



**Business Services Authority**

**NHS Business Services Authority**

**England Infected Blood Support Scheme**

**Annual Report 2019/20**

**EIBSS Annual Report 2019/20**

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## Introduction

On 1 November 2017, the 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 Health and Community Services area of Citizen Services. 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.

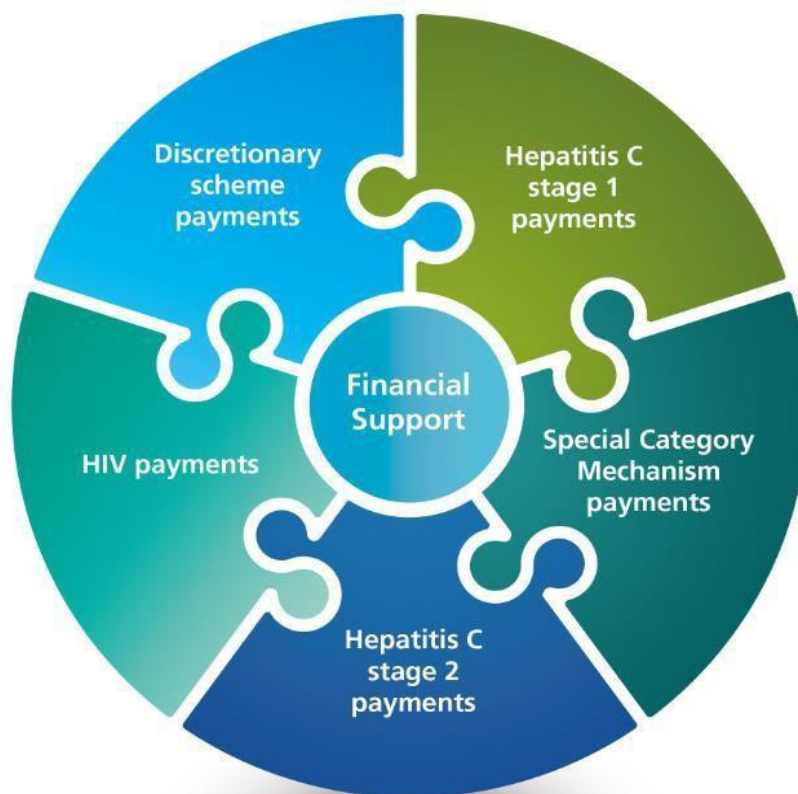
The scheme recognises that individuals living with hepatitis C and/or HIV face extra costs.

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 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.

**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 [www.nhsbsa.nhs.uk/eibss](http://www.nhsbsa.nhs.uk/eibss) 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

There are 3,058 people registered for support through the scheme. This is broken down into the following groups (*Data valid on 03.04.2020*);

<b>Beneficiary Group</b>	<b>Number of Beneficiaries registered</b>
Hepatitis C stage 1	1165
Hepatitis C stage 2	575
Special Category Mechanism	563
HIV	66
Co-infected (stage 1 and HIV)	87
Co-infected (stage 2 and HIV)	57
Co-infected (SCM and HIV)	88
Bereaved	457

## Payments 2019/20

From 1 April 2019 - 31 March 2020 EIBSS processed all annual and discretionary payments for registered Beneficiaries and their families. The levels of payments available in 2019/20 are shown in the table below.

On 30<sup>th</sup> April 2019, the Government announced that additional funding was to be made available to support those historically infected and affected with Hepatitis C and/or HIV from NHS blood or blood products.

All payments were backdated to the 1<sup>st</sup> April 2019 and will increase annually in line with the Consumer Price Index.

<b>Payment Type</b>	<b>Annual Payments</b>
Hepatitis C (stage 1)	£18,458
Hepatitis C (stage 1) with SCM	£28,000
Hepatitis C (stage 2)	£28,000
HIV	£28,000
Co-infected with HIV and Hepatitis C (stage 1)	£38,000
Co-infected with HIV and Hepatitis C (stage 1) with SCM	£44,000
Co-infected with HIV and Hepatitis C (stage 2)	£44,000

NHSBSA pays annual payments on a monthly or quarterly basis, depending on Beneficiary preference. In addition to the annual payments listed above, a separate winter fuel payment of £531 was paid in December 2019.

