



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

www.health-ni.gov.uk

Infected Blood Payment Scheme for NI

Beneficiary Survey

January 2024

Contents

Introduction.....	3
Survey findings	4
Section One: Customer Service.....	5
Section Two: Communication	6
Section Three: Financial support for bereaved spouses and partners	8
Section Four: Enhanced support for hepatitis C stage 1 beneficiaries.....	9
Section Five: Discretionary support	11
Section Six: Psychological Support.....	12
Section Seven: Additional comments and information	15
Overall feedback	16
Acknowledgments.....	17

Introduction

The Infected Blood Payment Scheme for Northern Ireland (NI Scheme) 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:

- monthly or quarterly support payments for beneficiaries;
- monthly or quarterly support payments for bereaved spouse / partner beneficiaries;
- one off ex-gratia payments in relation to HIV, chronic and advanced hepatitis C;
- one off ex-gratia bereavement payment to bereaved spouse / partner / estate;
- annual winter fuel payment;
- discretionary one-off grant support.

The NI Scheme was established in November 2017 and is administered by the Regional Business Services Organisation (RBSO) on behalf of the Department of Health NI (DoH NI).

In January 2020, the former Minister of Health in Northern Ireland, Robin Swann announced a three-phase review of the NI Scheme¹. In phase 1, interim payments were made to beneficiaries of the NI Scheme, addressing the divergence that had occurred as a result of increases in rates by the England Infected Blood Support Scheme the previous year.

In August 2020, as part of phase 2 of the Review, Minister Swann announced an increase in payments for beneficiaries of the Scheme², bringing rates into line with those in England. In Autumn 2020, a survey was carried out to seek the views of all beneficiaries on the range of support available on the NI Scheme. The survey report was published in February 2021³.

In March 2021, Minister Swann announced a number of reforms to the NI Scheme in order to achieve greater parity with the other UK Schemes. These reforms included an increase in lump sums for those who became infected with HIV and / or hepatitis C, annual financial support to bereaved spouses and partners and the introduction of enhanced financial support for eligible

¹www.health-ni.gov.uk/news/infected-blood-payments-announced-by-swann

²www.health-ni.gov.uk/news/swann-announces-increased-payments-infected-blood

³www.health-ni.gov.uk/sites/default/files/publications/health/doh-infected-blood-payment-scheme-survey%20oct%202020.pdf

hepatitis C stage 1 beneficiaries. More information on phases 1 and 2 of this review is available in the previous survey report.

The intention of phase 3 of the Review is to address recommendations from the UK-wide Infected Blood Inquiry, which commenced in 2018 and is expected to publish its final report in March 2024. Work on phase 3 has already commenced following the publication of the Inquiry's first interim report⁴ in July 2022, which saw interim payments of £100,000 made to all Scheme beneficiaries in October 2022. A second interim report⁵ was published in April 2023 and the UK Government has said it will respond following the publication of the Inquiry's final report.

As a number of new beneficiaries have joined the Scheme since the last survey, it is important to once again seek your views to help us understand what is working well and how we might improve any areas of support within the budget available.

Survey findings

In June 2023, a questionnaire was sent to all 106 beneficiaries of the NI Scheme and a total of 59 questionnaires were returned, giving a response rate of 56%. The results of the survey are set out below and will be taken into consideration in any potential further reform of the Scheme as the Review continues.

It is important to recognise the relatively small number of responses and caution should be exercised when drawing conclusions from the findings.

NOTE: Any documents referred to in this report with accompanying weblinks may be requested in hard copy. Please contact the Scheme Manager to request any hard copies.

⁴ [Infected Blood Inquiry Interim Report.pdf](#)

⁵ [Infected Blood Inquiry Second Interim Report.pdf](#)

Section One: Customer Service

Respondents were asked if they had joined the NI Scheme since the previous survey was carried out in October 2020, with 17 of the 59 respondents indicating they had.

Of these respondents, nearly all found it easy to apply to join the Scheme.

Around two-thirds of respondents (40 out of 59) noted that they had contacted the NI Scheme since October 2020 and nearly all reported that it was easy to do so and that their enquiries had been dealt with effectively.

