

# Scottish Infected Blood Support Scheme 2020 Customer Satisfaction Survey and 3-year Review of Service

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## Introduction

As part of our commitment to providing a high quality service to members, the Scottish Infected Blood Support Scheme (SIBSS) carried out a customer satisfaction survey in April 2020.

Out of the 540 scheme members surveyed, 395 returns were received, giving a response rate of 73%. This is an improvement on the 47% response rate received during the 2018 survey. It should be noted however, in the 2018 survey only 286 members classified as being 'happy to receive non-essential mailings' were contacted. This 2020 survey saw all members contacted due to the 3-year review being classified as an 'essential mailing'. For those members who currently do not receive non-essential mailings, i.e. the Newsletter, but would now wish to opt in to receive them, please complete the Contact Preference Form (Appendix 4). Likewise, those wishing to opt out of future 'non-essential' mailings can do so using the same form.

Survey results are set out below showing comparisons with our 2018 results. We are delighted to say this shows 91% rated the Overall Service as good or very good compared to 84% in 2018. This improvement has set the bar very high for future surveys; however, we are committed to continuous improvement and will use the information from this report to address any service issues raised in an effort to maintain our high standards.

The survey this year contained additional questions as part of our 3-year review. For everyone involved with SIBSS it is of paramount importance that we provide a high quality service to members and prospective members. To do this, we provide a number of routes for people to obtain advice and guidance not only on eligibility and how to apply, but also grants and support organisations. We endeavour to be consistent, but flexible where appropriate when interpreting the guidance on payment levels and to ensure these payments are made accurately and in a timely manner.

We are aware that we don't always get things right. Feedback generated from these surveys and other direct communications from members is a key source of information for us and we assess all contributions to inform the improvements we then try to implement. A detailed breakdown of members' comments and planned improvements are included in the feedback sections below.

## Acknowledgements

On behalf of SIBSS we'd like to thank members for their high level of engagement as it helps us shape the service to best meet their needs. We'd also like to thank the Advisory Group for their work in helping to develop the survey and the support they provide.

## Progress Report Timetable

Action	Target Date
Survey Report issued to members	17/08/2020
Action plan implemented	September 2020
Action plan reviewed	Quarterly October 2020 – March 2021

## Survey Results

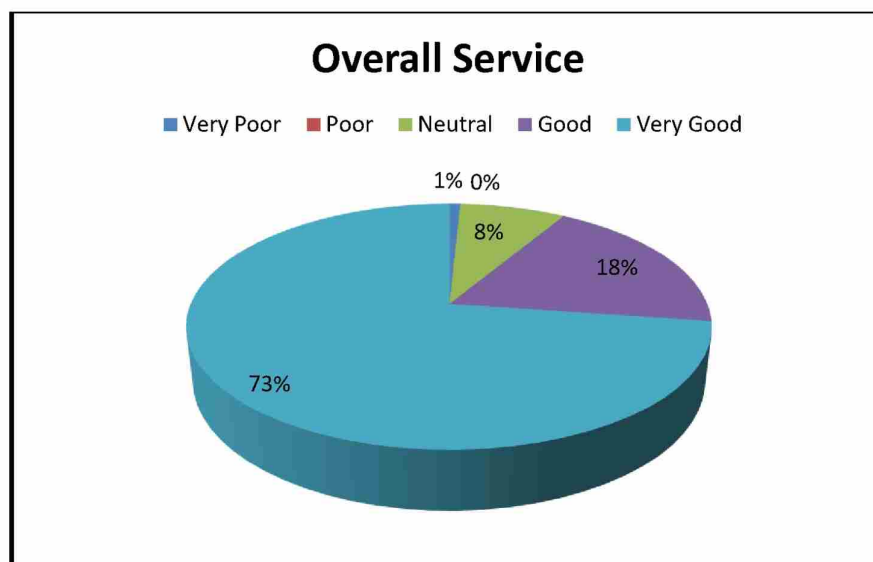
To gauge how well the SIBSS is performing, members were asked 10 questions to be graded from 'Very Good' to 'Very Poor' across 4 subject areas:

- 1) Overall Service
- 2) Payment Services
- 3) Customer Services
- 4) Communication

Each subject area is assessed in the sections below with a graphical representation of the scores. There is also a summary graphical breakdown provided in Appendix 2.

### 1) Overall Service

Scheme members were asked to give their thoughts on the overall service they receive from SIBSS.



Members said:	Our response:
<p>91% of scored responses rated the service as good or very good</p> <p>1% rated the service as poor or very poor</p>	<p>To receive such a positive score overall is very encouraging and there were numerous comments to this effect. These are referenced in feedback section.</p>
Comparison to 2018 Survey	

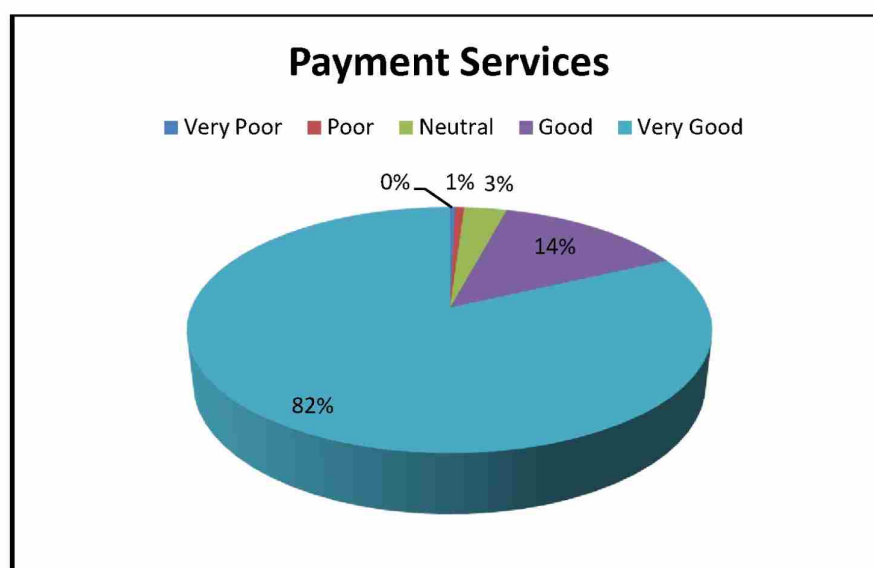
Comparing to the 2018 survey shows only 84% of members who rated the overall service as good or very good. This improvement is encouraging as it shows that members feel they are getting a better service, which is the fundamental consideration for us.

The number of negative responses dropping from 4% to 1% is another indicator that improvements put in place in the service are being witnessed and valued by members.

## 2) Payment Services

Members were asked to comment on:

- How well SIBSS processes any payments due to you.
- The accuracy of your payments.



Members said:	Our response:
<p>Of those members that provided a score in response to the question, 96% believe that SIBSS payments are processed well and that they are accurate.</p> <p>1% of members responded with a negative view of the process and accuracy of payments.</p>	<p>Following the negative responses, we reviewed all payments made and identified only 1 payment error over the period, which was addressed. A number of comments centred on the belief that the payment amount assigned was incorrect or an unhappiness with the tiered payment levels; this issue is covered in more detail in the feedback section.</p>
Comparison to 2018 Survey	

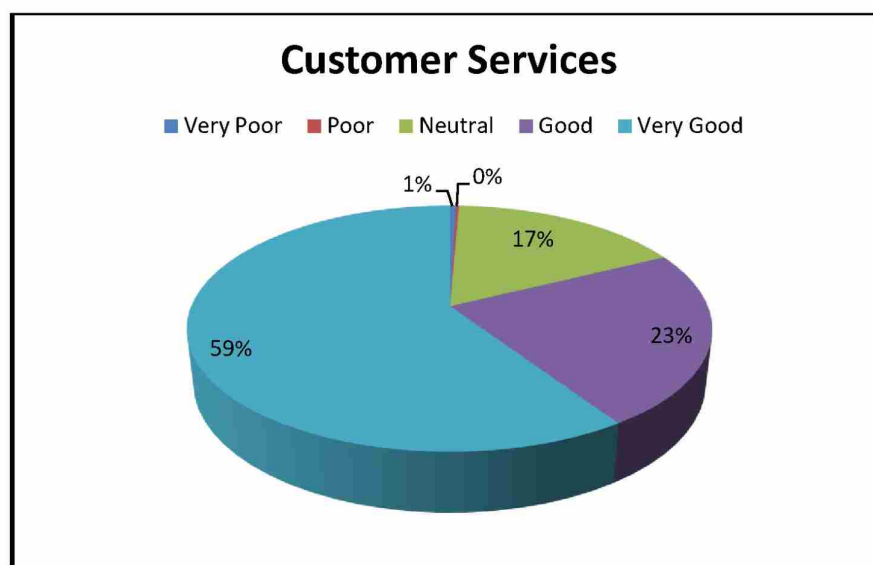
The 2018 results show a similar satisfaction level in that 96% of responses in 2018 believed that their payments were processed well and were accurate while 1% provided a negative response.

Additionally, in 2018 14% left this question blank, whereas the figure is now only 4%. This may in part be because the great majority of members can now access regular payments. This improved response rate better reflects the entirety of member views and highlights a high level of satisfaction in the payment process.

### 3) Customer Services

We asked scheme members:

- To tell us about the ease of contacting SIBSS?
- How effectively your queries are dealt with?
- How timely the advice is received to your query?
- How courteous your query is dealt with?
- To comment on the quality of the advice received
- The overall service provided by SIBSS



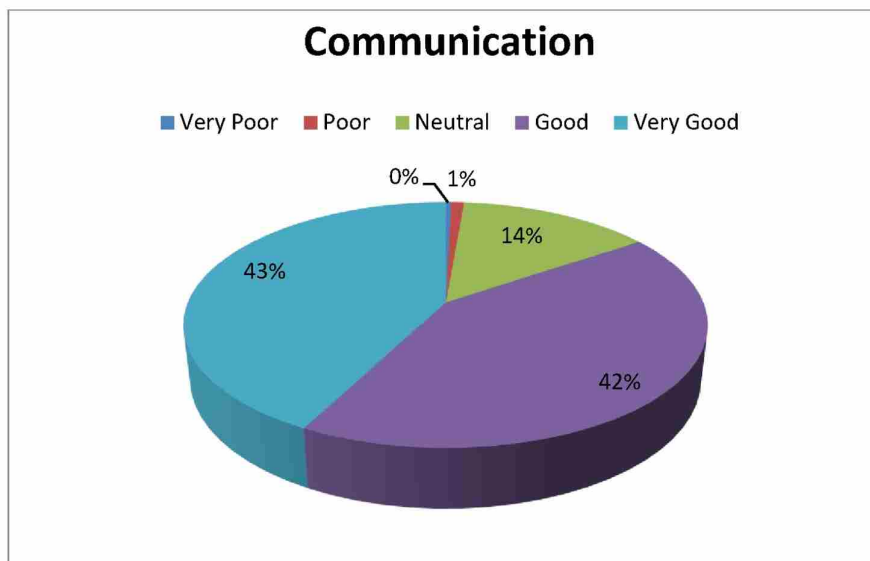


Members said:	Our response:
<p>85% of responders were happy with the ease of contacting the service and 82% felt their query(ies) was / were effectively dealt with.</p> <p>79% felt the advice provided was timely and 83% found interactions to be courteous.</p> <p>82% of members found the advice provided to be of a good quality.</p> <p>Across all areas the negative experience was consistently under 1% with 2 of the questions receiving only a single negative response.</p>	<p>Across all areas of customer service members found the service to be of a high standard, with very few negative responses.</p> <p>The team are on hand to help with any query relating to the scheme and can be contacted by phone or email – details of these are provided in the communication section.</p>
Comparison to 2018 Survey	
<p>In the 2018 survey the average scored positive result was 85% compared to 82% now, while the number of negative responses reduced from 3% to 1%. A factor in the reduction in positive answers was the increase in neutral responses and reduction in those who left it blank. Previously 8% scored these neutral while 29% left it blank. This year 16% scored these neutral with only 9% returning a blank. From reading the comments, a large number of members indicated a neutral score as they hadn't used certain services or had to contact SIBSS with any queries. As neutral scores factor into the calculation where blanks don't this reduces the percentage of positive and negative results. In view of the change to neutral responses from blank we feel overall that the service provided by the team to members is largely positive. We are not, however, complacent and so continuous engagement with members will seek opportunities to continuously improve our overall position.</p>	

## 4) Communication

We asked:

- How useful is the bi-annual SIBSS newsletter?
- How useful is the SIBSS Website?



Members said:	Our response:
Members rated the SIBSS newsletter as good or very good in 87% of scored survey responses.	The newsletter is a key communication route for those members who choose to receive it. To get such a positive response indicates it is still important and well received by members.
Members rated our website as good or very good in 82% of scored survey responses.	The website is a vital source of information on all aspects of the scheme and associated support services. It's therefore crucially important that members and those looking to apply are able to find clear concise advice. Again to get a positive response highlights that in most cases members can find what they need.
Comparison to 2018 Survey	
The website was the lowest rated aspect during the 2018 survey with a positive response for 69% for scored returns. Following updates to the website, such as the inclusion of the newsletter and survey results those numbers increased considerably to 82%. In addition the number of negative responses has dropped from 5% to 1%.	

## Feedback from Scheme Members

In addition to the structured scored questions, members were asked to provide further comment on why the service was good or failing them and also to elaborate on what things the Scheme could look to do and what things could be stopped as they don't add value.

Having read through the responses it was pleasing to see so much positive feedback directed at the team, particularly with regards to their interactions with members.

To build on the feedback we have split the responses into 3 key themes: Communication, Criteria and Payments. Members' feedback on suggested changes is highlighted and we have also set out our action plans for improvements linked to these, which we hope to implement.



## Communication

- Insufficient advice on what support is available through the scheme
- Wasn't aware of the newsletter
- Existence of SIBSS is not widely communicated to the public
- Not enough communication on a regular basis
- Should be a pro-active search for those infected

## Our response

The [SIBSS website](#) has been updated to better reflect the services offered. There are links to support organisations, such as charities who can provide advice and peer support and the haemophilia psychological support service, as well as advice on the tax and benefit exemptions. There is also detailed guidance on who is eligible and how they can access support.

The newsletter is normally issued twice each year. If you do not currently receive this, but wish to please complete the Contact Preference Form attached with this report. As there aren't regular changes to the scheme or services offered it is felt that a bi-annual newsletter allows us to cover any updates. We are aware that some members wish to speak to someone direct or send an email and so we would encourage you to get in touch if you need assistance on 0131 275 6754 or at [nss.sibss@nhs.net](mailto:nss.sibss@nhs.net). The team are available from 8:30am to 4:30pm Monday to Thursday and 8:30am to 4:00pm on Friday and will be happy to help.

Prior to SIBSS being set up, the Scottish Government ran a large awareness campaign in autumn 2016 and spring 2017, during which they issued posters and leaflets and advice through GP practices, dentists, libraries and other venues encouraging those who had a blood transfusion pre-September 1991 to come forward for a test for hepatitis c (HCV). In addition, SNBTS has conducted 'look back' exercises to try to identify previous recipients of any blood from a donor who was later identified as being infected with HIV or hepatitis c. In 2016, a [short-life working group](#) estimated there were between 0 and 32 people living in Scotland who were infected with HCV from a blood transfusion, but had not yet been diagnosed. With the publicity around the Infected Blood Inquiry, in conjunction with the awareness campaign it is likely that there are very few of the potential 32 individuals who remain undiagnosed.

## