

# **England Infected Blood Support Scheme Annual Report 2023 - 2024**

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#### Introduction

On 1 November 2017, the National Health Service Business Services Authority (NHSBSA) became directed by the Secretary of State for Health and Social Care to administer the England Infected Blood Support Scheme (EIBSS). EIBSS operates from Bridge House, Newcastle upon Tyne, and sits within the NHSBSA Infected Blood Payments Service area of Citizen Services. The scheme is delivered on behalf of the Department of Health and Social Care (DHSC).

NHSBSA administers the scheme for those eligible for support through EIBSS; providing financial and other support to those who were historically infected by HIV and/or hepatitis C through NHS supplied blood or blood products during the 1970s, 1980s and early 1990's. The scheme also provides support for their families, including spouses, parents, children, and dependents.

The scheme recognises that individuals living with hepatitis C and/or HIV face extra costs.

Financial support is available for:

- New successful applicants to the scheme
- Members of previous schemes

## **Financial Support**

There are different levels of support available to Beneficiaries:



**Hepatitis C Stage 1** – For those infected with hepatitis C as a result of treatment with NHS blood, blood products or tissue.

**Hepatitis C Stage 2** - For those stage 1 hepatitis C infected Beneficiaries who go on to develop:

- Cirrhosis
- Primary liver cancer
- B-cell non-Hodgkin's lymphoma
- Type 2 or 3 cryoglobulinemia accompanied by membranoproliferative glomerulonephritis (MPGN)

Additionally, those that receive a liver transplant, or are on the waiting list to receive one.

**Special Category Mechanism (SCM)** - For stage 1 Beneficiaries whose infection, its treatment, or associated conditions, has a long-term negative impact on their ability to carry out daily activities or the condition has worsened, but is not stage 2.

**HIV** - For those infected with HIV as a result of NHS treatment with NHS blood, blood products or tissue.

Winter Fuel Payments - One-off payments for all Beneficiaries paid Annually in December.

**Discretionary Scheme** – There are different elements of discretionary scheme payments:

**Bereaved Partner Payments** - In the event of a death of a registered Infected Beneficiary, EIBSS will pay the surviving Partner the equivalent regular payment for 1 year at 100%, and subsequent years will be paid at a rate of 75% of the Beneficiary payment.

**Estates Payments –** Following the death of a registered Beneficiary, and in the absence of a surviving Partner, the Estate can apply for a one-off Lump Sum bereavement payment within 6 months of the death.

**One-off payment** - Financial support that Beneficiaries and bereaved spouses or partners may apply for, to cover the cost of certain essential, health-related items or services.

**Child Payments –** Means tested payments to help the Primary Carer with the costs of bringing up children of an infected Beneficiary.

## **Other Support**

#### **Welfare Advice**

NHSBSA provides a welfare advice service via two in-house benefit advisers; the previous scheme administrators offered a similar service with one adviser. Alternatively, Beneficiaries can choose to source their own benefits advice and EIBSS will cover the cost. EIBSS can assist Beneficiaries in locating local benefits advice if they choose this option.

## Talking therapy support

Being infected with hepatitis C or HIV from blood or blood products may have affected you and your family members in different ways. This may include having an impact on your psychological wellbeing or mental health.

Support is available through talking therapies, also known as psychological therapies, our website contains more information about <u>Talking therapy support</u>.

## **Beneficiary Volumes**

There are 3,673 people registered for support through the scheme.

This is broken down into the following groups (Data valid on 01.04.2024).

Beneficiary Group	Number of Beneficiaries registered
Hepatitis C stage 1	1,390
Special Category Mechanism (SCM)	538
Hepatitis C stage 2	552
HIV	68
Co-infected (stage 1 and HIV)	79
Co-infected (SCM and HIV)	84
Co-infected (stage 2 and HIV)	55
Carers & Dependents	135
Bereaved Partner	772

## **Payment rates 2023 – 2024**

## **Annual payments**

Between 1 April 2023 to 31 March 2024 EIBSS processed annual payments for registered Beneficiaries and their Bereaved Partners. The levels of payments paid in 2023 - 2024 are shown in the table below and increase annually in line with the Consumer Price Index.

Payment Type	Annual Payments
Hepatitis C (stage 1)	£21,467
Hepatitis C (stage 1) with SCM	£32,555
Hepatitis C (stage 2)	£32,555
HIV	£32,555
Co-infected with HIV and Hepatitis C (stage 1)	£44,189
Co-infected with HIV and Hepatitis C (stage 1) with SCM	£51,162
Co-infected with HIV and Hepatitis C (stage 2)	£51,162

NHSBSA pays annual payments on a monthly or quarterly basis. All new Beneficiaries are paid monthly. Additionally, Bereaved Partners receive a 100% equivalent payment for the first 12 months, then payment levels decrease to 75% on an ongoing basis.