Similarly, all respondents were satisfied with the time taken for their enquiry to be dealt with.

40 respondents reported being in contact with the Scheme

98% thought it was easy to contact the Scheme
(39 respondents)

98% felt their enquiries were dealt with effectively
(39 respondents)

100% were satisfied with the time it took to deal with enquiries
(40 respondents)

The majority of respondents rated the overall service provided by BSO as good or very good, with no respondents describing the service as poor or very poor.

NOTE *There were no additional comments or feedback received regarding customer service.*

Section Two: Communication

Around half of the respondents had used the BSO website (29 respondents) with 25 out of the 29 noting that it was useful.

Comments from respondents

A small number of respondents provided feedback on the usefulness of the website, including that there could be more information on the support that is available, specifically discretionary support. It was also suggested that the BSO website could be upgraded significantly.

Observations

Work is currently ongoing, in collaboration with the Infected Blood Payment Scheme (NI) Stakeholder Group, to improve the information on both the NI Direct and BSO websites. The purpose of this work is to ensure that information online is easy to access and is presented in a way that is clear and easy to understand.

Almost all of the respondents who had read the first ever NI Scheme newsletter found it to be useful. It should be noted that around a fifth of respondents (11) indicated that they did not receive the newsletter.

When asked how frequently they would like to receive a newsletter, around half (30 respondents) preferred every three months, a third (19 respondents) preferred every six months and a smaller proportion opted for once a year or not at all.

Comments from respondents

There were 13 respondents who provided comments on the Scheme newsletter. Comments suggested that the majority of respondents were satisfied and found the newsletter informative and easy to read. Whilst eight respondents stated that in future editions, they would like more information on the following:

- Information on new Scheme developments including non-financial means of support such as mental health support;
- Updates relating to the Infected Blood Inquiry, including progress made on Sir Brian Langstaff's compensation recommendations;
- More information on Government blood safety / infected blood policy;
- Information relating to Scheme payments, such as eligibility criteria and payments to those bereaved and others affected;
- User-friendly updates particularly regarding the compensation framework, Inquiry reports and UK Government responses.

Observations

The NI Scheme Manager confirmed that the first edition of the newsletter was sent to all 106 beneficiaries of the NI Scheme on 30th March 2023 (46 were sent by post and 60 by email).

The Department welcomes the comments provided by respondents and will include any new Scheme developments in future newsletters and information online. DoH NI is committed to improving the website experience for beneficiaries and to present the public facing information in a user-friendly format.

The Infected Blood Inquiry is sponsored by the UK Cabinet Office and has a comprehensive website which provides detailed updates on all of its work to date. The website is available at: www.infectedbloodinquiry.org.uk.

Work on responding to the recommendations in the Inquiry's second interim report is being led by the UK Government (UKG). The UKG has said it will respond when the Inquiry's final report is published (expected March 2024). The latest statement from the Minister for the Cabinet Office can be found here: [Infected Blood Inquiry: Government Response - Hansard - UK Parliament](#).

DoH NI will continue to actively engage in four nations discussions and will provide information about any decisions which might affect beneficiaries of the NI Scheme as soon as possible.

Respondents were offered the opportunity to detail anything else they would like to see that may improve communication and eight respondents included suggestions.

Comments from respondents

Eight respondents provided comments on how communication could be improved, including the suggestion of using social media and an online system to store and access documentation. Other suggestions to improve communication included providing information on relevant DoH and BSO staff and their responsibilities, producing the newsletter quarterly and use of simple language / terminology and the avoidance of jargon.

Observations

In Summer 2023, DoH NI Press Office issued a series of Tweets to promote the support available through the NI Scheme on social media. In conjunction with the NI Scheme Stakeholder Group, consideration will be given to new and innovative ways to improve communication and promotion of the scheme in the future.

Due to the changing nature of roles and responsibilities of civil servants, it would not be possible to provide details of individual teams. The frequency of newsletters will be decided following this report and will be kept under review in consultation with the Scheme Stakeholder Group.

Section Three: Financial support for bereaved spouses and partners

The majority of respondents (93%, 55 respondents) indicated they were aware that annual financial support payments are available to the spouse or long-term partner of Scheme beneficiaries who have passed away.

