# NHS Business Services Authority England Infected Blood Support Scheme Annual Report 2018/2019

EIBSS Annual Report 2018/19

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# Introduction

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

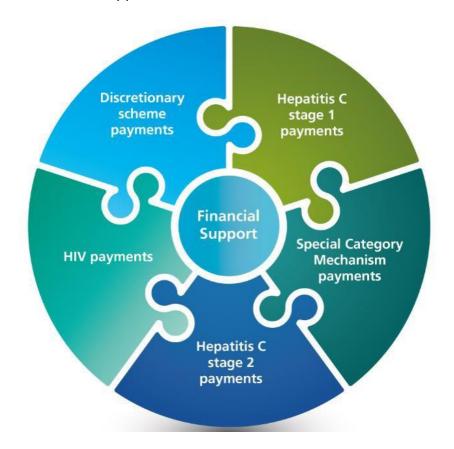
NHSBSA administers the scheme for those eligible for support through EIBSS; providing financial and other support to those who were historically infected by HIV and/or hepatitis C through NHS supplied blood and blood products during the 1970s and 1980s. The scheme also provides support for their families, 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 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 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 before October 1985.

Winter Fuel payments - one-off payments for all beneficiaries paid in December.

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

- Income Top Up Is a discretionary monthly payment to increase household income to help with general living costs. An assessment is made of household income and if the income is below set thresholds an application can be made to receive payments.
- One off payments financial support that beneficiaries and bereaved spouses/partners may apply for to cover the cost of certain essential, health-related items or services.
- Payments for children to help with the costs of bringing up children of an infected beneficiary.

# **Application Process**

Applications for each of the support elements can be made by downloading the appropriate application form at <u>www.nhsbsa.nhs.uk/eibss</u> or by contacting the EIBSS support team, who can post an application to the requestor.

#### **Medical Assessors**

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

#### **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.

#### **Welfare Advice**

NHSBSA provides a welfare advice service via a welfare adviser; the previous scheme administrators offered the same service. Alternatively, beneficiaries can choose to source their own welfare advice and EIBSS will cover the cost. EIBSS are able to assist beneficiaries in locating local welfare advice; if they choose this option.

## **Beneficiaries**

As at the end of March 2019 there are 2,993 people registered for support through the scheme. This is broken down into the following groups:

Beneficiary Group	Number of beneficiaries registered
Hepatitis C stage 1	1153
Hepatitis C stage 2	579
Special Category Mechanism	535
HIV	65
Co-infected (stage 1 and HIV)	90
Co-infected (stage 2 and HIV)	58
Co-infected (SCM and HIV)	88
Bereaved	425

### **Payments**

From 1 April 2018 - 31 March 2019 EIBSS processed all annual and discretionary payments for registered beneficiaries and their families. The levels of payment available in 2018/19 are shown in the table below.

Payment type	Annual payments in 2018/19
Hepatitis C (stage 1)	£4,519
Hepatitis C (stage 1) with SCM	£18,519
Hepatitis C (stage 2)	£18,519
HIV	£18,519
co-infected with HIV and hepatitis C (stage 1)	£22,519
co-infected with HIV and hepatitis C (stage 1) with SCM	£36,519
co-infected with HIV and hepatitis C (stage 2)	£36,519

NHSBSA pays annual payments on a monthly or quarterly basis, depending on beneficiary preference. Annual payments include a winter fuel payment made in December each year. 2018/19 payments included a winter fuel payment of £519.

A one-off lump sum payment of £20,000 is reserved for a new applicant registered for hepatitis C stage 1 payments and a one-off lump sum of £50,000 to those who develop a hepatitis C stage 2 condition. A one-off lump sum is also paid to a new applicant registered for HIV payments. The lump sum amount is subject to the applicant's eligibility criteria at the time of infection and depends on their circumstances and whether they are a primary beneficiary or a secondary infectee.

A one-off lump sum payment of £10,000 is also available for bereaved partner/spouses of deceased beneficiaries provided they meet certain criteria.

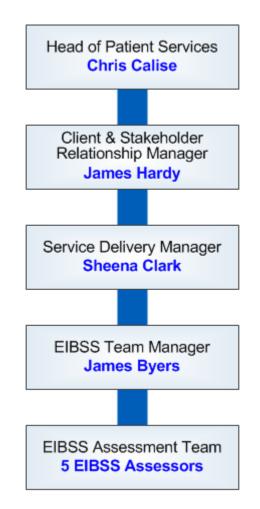
#### Stakeholder engagement

NHSBSA continues to engage with several stakeholders, including the Haemophilia Society and Hepatitis C Trust. Any feedback is shared with DHSC.

#### **Beneficiary engagement**

NHSBSA has continued to hold beneficiary focus groups aimed at developing and improving the scheme. These are held every 2 months across England and travel expenses continue to be covered for beneficiaries. All beneficiaries are invited to participate in the focus groups.

## **EIBSS Structure**



# **Performance summary**

The below table indicates NHSBSA performance against key performance indicators agreed with DHSC.

