

Foreword from Health Minister Robin Swann, MLA

Review of the Northern Ireland Infected Blood Payment Scheme – Survey

When I took up post as Minister of Health in January of this year, the issue of support for those of you who have been impacted by infected blood was an immediate priority for me.

I am fully aware of the impact this has had on your lives and I stated my intention to carry out a three phase review of the Northern Ireland (NI) Infected Blood Payment Scheme.

Phase 1 addressed the immediate difference between the rates paid to Northern Ireland scheme beneficiaries when compared with those in England, who have received significantly higher levels of payment since April 2019.

I announced payments in January and March of this year that meant infected beneficiaries on the NI scheme were no worse off in terms of financial support on the scheme than their counterparts in England for the 2019/20 financial year. In addition, I was pleased to also be able to announce payments for non-infected widows and widower on the NI Scheme.

Following this I was delighted to recently announce a permanent uplift in payments to infected beneficiaries on the NI scheme, which brings rates up to the same level as those paid in England. I am keen to build on this progress as I continue phase 2 of my review, considering other aspects of the scheme.

When I met with groups representing those infected and /or affected by contaminated blood earlier this year, I said that I wanted to include our beneficiaries in the ongoing review. It is important to me that I involve you in this work so that I fully understand your views on what support you need to help you to live as normal a life as possible. I want to give fair and equal consideration to the needs of all of you who have suffered as a result of infected blood, including those who have been bereaved.

In order to involve you in this work, I have attached a survey covering a range of support currently available. I would be very grateful if you would take the time to consider and respond to all of the questions and I invite you to express your views in full and include any additional suggestions you would like to be taken into consideration. You are welcome to attach any supplementary supporting information you feel is relevant to the survey, but I would ask that you restrict this to no more than one side of an A4 page to allow the results of the survey to be analysed promptly. It is also important that you **do not include any personal information**.

It is vital that I hear your views as this will allow me to take these into consideration when making decisions on the best way forward to ensure that our financial support scheme best meets the needs of our beneficiaries here in Northern Ireland. Please be assured that this survey is completely anonymous and you will be reimbursed for any postage costs.

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Please be assured that you have my full support and your feedback will be taken into consideration as work is progressed on the review of the NI Scheme.

Thank you in advance for your assistance and for your patience and I look forward to seeing your responses.

Yours Sincerely

GRO-C

Robin Swann, MLA

Minister of Health

INFECTED BLOOD PAYMENT SCHEME - QUESTIONNAIRE

It is important that no personal information is provided in response to this survey. This includes names, age, gender or any other information that may identify you.

Being transparent and providing accessible information to individuals is key to the Department of Health's (DoH) commitment to building trust and confidence in our ability to process the information you share with us.

It is important therefore to note that your response, and all other responses to this consultation, may be disclosed on request in accordance with the Freedom of Information Act 2000 (FOIA) and the Environmental Information Regulations 2004 (EIR).

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

How will your information be used and shared?

The information you provide will only be processed to generate a report to the Minister of Health in order to inform his decision making on future reform of the NI Infected Blood Payment Scheme. It will be shared only with the relevant officials within the Department of Health in order to produce the report. It is intended that the report will be completed by November 2020.

How long will we keep your information?

We will retain consultation response information until our work on the subject matter of the consultation is complete, and in line with the Department's approved Retention and Disposal Schedule [Good Management, Good Records](#)

Section 1 – Financial Support for the Bereaved

Q 1 - Are you aware that there is a £10,000 bereavement payment available to spouses of those who have passed away as a result of receiving NHS-supplied infected blood (providing they were co-habiting at the time)? *(Please circle one option only)*

- yes - I received the £10,000 bereavement payment
- yes – I have chosen not to claim the £10,000 bereavement payment
- yes – my claim was turned down
- no – I was not aware that a £10,000 bereavement payment was available
- not applicable

Please provide any comments or details of how you think financial support to the bereaved could be improved in the box below?

Section 2 – Income Top-Ups

Income top-ups are a discretionary monthly payment to increase household income to help with general living costs. An assessment is made of the individual's household income and if the income is below set thresholds an application can be made to receive payments.