Over three-quarters of the 55 respondents (43 respondents) were aware that the bereaved support payments are 100% of the rate their late spouse/partner was receiving at the time of their passing (for the first year) and 75% every year after that.

Over two-thirds (41) of respondents were aware that a one-off £10,000 bereavement lump sum payment is available to the spouse, long-term partner or estate of a Scheme beneficiary who has passed away.

Comments from respondents

Seven respondents provided comments on financial support for bereaved spouses/partners, covering themes such as:

- Awareness
- Eligibility
- Amount

Feedback from some respondents suggested that they were satisfied with the amount of financial support provided to bereaved spouses/partners.

Other comments suggested that more information could be provided on financial support available for those bereaved, particularly in relation to eligibility for support.

Observations

The Department welcomes feedback from bereaved spouses/partners who responded stating that they are happy with the level of support they receive from the Scheme.

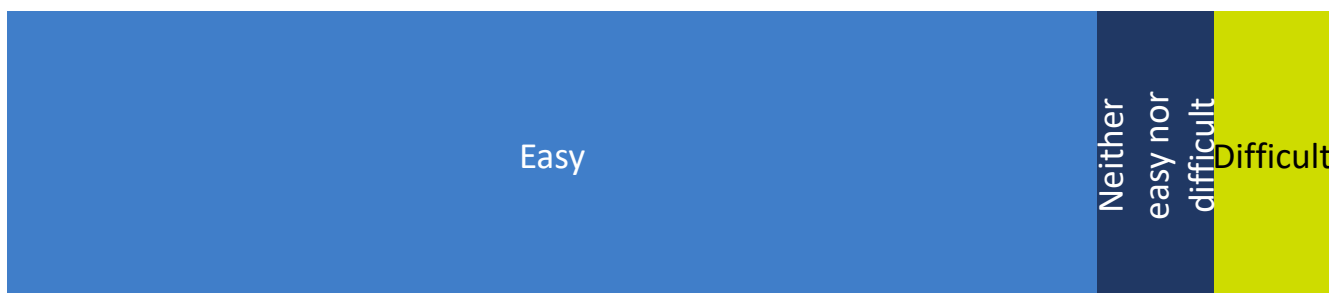
DoH NI will continue to provide information on eligibility and payment levels in future Scheme newsletters and in new and improved online information.

DoH NI will work with the NI Scheme Manager to ensure that hard copy information is made available to those who cannot access or prefer not to use electronic communication methods.

Section Four: Enhanced support for hepatitis C stage 1 beneficiaries

Additional financial support for eligible hepatitis C stage 1 beneficiaries was introduced on the Infected Blood Payment Scheme (NI) in June 2022. This payment category is called hepatitis C stage 1 (enhanced).

The majority of respondents were aware that these payments are available, with 35 out of the 59 respondents indicating they currently receive this support. Of those who receive this additional support, four-fifths found the application process easy.



34 respondents

Comments from respondents

14 respondents provided comments on hepatitis C (HCV) stage 1 (enhanced) support, covering themes such as:

- Eligibility criteria
- Application process
- Financial support

Some respondents commented that the application process was easy and praised the medical staff and social workers in the multi-disciplinary team at the NI Haemophilia Comprehensive Care Centre the Belfast Health and Social Care Trust, as well as the NI Scheme Manager at the BSO who provided advice and assisted with the application process.

Other respondents indicated that they found aspects of the application process stressful and traumatic, such as the need to seek medical professional sign-off.

Some respondents expressed dissatisfaction with the eligibility criteria, with some suggesting that it prioritised mental health issues and removed the clear distinction between HCV stages 1 and 2 payment levels, which is necessary to recognise the difference in chronic and advanced HCV.

Some comments suggested this support is beneficial to help pay for day-to-day tasks such as housework.

Some respondents raised issues about difficulties encountered with their GP and highlighted delays in reviewing and processing their applications, and the difficulty in obtaining medical evidence if not resident in Northern Ireland.

Observations

The Department worked with stakeholders including beneficiaries of the Scheme and clinicians during a period of consultation to develop an assessment process which aims to balance the requirement for medical evidence to support the application, whilst minimising potential stress and difficulty for the applicant.

