services can be improved in any way. This will require wider consultation and funding. Telephone counselling has been available throughout the pandemic.

Section Nine: Additional comments and information

Respondents were asked to rate the following types of support in the order that was of most importance to them, with one being the most important and six being the least important:

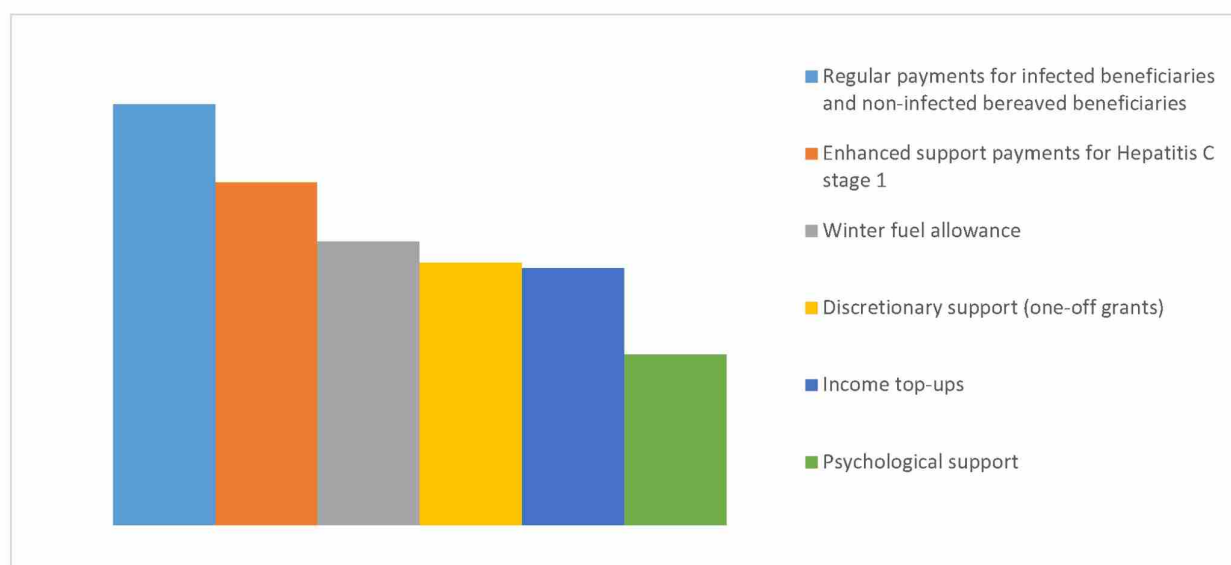
Discretionary support (one-off grants)
Enhanced support payments for Hepatitis C stage 1
Income top-ups
Psychological support
Regular payments for infected beneficiaries and non-infected bereaved beneficiaries
Winter fuel allowance

In total, 41 respondents provided a ranking from one to six across the above support types; 11 respondents provided a ranking for less than six options, and four respondents did not assign a single ranking per support type.

Considering the 52 respondents that provided a single ranking per support type, the most common first preference was *regular payments for infected beneficiaries and non-infected bereaved beneficiaries* with over half of respondents (28) choosing this option; the second most common response was enhanced support payments for Hepatitis C stage 1 (15 respondents).

Rankings – 56 respondents

Considering the rankings given by respondents, the highest ranked option was *regular payments for infected beneficiaries and non-infected bereaved beneficiaries*.



Comments from respondents

Respondents were given the opportunity to provide additional comments in relation to any aspect of the NI Infected Blood Scheme. 16 respondents provided further comments.

Comments suggested that non-infected bereaved and families needed better financial support. There was a suggestion that people who received blood from vCJD donors should receive financial support. Some commented that they would like better communication and regular updates. There were suggestions in relation to clinical care and treatment (which does not fall within the remit of this Scheme survey) including that there should be better follow up treatment after discharge for liver condition, perhaps three to five year routine check-ups. Other comments suggested there needed to be more information available to raise awareness of Hepatitis.

Observations by DoH

The ongoing review of NI Scheme is considering annual financial support for non-infected bereaved. DoH will refer feedback on matters relating to treatment and clinical care, to the relevant officials.