#### **Service delivery**

Key Performance Indicator	Target	Achieved for 2018/19
% of annual payments made at agreed time each month	100.00%	100.00%*
% of new applications acknowledged within 5 working days	100.00%	100.00%
% of beneficiary correspondence responded to within 5 working days	90.00%	99.17%
% of beneficiary correspondence responded to within 10 working days	100.00%	100.00%
% of complaints acknowledged within 2 working days	100.00%	100.00%
% of complaints responded to within 10 working days	90.00%	100.00%
% of complaints responded to within 15 working days	100.00%	100.00%
% of new applications processed to completion within 30 working days	90.00%	99.00%
% of applications through the SCM processed and payments made to individuals within 120 working days	90.00%	100.00%
% of appeals processed and completed within 60 working days	90.00%	100.00%

\*NHSBSA acknowledges that where our automated payments system has failed then a faster payment mechanism has been used to pay beneficiaries on the same day. Where any overpayments have occurred in a small number of cases, the recouping of said overpayments has been agreed with beneficiaries and phased over a number of months where appropriate to avoid adversely affecting individuals.

### **Application volume**

EIBSS received 307 regular payment applications in 2018/19. <u>Please note that where there are</u> less than 5 applications, we are unable to provide the exact number for data protection purposes.

2018/19		
Application type	Number of applications received	
Hepatitis C stage 1 payments	123	
SCM payments	99	
Hepatitis C stage 2 payments	75	
HIV payments	10	
Total	307	

#### **Application outcome**



Declined Applications- The foremost reason was a lack of evidence/proof to support the claim.

Further information required is where EIBSS are still awaiting additional information from the applicant.

From the 59 approved applications received in 2018/19, 19 beneficiaries met the eligibility criteria for SCM or hepatitis C stage 2 payments.

SCM



Declined Applications- The foremost reason was assessed by clinicians to be an unsupported link of symptoms to Hepatitis C Virus (HCV) and/or treatment.

Further information required is where EIBSS are still awaiting additional information from the applicant.



Declined Applications- The foremost reason was a lack of evidence/proof to support the claim. Further information required is where EIBSS are still awaiting additional information from the applicant.

HIV

	<5	<5	<5
Ap	proved	Declined	Further information required

Declined Applications- The foremost reason was that it was not probable that the infection was contracted through a blood transfusion.



2018/19		
Application type	Number of appeals approved	Number of appeals declined
Hepatitis C stage 1	<5	31
SCM payments	6	26
Hepatitis C stage 2	<5	<5
HIV payments	<5	<5
Total	9	<b>61</b>

An applicant can appeal if they disagree with the outcome of their application to EIBSS. For 2018/19 there was a 12.86% approval rate following an appeal.

#### **Discretionary Payments**

Discretionary payments include income top-up payments and 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.

During 2018/19 we approved 1,601 applications for a one-off payment.

#### **Correspondence received**

During 2018/19 we received and responded to over 7,000 items of beneficiary correspondence (post and email). This included MP correspondence on behalf of beneficiaries.

The NHSBSA complaints policy also covers EIBSS. During the year 2018/19 we received 11 complaints under this policy.

# Finance

In 2018/19 EIBSS administered the following payments.

Total EIBSS expenditure 2018/19		
Payment type	<b>Total (£)</b> (rounded to the nearest pound)	
Non-discretionary payments	40,101,016	
Discretionary payments	6,061,478	
TOTAL	46,162,494	

Non-discretionary Payments 2018/19		
Payment type	<b>Total (£)</b> (rounded to the nearest pound)	
Regular Hepatitis C stage 1	5,492,360	
One-off Hepatitis C stage 1	1,561,000	
Regular Hepatitis C stage 2	11,682,871	
One-off Hepatitis C stage 2	2,768,000	
Regular HIV	5,470,738	
One-off HIV	127,500	
Regular SCM	11,424,391	
Annual winter fuel	1,574,156	
TOTAL	40,101,016	

Discretionary Payments 2018/19		
Payment type	<b>Total (£)</b> (rounded to the nearest pound)	
Adaptations to Accommodation	6,718	
Benefits & Money Man advice	608	
Bereaved Payment	365,500	
Car Repairs	177	
Child Supplement	326,556	
Child Supplement (backdated)	124,115	
Counselling Dental	7,600	
Discretionary Payments	5,465 0	
Financial Assistance	3,350	
Funeral Grant	179,824	
Funeral Plan	30,785	
Hospital Travel Costs	1,180	
Hotel Costs for Hospital Stay	338	
Household Repairs	48,208	
Income Top-up	3,701,544	
Income Top-up (backdated)	1,167,586	
Mobility Aids & Equipment	22,111	
Motability Deposit	2,199	
PPC	20,178	
Respite Break	16,363	
Specialist Bed & Mattress	12,589	
Support Payment – Medical Expenses	2,695	
Training	15,789	
TOTAL	6,061,478	

#### 2019/20 Forward View

NHSBSA intends to build on the current engagement with beneficiaries and carry out further beneficiary focus groups in 2019/20. This will allow us to continue gathering the opinions of beneficiaries, helping to identify any improvements that can be made to the service.

On Tuesday 30 April 2019, the Government announced that additional funding was made available to support those infected and affected by the infected blood tragedy. As a result revised payments will be made to all beneficiaries and bereaved if applicable in July 2019 with payments backdated to 1<sup>st</sup> April 2019.