Q 2 - Were you aware that income top-up payments are available? *(Please circle one option only)*

- Yes
- No

Q 2.1 - If you currently receive income top-ups, how satisfied or dissatisfied are you with the amount you receive? *(Please circle one option only)*

- Very satisfied
- Satisfied
- Neither satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- I do not receive income top-ups

If you selected dissatisfied or “very dissatisfied”, please provide details in the box below.

Section 3 - Winter Fuel Payments

Q 3 - Are you aware that you can apply for a winter fuel payment? *(Please circle one option only)*

- Yes
- No

Q 3.1 - If you have received the winter fuel payment, how satisfied or dissatisfied are you that the amount meets your needs? *(Please circle one option only)*

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied

- Very dissatisfied
- I have not received the winter fuel payment

If you selected dissatisfied or “very dissatisfied”, please provide details in the box below.

Section 4 – Discretionary Support (One off grants)

Discretionary financial support is available on the NI Infected Blood Payment Scheme to provide additional, time-limited financial support to beneficiaries and their families in order to address immediate needs and is mainly targeted for those in financial hardship, such as financial support for respite breaks.

Q 4 - Were you aware that discretionary financial support is available? *(Please circle one option only)*

- Yes
- No

Q 4.1 - Have you ever received discretionary financial support? *(Please circle one option only)*

- Yes
- No

Q 4.2 - If you have received discretionary financial support, how satisfied or dissatisfied have you been that this met your needs in the circumstances? *(Please circle one option only)*

- Very satisfied
- Satisfied

- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- Not applicable

If you selected “dissatisfied” or “very dissatisfied”, please provide details in the box below.

Section 5 - Enhanced support for Hepatitis Stage 1 beneficiaries

England have a Special Category Mechanism (SCM) which allows stage 1 beneficiaries to receive stage 2 payment rates if they meet certain criteria.

Scotland and Wales have different models for enhanced support for Hepatitis C stage 1 beneficiaries, which allow them to claim a higher rate of payment based on how severely their condition impacts their day to day lives.

Northern Ireland does not currently offer any enhanced support for stage 1 beneficiaries.

More information on what is available in England, Scotland and Wales is attached at **annex A** of this survey to help you with your response to this question.

Q 5 - Would you be in favour of enhanced support for Hepatitis Stage 1 beneficiaries being introduced in Northern Ireland? *(Please circle one option only)*

- Yes
- No
- Not sure

Q 5.1 - If yes, which approach would you like to see introduced in Northern Ireland? *(you may circle more than one option)*

- Special Category Mechanism – England
- Tiered payment system (low/ moderate/ severe) - Scotland
- Enhanced payment – Wales
- Other

If you have selected more than one option, please state your preference or provide further comments using the box below.

If you have selected other, please provide comments in the box below.

Section 6 – customer service

The Business Services Organisation (BSO) administers the NI Infected Blood Payment Scheme on behalf of the Department of Health.

Q 6 - Have you contacted the NI Infected Blood Payment Scheme? *(Please circle one option only)*

- Yes
- No

Q 6.1 - Do you find it easy or difficult to contact the NI Infected Blood Payment Scheme?
(Please circle one option only)

- Very easy
- Easy
- Neither easy or difficult
- Difficult
- Very difficult
- Not applicable

If you selected “difficult” or “very difficult”, please provide details in the box below.

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Q 6.2 - How have your enquiries been dealt with? *(Please circle one option only)*

- Very effectively
- Effectively
- Neither effectively or ineffectively
- Ineffectively
- Very ineffectively
- Not applicable

If you selected “ineffectively” or “very ineffectively”, please provide details in the box below.

Q 6.3 - How satisfied or dissatisfied are you with the time it took for your enquiries to be dealt with? *(Please circle one option only)*

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- Not applicable

If you selected “dissatisfied” or “very dissatisfied”, please provide details in the box below.

Q 6.4 - How would you rate the overall service provided by BSO? *(Please circle one option only)*

- Very good
- Good
- Neither good or poor
- Poor
- Very poor
- Not applicable

If you selected “poor” or “very poor”, please provide details in the box below.