A one-off non-discretionary lump sum payment of £20,000 is reserved for a new applicant registered for hepatitis C stage 1 payments and a one-off non-discretionary lump sum payment of £50,000 to those who develop a hepatitis C stage 2 condition.

A one-off non-discretionary lump sum payment is also paid to a new applicant registered for HIV payments. The lump sum payment 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 Beneficiary.

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

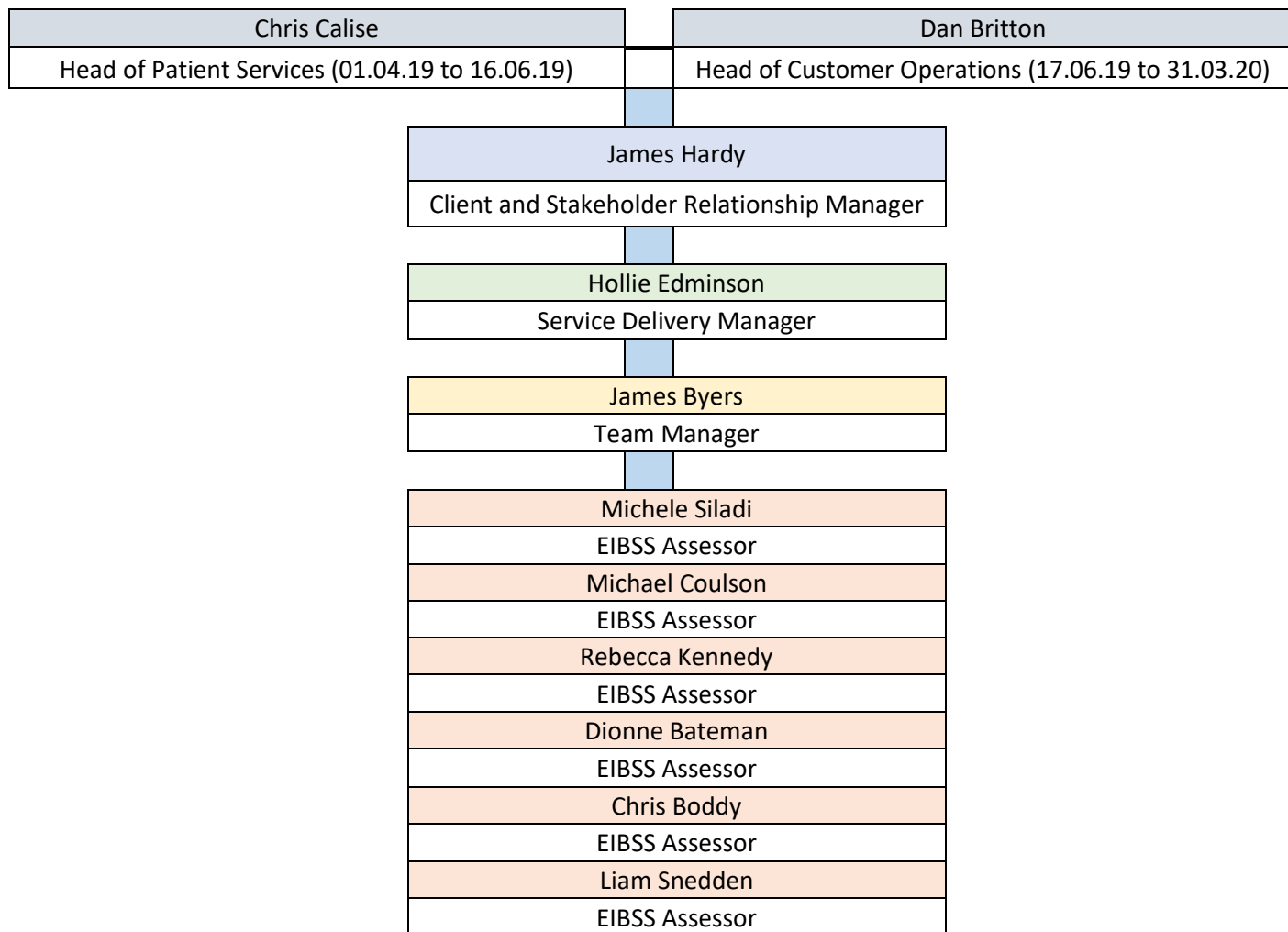
## **Stakeholder Engagement**

NHSBSA continues to engage with several stakeholders, including the Hemophilia 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