Furthermore, to the annual payments above, a separate winter fuel payment is also made in December each year. For 2023 – 2024, the winter fuel payment was £618.

## **Lump Sum payments**

A one-off non-discretionary lump sum payment of £50,000 was paid for new applicants registered for hepatitis C stage 1 payments and a one-off non-discretionary lump sum payment of £20,000 to those who developed a hepatitis C stage 2 condition.

A one-off non-discretionary lump sum payment was also paid to new applicants registered for HIV payments of £80,500.

A one-off non-discretionary lump sum payment of £10,000 was also available for bereaved partner/spouses and Estates of deceased Beneficiaries provided they met certain criteria.

## **Engagement**

#### Stakeholder Engagement

NHSBSA continues to engage with several stakeholders, such as the Terence Higgins Trust, The Haemophilia Society, Hepatitis C Trust, and feedback is shared with DHSC.

#### **Beneficiary Engagement**

NHSBSA has continued to hold Beneficiary focus groups online and in-person, with the aim of updating Beneficiaries and improving the scheme. All Beneficiaries are welcome to participate in the focus groups and can register their interest at any time, either by contacting the EIBSS team directly, or registering on the EIBSS website <a href="here">here</a>.

## **EIBSS Structure**

## **Citizen Services**

## **Customer Operations**

## **Infected Blood Payments Service**

#### **Head of Service**

Kate Nesbitt

#### **Head of Service**

Michael Gutteridge

## **Implementation & Performance Manager**

James Hardy

#### **Senior Service Delivery Manager**

Lotti Jackson

## **Senior Service Delivery Manager**

Mal Ross

#### **Service Delivery Manager**

Hollie Edminson

#### **Service Delivery Manager**

Joseph Helliwell

#### **Team Manager – EIBSS**

Sarah Patterson

#### **Team Manager - Estates Interim Payments**

Caitlyn Armstrong Johnson

#### **EIBSS Team**

10 Assessors & Benefits Advisors

#### **Estates Interim Payment Team**

25 Assessors

## **Performance Summary**

NHSBSA performance against Key Performance Indicators agreed with DHSC in table below.

#### Service Delivery 2023 – 2024

Indicator	KPI	Target	Actual %
Payments	Annual (regular) payments to be made at agreed time each Month/Quarter	100%	100%
Correspondence	Beneficiary correspondence responded to within 5 working days	90%	99.19%
Correspondence	Beneficiary correspondence responded to within 10 working days (this should be full response)	100%	99.73%
Complaints	Complaints acknowledged within 3 working days (so that the individual knows that the complaint has been received)	100%	100%
Complaints	Informal complaints responded to within 10 working days. This should be a full response to the complaint	100%	100%
Complaints	Stage 2 complaints responded to within 15 working days. This should be a full response to the complaint	100%	100%
Applications	New applications acknowledged within 5 working days, so the Applicant knows the application has been received	100%	100%
Applications	New applications processed to completion within 30 working days	90%	99.91%
Appeals	Appeals processed and completed within 60 working days	90%	71.64%

The England Infected Blood Support Scheme (EIBSS) met or exceeded targets for 7 out of 9 of the service KPIs in 2023 - 2024.

The two missed KPIs were due to a substantial increase in volume of Correspondence, Applications, and Appeals following the Interim Compensation payment announcement by Government, accepting the Infected Blood Inquiry second interim report recommendations.

#### **Correspondence Received**

During 2023 - 2024 the EIBSS received 9,473 items of Beneficiary correspondence (post and email) and responded to 9,401 or 99.24% within the 10-day KPI. This included MP correspondence on behalf of Beneficiaries.

The NHSBSA complaints policy also covers the EIBSS.

During the year 2023 – 2024 the EIBSS received 40 complaints under this policy, and all were resolved within agreed timescales. This was a reduction from 45 complaints made in the previous year.

## **Applications**

#### **Application Process**

Applications for each of the support elements can be made by downloading the appropriate application form at <a href="https://www.nhsbsa.nhs.uk/eibss">www.nhsbsa.nhs.uk/eibss</a> or by contacting the EIBSS support team, who can send an application to the requestor.

#### **Appeals Process**

An applicant can appeal if they disagree with the outcome of their application to EIBSS. Appeals are heard by a panel of independent medical experts headed by a legal chairperson. As with the medical assessors, medical appeals panel members also have relevant clinical or similar experience in this field.

All applications to EIBSS which require medical practitioner evidence are assessed by medical experts with relevant clinical or similar experience in this field.

#### Received

EIBSS received 321 regular payment applications in 2023 – 2024, which was a 31% reduction – or 145 application reduction on the previous year.

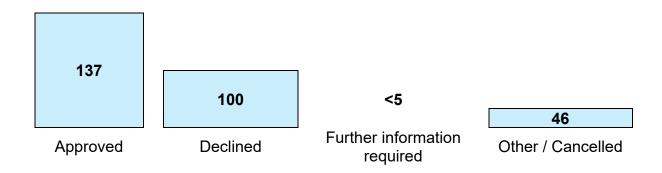
Please note that where there are less than 5 applications, we are unable to provide the exact number for data protection purposes.

Application Type	Applications received
Hepatitis C stage 1 payments	224
Special Category Mechanism (SCM) payments	11
Hepatitis C stage 2 payments	54
HIV & Co-infected payments	32

#### **Outcomes**

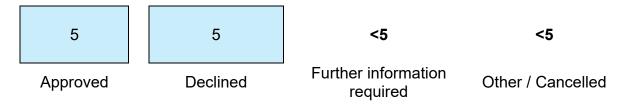
The total number of outcomes below, will differ from the number of applications received, shown in the table above. This difference is due to the application being received in one financial year and the related outcome being provided in the next financial year.

## **Hepatitis C Stage 1**



- Declined Applications The main reason was a lack of evidence/proof to support the applications.
- Further information required EIBSS are still awaiting additional information from the applicants.
- Other / Cancelled Applications which were either cancelled, superseded by another application, or have gone to appeal.

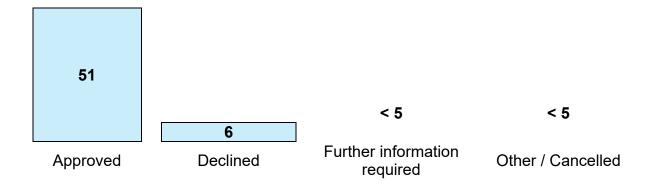
## **Special Category Mechanism (SCM)**



- Declined Applications The main reason was a lack of evidence/proof to support the applications.
- Further information required EIBSS are still awaiting additional information from the applicants.
- Other / Cancelled Applications which were either cancelled, superseded by another application, or have gone to appeal.

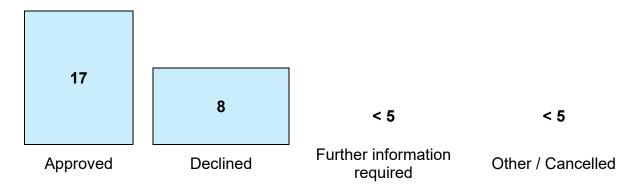
## **Hepatitis C Stage 2**

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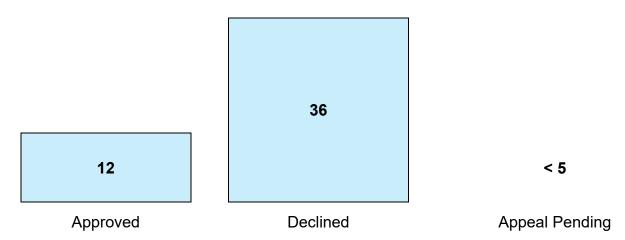
- Declined Applications The main reason was a lack of evidence/proof to support the applications.
- Further information required EIBSS are still awaiting additional information from the applicants.
- Other / Cancelled Applications which were either cancelled, superseded by another application, or have gone to appeal.

#### **HIV & Co-infected**



- Declined Applications The main reason was a lack of evidence/proof to support the applications.
- Further information required EIBSS are still awaiting additional information from the applicants.
- Other / Cancelled Applications which were either cancelled, superseded by another application, or have gone to appeal.

## **Appeals 2023 – 2024**



Please note that where there are less than 5 applications, we are unable to provide the exact number for data protection purposes.

Application Type	Appeals Approved	Appeals Declined
Hepatitis C stage 1 payments	10	32
Special Category Mechanism (SCM) payments	<5	<5
Hepatitis C stage 2 payments	<5	<5
HIV payments	<5	<5

An applicant can appeal if they disagree with the outcome of their application to EIBSS.

#### **Finance**

#### **Interim Compensation Payments**

In 2023 – 2024, the NHSBSA have continued to make Interim Compensation Payments of £100,000 to all eligible Beneficiaries and Bereaved Partners on the EIBSS.

This compensation payment is separate to any infected blood support payment, and therefore, is included here for information only, and is not included in any other part of this report.

Interim Compensation Payments		
Payment Type	Total	
Interim Compensation - £100,000 per eligible beneficiary	£18,200,000	

## **EIBSS Discretionary Payments**

Discretionary payments include payments for one-off items/circumstances. The purpose of discretionary support is to provide additional, time-limited financial and non-financial support to Beneficiaries and their families. This is to address immediate infection-related needs that have a direct effect on Beneficiaries' independence but are not otherwise being met.

## **EIBSS Total Expenditure**

EIBSS administered the following payments in 2023 – 2024

Total EIBSS Expenditure for 2023 - 2024		
Payment Type	Total	
Non-Discretionary Payments	£91,877,741.76	
Discretionary Payments	£1,734,851.05	
Lump Sum, Bereaved Partner & LEAP Payments	£21,590,594.23	
Total	£115,203,187.04	

# **EIBSS Non-Discretionary Payments 2023 - 2024**

Payment Type	Total
Regular Hepatitis C Stage 1	£29,449,141.86
One-Off Hepatitis C Stage 1	£9,435,117.08
Regular Special Category Mechanism (SCM)	£17,780,456.22
One-Off Special Category Mechanism (SCM)	£18,336.44
Regular Hepatitis C Stage 2	£17,951,369.71
One-Off Hepatitis C Stage 2	£1,645,159.70
Regular HIV	£2,145,916.93
One-Off HIV	£579,257.97
Regular Co-infected (HIV & Stage 1)	£3,524,072.85
One-Off Co-infected (HIV & Stage 1)	£11,189.00
Regular Co-infected (HIV & Stage 2)	£2,822,437.00
One-Off Co-infected (HIV & Stage 2)	-£12.50
Regular Co-infected (HIV & SCM)	£4,310,398.50
Annual Winter Fuel	£2,204,901.00
Total	£91,877,741.76

# **EIBSS Discretionary Payments 2023 - 2024**

Payment Type	Total
Adaptions to accommodation	£20,000.00
Benefits & Money Man. Advice	£1,040.00
Bereaved Payment	£572,464.08
Car repairs	£15,813.95
Child supplement	£438,350.00
Child supplement backdated	£46,350.00
Counselling	£91,317.80
Dental	£11,424.72
Focus Group Expenses	£2,315.74
Funeral grant	£278,884.32
Funeral plan	£30,620.00
Further counselling	£21,970.00
Hospital travel costs	£5,618.76
Household repairs	£88,092.03
Income Top-up	£3,441.66
Mobility Aids & Equipment	£6,233.32
Motability deposit	£500.00
PPC	£38,470.15
Respite break	£35,371.57
Specialist bed and mattress	£7,008.00
Support Payment – Medical Expenses	£369.29
Training	£19,195.66
Total	£1,734,851.05

## **EIBSS LEAP & Bereaved Partner Payments 2023 - 2024**

Payment Type	Total
Bereavement Lump Sum	£30,000.00
Bereaved Partner - Hepatitis C Stage 1	£2,800,083.16
Bereaved Partner - Hepatitis C Stage 1 (Backdated)	£89,871.82
Bereaved Partner - Hepatitis C Stage 1 (Protected)	£20,856.76
Bereaved Partner - Hepatitis C Stage 1 (Lump Sum)	£30,000.00
Bereaved Partner - SCM	£504,480.74
Bereaved Partner - SCM (Backdated)	£15,779.88
Bereaved Partner - Hepatitis C Stage 2	£7,937,582.12
Bereaved Partner - Hepatitis C Stage 2 (Backdated)	£103,717.94
Bereaved Partner - HIV	£2,635,273.75
Bereaved Partner - HIV (Backdated)	£31,559.68
Bereaved Partner - HIV (Lump Sum)	£80,500.00
Bereaved Partner - HIV & Stage 1	£2,870,109.25
Bereaved Partner - HIV & Stage 1 (Backdated)	£53,418.16
Bereaved Partner - HIV & SCM	£78,024.08
Bereaved Partner - HIV & Stage 2	£4,259,336.89
Estate Bereaved (Lump Sum)	£50,000.00
Total	£21,590,594.23

## 2024 - 2025 Forward View

We are continuing with Focus Groups in 2024 - 2025 to ensure as many Beneficiaries as possible have the opportunity to attend, and we will also be arranging a return to in person Focus Groups, with London, Leeds & Newcastle being the preferred locations requested by Beneficiaries.

Beneficiaries can register their interest in attending by completing the online form on the website here.