Section 7 – Communication

Q 7 - If you have used the BSO website, how useful or not is it for finding the information you need? *(Please circle one option only)*

- Very useful
- Useful
- Neither useful or not useful
- Not useful
- Not useful at all
- I haven't used the website

If you selected "not useful" or "not useful at all", please provide details in the box below.

Q 7.1 - Is there anything else you would like to see that would improve communication?

Section 8 – Psychological / Mental Health Support

Q 8 - Did you know there is psychological support available from the Belfast Health & Social Care Trust (BHSCT) for patients and families affected by contaminated blood or the Infected Blood Inquiry? *(Please circle one option only and answer the question beneath that option)*

- No, I was not aware of the service

Please use the box below to comment on how you feel awareness could be improved

- Yes, I am currently using the service

Q 8.1 – If you answered yes above, how satisfied or dissatisfied are you with it? (Please circle one option only)

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied

- Yes, I have used the service in the past 18 months but am no longer using it

Q 8.2 – If you answered yes above, how satisfied or dissatisfied were you with it? (Please circle one option only)

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied

If you are no longer using the service please use the box below to provide a reason why

- Yes, I am aware of the service, but have not used it

Please use the box below to comment on why you have not used the service.



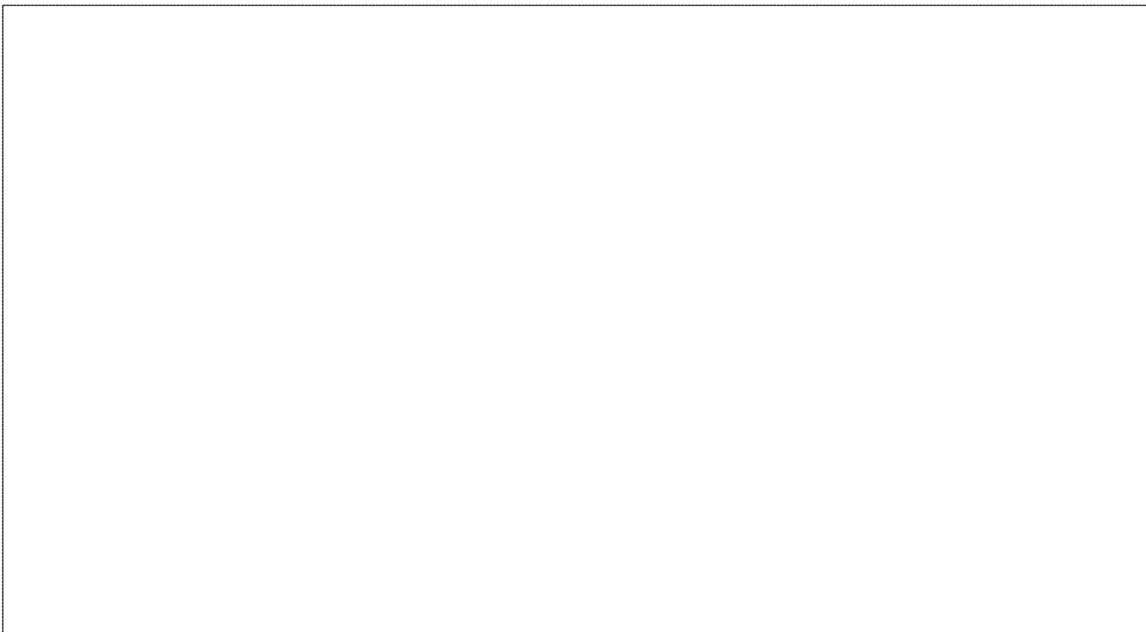
Q 8.3 - If you have been using the service during the changes in face to face delivery to either online or telephone review caused by Covid-19 how satisfied or dissatisfied have you been? (Please circle one option only)

- Very satisfied
- Satisfied
- Neither satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- Not applicable

Q 8.4 - Would you like the option of a continued telephone or online service? (Please circle one option only)