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 is required to determine so far as is possible a link to HCV infection and / or treatment.

It is important to note that with the exception of the medical declaration in the application form, no supporting medical evidence is required when making an application for the HCV stage 1 (enhanced) payment; the process only requires a declaration from the applicant's treating clinician to verify the condition or health difficulties, on the basis of which the application is being made.

The process is also consistent with the principles of responsible management of taxpayer's money.

It is important to clarify that the assessment process does not, and is not intended to, prioritise mental health conditions but recognises that mental health should be treated with equal importance to physical health. If an applicant's mental health is adversely affected as a result of the infection following NHS treatment in Northern Ireland, the process is designed to provide the appropriate level of support.

The Department is encouraged to hear the positive comments in relation to the introduction of enhanced support for HCV stage 1 payments, and the support applicants have received from the Haemophilia Centre at BHSCT and the NI Scheme Manager and team.

Section Five: Discretionary support

Around three-fifths (37 of the 59 respondents) were aware that discretionary financial support is available in the form of one-off grants, with seven respondents indicating they had received such support since October 2020.

All those who received a discretionary grant reported that they were satisfied that “*it met their needs in the circumstances*”.

Comments from respondents

A small number of respondents provided comments relating to discretionary support.

Some respondents expressed disappointment that their applications had not been successful.

Other comments suggested that there should be more information provided on what discretionary support grants are available.

Observations

Discretionary one-off grants are a form of financial support available on the NI Scheme, which beneficiaries may apply for to cover the cost of certain essential items or services.

The grants are intended to provide additional, time-limited financial support to beneficiaries in times of severe financial hardship in order to address immediate needs, which:

- (a) are having a direct effect on an individual’s independence, and;
- (b) have been brought about as a direct result of their infection and / or its treatment and are **otherwise unable to be met**.

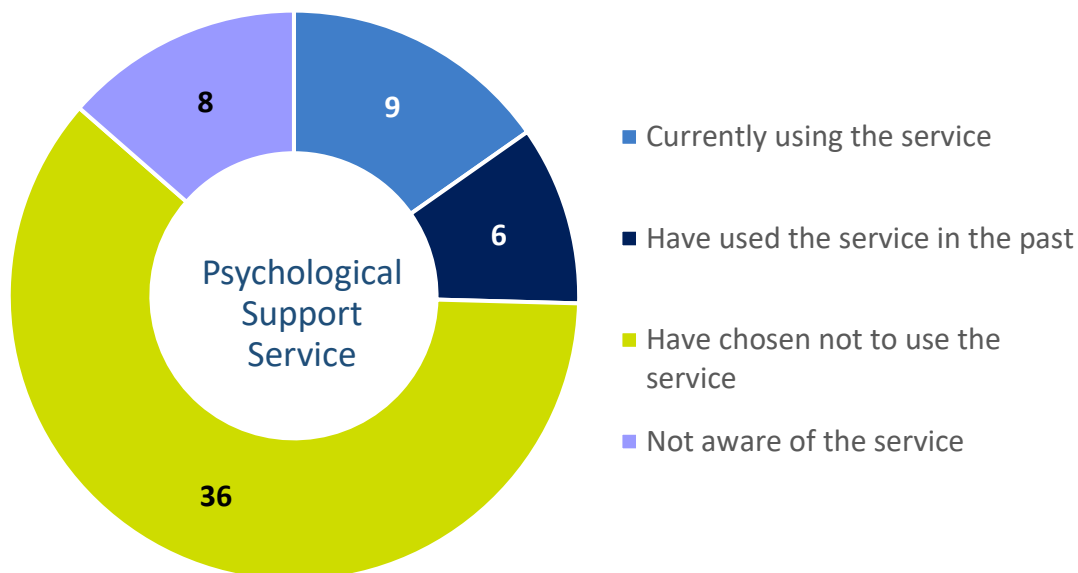
It would not be appropriate for the Department to comment on the outcome of individual applications.

If an application has been unsuccessful, the decision may be appealed by contacting the Scheme Manager within three months.

DoH NI will liaise with the BSO to promote discretionary support through the NI Scheme newsletter, and will ensure that all public facing information is up to date so that beneficiaries are aware of the support available and how to apply.