\* Structure current at 03.04.2020

## Performance Summary

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

### Service Delivery 2019/20

Key Performance Indicator	Target	Achieved
% of annual payments made at agreed time each month	100%	100% *
% of new applications acknowledged within 5 working days	100%	100%
% of Beneficiary correspondence responded to within 5 working days	90%	100%
% of Beneficiary correspondence responded to within 10 working days	100%	100%
% of complaints acknowledged within 2 working days	100%	100%
% of complaints responded to within 10 working days	90%	100%
% of complaints responded to within 15 working days	100%	93.33% **
% of new applications processed to completion within 30 working days	90%	97.59%
% of applications through the SCM processed and payments made to individuals within 120 working days	90%	100%
% of appeals processed and completed within 60 working days	90%	100%

\*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.

\*\* 15 complaints received in total – 1 was resolved on working day 16 (instead of Day 15) = 93.33%, otherwise would have been 100% achieved target.



## Correspondence Received

During 2019/20 EIBSS received and responded to over 5,000 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 2019/20 EIBSS received 15 complaints under this policy. 1 was resolved on working day 16 (instead of Day 15), otherwise all 15 would have been resolved within agreed timescales.

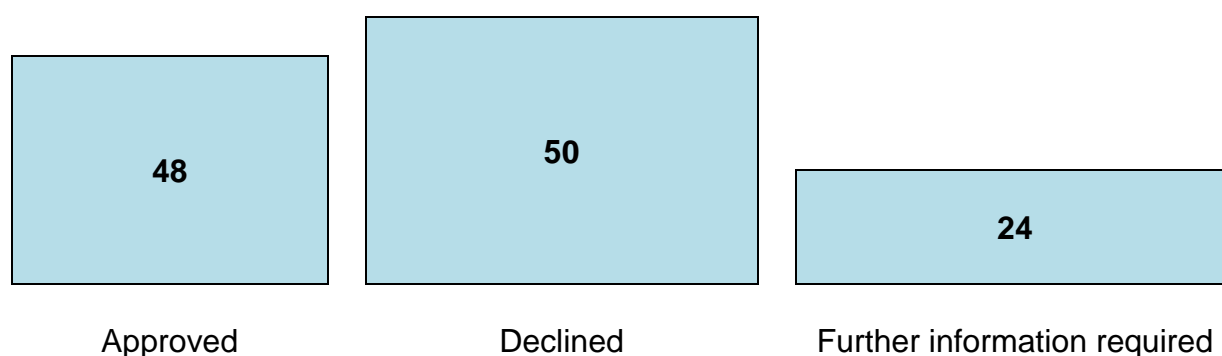
## Application Volume

EIBSS received 224 regular payment applications in 2019/20.

Application Type	Applications received
Hepatitis C stage 1 payments	122
Special Category Mechanism (SCM) payments	41
Hepatitis C stage 2 payments	52
HIV payments	9
<b>Total</b>	<b>224</b>

## Application Outcomes

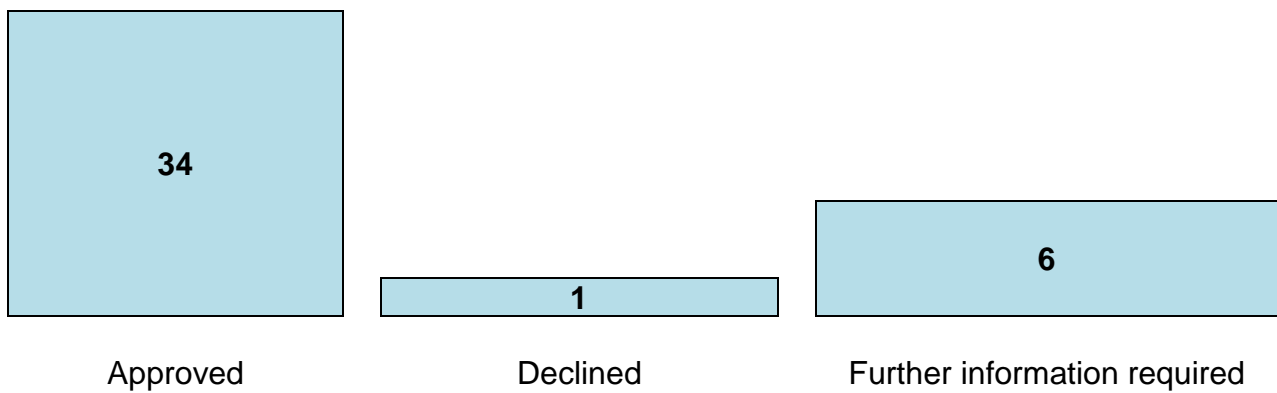
### Hepatitis C Stage 1



For 2019/20 there was a 39.34% approval rate in Hepatitis C stage 1 decisions.

- Declined Applications - The main reason was a lack of evidence/proof to support the claim.
- Further information required - EIBSS are still awaiting additional information from the applicant.
- From the approved applications received in 2019/20, 24 Beneficiaries met the eligibility criteria for SCM or Hepatitis C stage 2 payments.

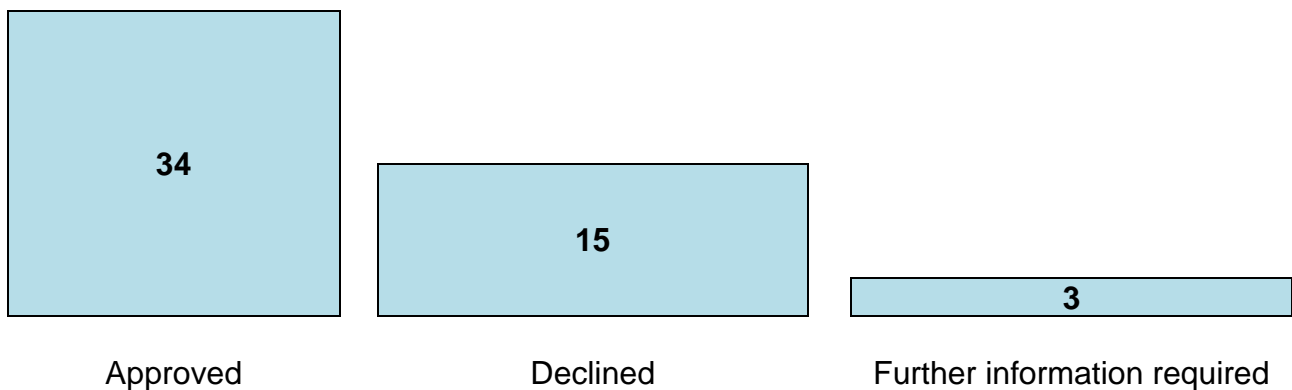
## Special Category Mechanism (SCM)



For 2019/20 there was an 82.92% approval rate in Special Category Mechanism (SCM) decisions.

- Declined Application - The main reason assessed by Clinicians was to be an unsupported link of symptoms to the Hepatitis C Virus (HCV) and/or treatment.
- Further information required - EIBSS are still awaiting additional information from the applicant.

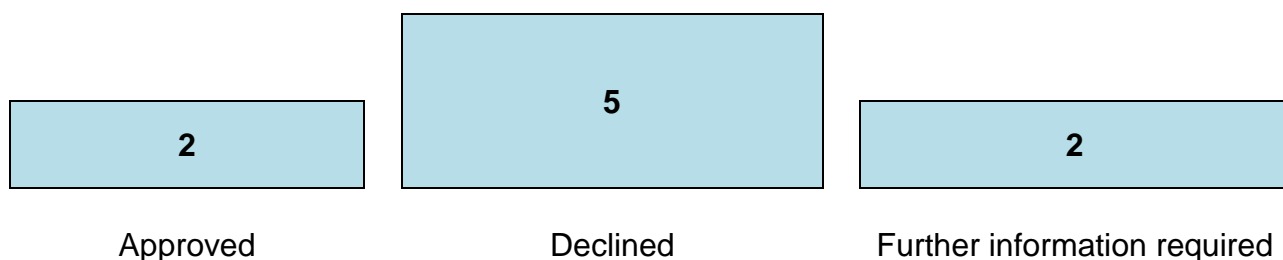
## Hepatitis C Stage 2



For 2019/20 there was a 65.38% approval rate in Hepatitis C stage 2 decisions.