- Yes, both
- Yes, telephone
- Yes, online
- No
- Not sure

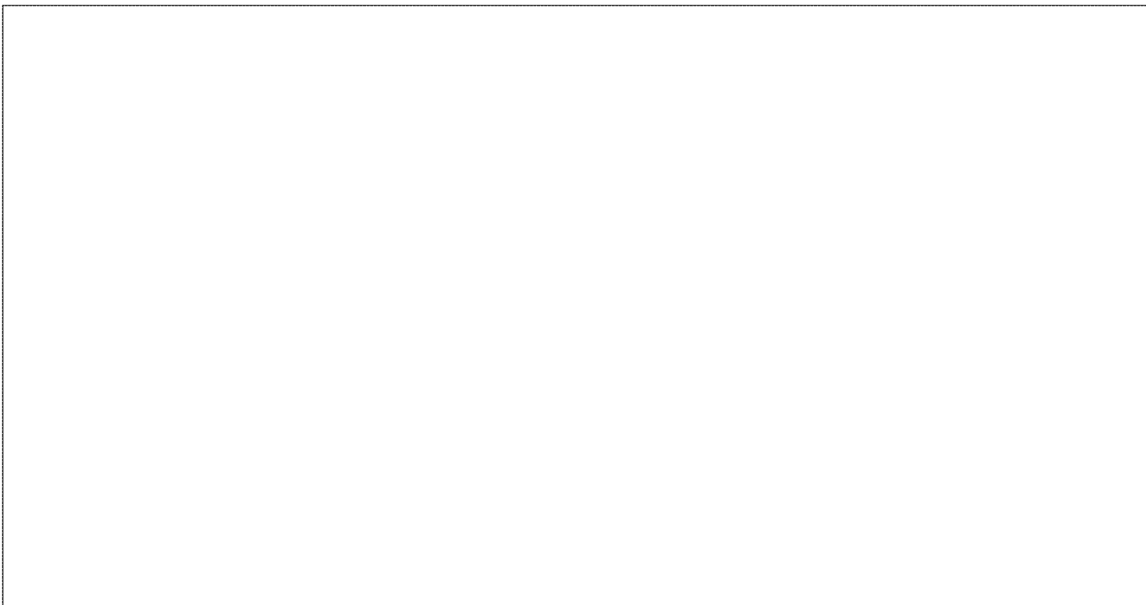
Please use the box below to provide any comments



Q 8.5 - Are you currently using or have you in the past used any other psychological services in relation to coping with your health condition? *(Please circle one option only)*

- Yes, currently
- Yes, in the past
- No

If yes, please describe the type of support you received and how recently you used it in the box provided.



Q 8.6 - How satisfied or dissatisfied are / were you with the service? (Please circle one option only)

- Very satisfied
- Satisfied
- Neither satisfied or dissatisfied
- Dissatisfied
- Very dissatisfied
- Not applicable

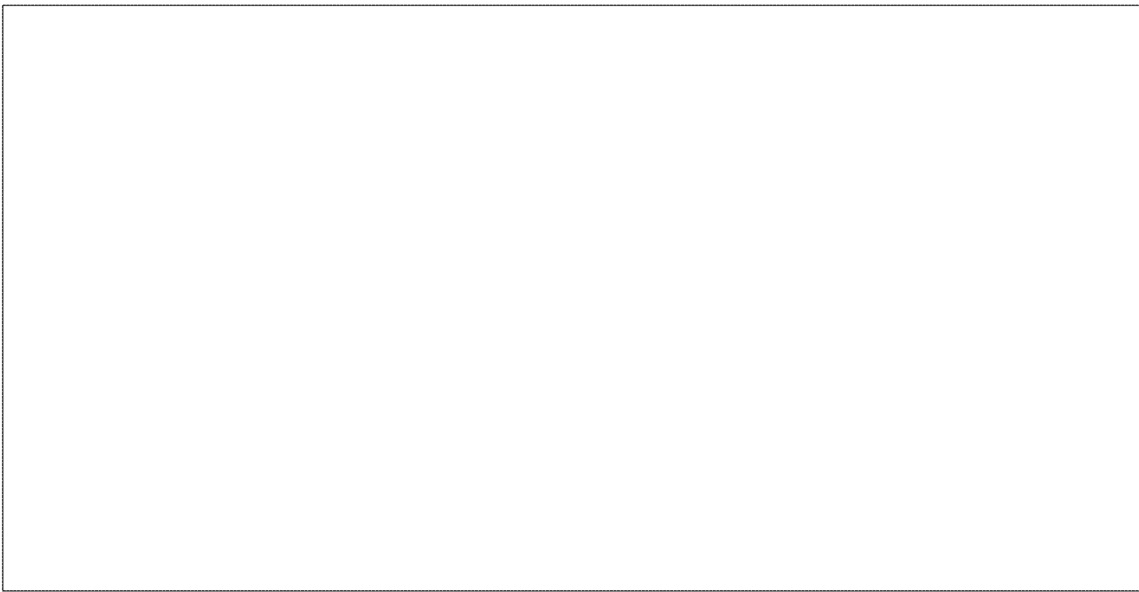
Q 8.7 - If you or your immediate family do not currently receive any form of psychological or mental health support in relation to infected blood, would you wish to receive support? (Please circle one option only)

- Yes, for myself
- Yes, for my family
- Yes, for both
- No
- Not sure

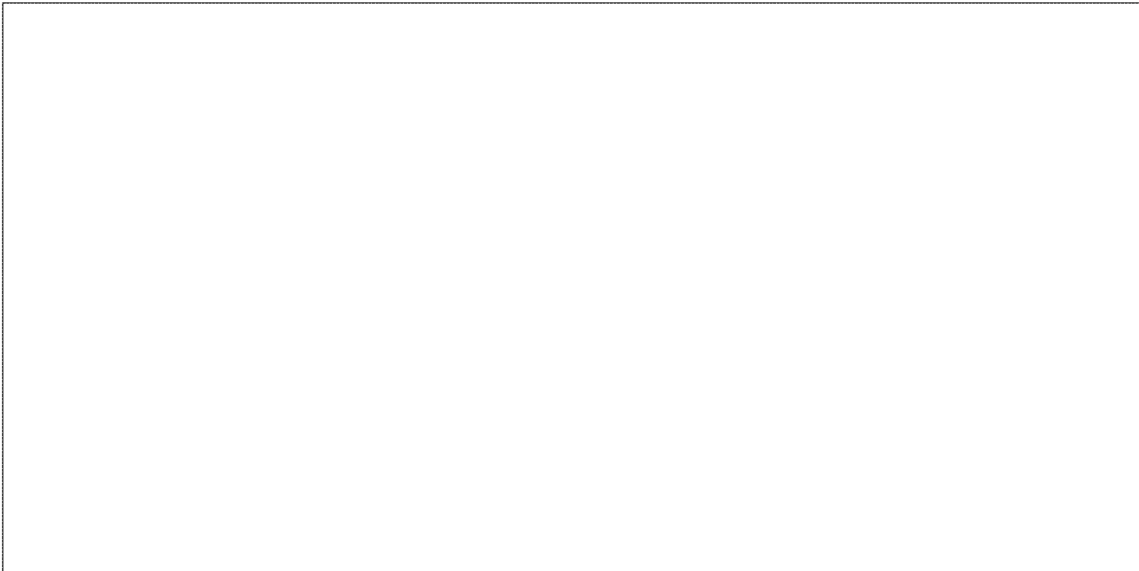
Q 8.8 - If “yes” for you or your family, which of any of the following factors would be important to you? (you may circle more than one option)

- 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 Hemophilia Centre
- Other

If you selected other please use the box below to comment



Please use the space below to add any other comments or suggestions about psychological or mental health support



Section 9 - Additional comments and information

Please use this space to include any additional comments or feedback you would like us to consider in relation to any aspects of the NI Infected Blood Scheme administration.

Q 9 – Please rate the following types of support in the order which is most important to you with 1 being the most important and 6 being the least important? *(Please write a number beside each option)*

- 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

Q9.1 - To help us better understand your responses please select from the following which best describes the support you currently receive from the Scheme? *(Please circle one option only)*

- Regular payments for Hepatitis C stage 1
- Regular payments for Hepatitis C stage 2, HIV or Hepatitis C/HIV co-infection
- I don't receive regular payments for any of the above

Enhanced support for Hepatitis C Stage 1

England - Special Category Mechanism (SCM)

The following table shows the annual payments in England to the different categories of claimant, including Hep C stage 1 with SCM (highlighted in bold).