Section Six: Psychological Support

The majority of respondents (51) were aware that a dedicated regional psychological support service is available from the Belfast Health and Social Care Trust for patients and families affected by contaminated blood or the Infected Blood Inquiry. Of those, nine respondents indicated they currently use the service, six had used it in the past and 36 had chosen not to use the service. A small number of respondents (eight) were not aware of the service.



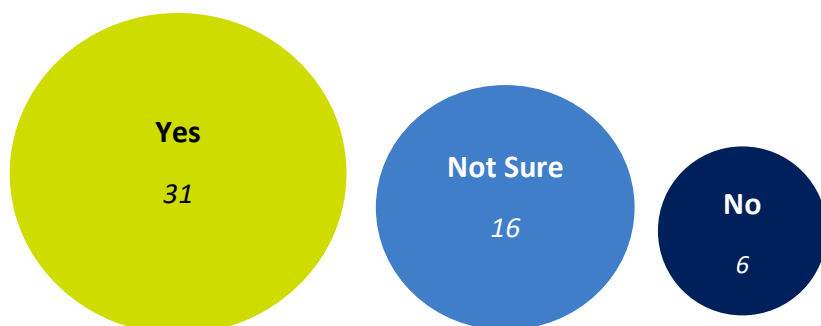
Of those who had chosen not to use the service, around a third (11 out of 36 respondents) indicated they would consider using the service in the future, as did half of those who had not been aware of the service (4 out of 8 respondents).

Of those respondents who had used the Psychological Support Service, the majority were satisfied or very satisfied with the service. No respondents were dissatisfied.

Telephone / online services

Of the 9 respondents currently using the service, two-thirds indicated they had been given the option of the service continuing both by telephone or online.

When asked if they would like the option of a telephone or online service to continue to be provided, 53 respondents provided a response.



Other psychological services

Around two-thirds of respondents (39) had not used any other psychological services in relation to coping with their health condition. Of the remaining respondents, eight were currently using another psychological service and 11 had done so in the past, with two-thirds (13 respondents) indicating that they were satisfied with the service they received.

Support

Respondents were asked whether they or their family would wish to receive a form of psychological or mental health support in relation to infected blood if they were not currently doing so.

Over a quarter (16 respondents) indicated they would not wish to receive such support, around half (27 respondents) said they were not sure, with the remaining 15 respondents indicating they would like some form of support for themselves or their family.

Respondents who indicated they would like support were asked to rate the following factors in the order that was of most importance to them, with 1 being the most important and 5 being the least important:

- A location near your home;
- Being seen face to face;
- A therapist with specialist knowledge of the Infected Blood Inquiry;
- A therapist who works closely with the NI Haemophilia Centre;
- A telephone or online service.

Fourteen such respondents provided a ranking from 1 to 5 in relation to factors that would be important to them in accessing support; from the list provided, the most common first preference was being seen face to face (5 respondents). Similarly, when considering the rankings given by respondents, the highest ranked option was being seen face to face.

Comments from respondents

16 respondents provided feedback on issues relating to psychological / mental health support.

This included feedback on how awareness of the service could be improved, the reasons for not using the service and their experiences of the service more generally.

Some respondents commented that awareness for the service could be improved through various media channels including TV advertising, frequent newsletters, newspaper articles and sending information to families of the infected.

Some stressed the importance of the telephone and online service and suggested that it would be beneficial if psychological support services were available in their hometowns, due to the associated costs and time spent travelling to face-to-face appointments in Belfast.

Others stated their reluctance to avail of psychological services due to their age or distrust of NHS services.

Observations

Overall, the Belfast Health and Social Care Trust (BHSCT) is pleased that families and patients have had positive experiences of using the psychological service and appreciate the challenges of accessing ongoing support within the health service.

BHSCT is hopeful that providing the service in a variety of ways, including face-to-face, telephone and online will continue to support engagement.

In order to raise awareness of the service, BHSCT has developed a patient / family information leaflet which is available for patients within clinics, and for clinicians to discuss referral to this service with patients and their families.

The leaflet was made available to the BSO for beneficiaries registered with the Infected Blood Payment Scheme NI and to groups such as the Haemophilia Society, Liver Trust and MacMillan Cancer Support Service.

Posters were also distributed and displayed in Haemophilia clinics, Hepatology Clinics and Dental Departments within the Trust to raise awareness of this service.

To date, BHSCT has not refused anyone who wished to access the service.

The use of other media, such as advertising, to promote the service would incur significant costs which could not be funded from existing Scheme budget, and any additional costs would need to be considered in the context of challenging budget pressures across the health and social care services in Northern Ireland.

Section Seven: 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 five being the least important.

- Discretionary support (one-off grants)
- Hepatitis C stage 1 (enhanced) support
- Psychological support
- Regular payments for beneficiaries
- Winter fuel allowance

In total, 57 respondents provided a ranking from 1 to 5, with the most common first preference *regular payments for beneficiaries* and *hepatitis C stage 1 (enhanced)*. Similarly, when considering the rankings given by respondents, these were the two highest ranked options.

On examination of the survey responses to the above question, concerns were raised that this question and the answer options may have been misinterpreted by some respondents. For example, there were some respondents who ranked winter fuel allowance (a small annual payment) as of greater importance than regular payments. Other respondents commented that the ranking question was unclear and wanted to rank some options as of equal importance.

The main themes have been outlined above; however, caution is advised when drawing conclusions from the information. Similarly to the previous survey, 'regular payments' was the most common first preference, with hepatitis C stage 1 (enhanced) support ranked the second most common. If those responses flagged as potentially misunderstanding the ranking question were removed, both the highest ranked options would remain the same with 'regular payments for infected beneficiaries and non-infected bereaved beneficiaries' still the most common first preference. The remaining ranked findings would differ slightly though the general theme is the same.

Overall feedback

Around three-quarters of respondents indicated they would be interested in participating in a similar survey in future with the majority noting a preference for a biennial survey.

Respondents were given the opportunity to provide additional comments in relation to any aspect of the NI Infected Blood Scheme. 14 provided further comments.

Overall Comments from respondents

Many commented on the administration of the NI Scheme by the BSO, reflecting positive experiences and describing it as well-managed, with information delivered in a clear and concise way. Notably, some praised the Scheme Manager for the exceptional help, support and empathy shown throughout the application and payment process, describing it as life-changing.

Some stated that they felt there should be more support and understanding shown by GPs with others stating a medical follow up would be desirable, whilst acknowledging it may be outside the Scheme's remit.

Respondents indicated the importance of the Infected Blood Inquiry in highlighting the events that occurred and the traumatic experiences of the victims and their families. Others stated their desire for the Inquiry to conclude soon and the need for the Government to urgently make progress on compensation payments, including to further groups such as children and parents of those who have died.

Observations

Work on responding to the Infected Blood Inquiry's second interim report is being led by the UK Government. The DoH NI looks forward to working with the Cabinet Office, DHSC and the other UK Devolved Administrations in considering the Inquiry's recommendations, in order to respond to the Inquiry's final report when it is published. Another important consideration is the current absence of a functioning Executive in Northern Ireland, which has already been raised with UKG.

All beneficiaries on the NI Scheme (including bereaved partners) received an interim payment of £100,000 following the Government's acceptance of the Inquiry's recommendation in its first interim report, published in July 2022.

The DoH NI is encouraged to hear the positive comments which have been reserved for the Scheme Manager and the overall administration of the NI scheme.

The results in this survey will be analysed in order to make an informed decision on the frequency of future surveys. DoH NI liaised with a team of statisticians to design ranking questions, which were consistent with best practice. The ranking questions were not designed to give equal weighting to each answer. Rather, they were designed to establish an order of importance.

The work of GPs falls outside of NI Scheme remit and beneficiaries who experience difficulties with their GP practice should follow normal GP complaints procedures.

Acknowledgments

The Department of Health NI is grateful to the Regional Business Services Organisation (RBSO) for issuing the questionnaires and collecting the responses on the Department's behalf, colleagues in the Belfast Health and Social Care Trust (BHSCT), including those in the Psychology Department, for their input in developing the questionnaire and to all beneficiaries of the Scheme who took the time to complete and return responses.