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

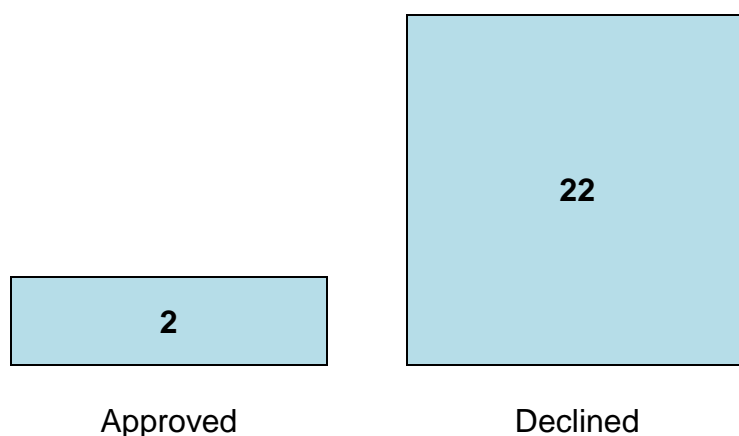
## HIV



For 2019/20 there was a 22.22% approval rate in HIV decisions.

- Declined Applications - The main reason was that it was not probable that the infection was contracted through a blood transfusion.
- Further information required - EIBSS are still awaiting additional information from the applicant.

## Appeals 2019/20



Application Type	Appeals Approved	Appeals Declined
Hepatitis C stage 1 payments	1	17
Special Category Mechanism (SCM) payments	0	0
Hepatitis C stage 2 payments	1	2
HIV payments	0	3
<b>Total</b>	<b>2</b>	<b>22</b>

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

For 2019/20 there was a 9.09% approval rate following an appeal, due to additional supporting evidence being provided by the Applicant.

## 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.

## Finance

In 2019/20 EIBSS administered the following payments.

<b>Total EIBSS Expenditure for 2019/20</b>	
<b>Payment Type</b>	<b>Total</b>
Non-Discretionary Payments	£69,636,827
Discretionary Payments	£5,495,457
<b>Total</b>	<b>£75,132,284</b>

<b>Non-Discretionary Payments 2019/20</b>	
<b>Payment Type</b>	<b>Total</b>
Regular Hepatitis C Stage 1	£21,854,836
One-Off Hepatitis C Stage 1	£1,400,000
Special Category Mechanism (SCM)	£15,692,020
Regular Hepatitis C Stage 2	£16,440,150
One-Off Hepatitis C Stage 2	£1,875,000
Regular HIV	£2,892,558
One-Off HIV	£141,000
Regular Co-infected (HIV & Stage 1)	£2,815,156
Regular Co-infected (HIV & Stage 2)	£1,922,844
Regular Co-infected (HIV & SCM)	£2,981,106
Annual Winter Fuel	£1,622,157
<b>Total</b>	<b>£69,636,827</b>

<b>Discretionary Payments 2019/20</b>	
<b>Payment Type</b>	<b>Total</b>
Adaptations to Accommodation	£5,779
Bereaved Payment	£310,000
Car Repairs	£11,156
Child Supplement	£607,150
Child Supplement (backdated)	£29,700
Counselling	£17,524
Dental	£5,840
Financial Assistance	£880
Funeral Grant	£208,511
Funeral Plan	£34,455
Hospital Travel Costs	£4,783
Household Repairs	£60,850
Income Top-Up	£3,641,168
Income Top-Up (backdated)	£448,650
Mobility Aids & Equipment	£11,343
Motability Deposit	£4,650
PPC	£25,775
Respite Break	£27,384
Specialist Bed & Mattress	£17,583
Support Payment – Medical Expenses	£295
Training	£21,981
<b>Total</b>	<b>£5,495,457</b>

## 2020/21 Forward View

There has been disruption to the focus group schedule due to covid-19 restrictions. We are currently investigating digital alternatives to the usual face to face meetings as we intend to build on the current engagement with Beneficiaries and carry out further Focus Groups in 2020/21 where possible.

We will also be arranging a Newsletter to all Scheme Members mid-way through the year to provide appropriate updates and communications, with a Satisfaction Survey to follow. This will allow us to continue gathering the opinions of Beneficiaries, helping to identify any improvements that can be made to the service.