Beneficiary	Annual non-discretionary payment (£) in England
Hepatitis C Stage 1	18,772
Hepatitis C Stage 1 + SCM	28,476
Hepatitis C Stage 2	28,476
HIV	28,476
Co-infected Stage 1	38,646
Co-infected SCM	44,748
Co-infected Stage 2	44,748

Table 1

In England, beneficiaries may qualify for regular payments, equivalent to those paid at Stage 2, if:

- they are a successful stage 1 applicant;
- they feel the infection, its treatment or associated conditions has a long-term negative impact on their ability to carry out daily activities;
- the infection has worsened, but is not covered by the stage 2 conditions.

They need to confirm they have:

- autoimmune disease which was due to, or worsened by, interferon treatment.
This includes:
 - Coombs positive haemolytic anaemia;
 - idiopathic fibrosing alveolitis of the lung;
 - rheumatoid arthritis;
- sporadic porphyria cutanea tarda (causing photosensitivity with blistering);
- immune thrombocytopenic purpura, if autoimmune with antiplatelet antibodies;
- type 2 or 3 mixed cryoglobulinaemia, if accompanied by:
 - cerebral vasculitis;
 - dermal vasculitis;
 - peripheral neuropathy with neuropathic pain;
- been affected in performing your daily duties due to the infection or the treatment.

Upon receipt of an application under the SCM, the English scheme assesses the application, based on criteria provided by the Department of Health & Social Care (DHSC). If an application passes, the individual will receive the higher annual

payment amount backdated to the date NHS Business Services Authority received the complete application. If an application fails, the individual can appeal or can choose to wait six months (from the date of the original application) to reapply – if their circumstances have changed. If their SCM application is refused, they can reapply after six months if their condition has worsened.

Scotland – Hepatitis C Tiered Impact System

In Scotland, Hepatitis C beneficiaries can apply for an annual payment by filling in an application form and stating whether their life is severely or moderately affected by hepatitis c infection, or a whether hepatitis c infection does not have a noticeable day to day impact on life. The Scottish scheme provides guidance on what should count with in each category and does not require evidence to back up the category selected, however information must be provided showing examples the impact hepatitis C has on life and the majority of applications are not subject to any additional checks. Scottish beneficiaries are required to re-assess the impact of their Hepatitis C every three years so that payments can be amended if the impact has either reduced significantly or got significantly worse.

The following table shows Scotland's payment rates with the payment rates for Hepatitis C impact tiers highlighted in bold.

Category	Annual amount
Hepatitis C Stage 1 – No day to day impact	£1,000
Hepatitis C Stage 1 – Moderate	£6,407
Hepatitis C Stage 1 – Severe	£19,221
Advanced Hepatitis C (Stage 2)	£27,459
HIV	£27,459
HIV Co-infected (no diff re Hep C S1 or 2)	£37, 629

Table 2

Wales - Enhanced Hepatitis C Stage 1+ Scheme

Wales offer an enhanced payment, referred to as the Enhanced Hep C Stage 1+ Scheme payment, for those with existing Stage 1 hepatitis C who are suffering from mental health symptoms which they consider to be related to their being infected with hepatitis C and where the mental health symptoms that they are experiencing have an effect on their ability to carry out day to day activities. The enhanced payment is equivalent to the current rate of payment for those at Stage 2, hepatitis C infection and claimants self-assess if they believe they are entitled to this higher rate.

The following table shows the payment rates available in Wales with the Enhanced Hepatitis C rates highlighted in bold.

Category	Annual amount
Hepatitis C Stage 1	£4,790
Hepatitis C Stage 2 or Hepatitis C Stage 1 in receipt of Enhanced Stage 1+	£19,172
HIV	£19,172
HIV and Hepatitis C Stage 1.	£23,317
HIV and Hepatitis C Stage 2 or HIV and Hepatitis C stage 1 in receipt of Enhanced stage 1+	£37,826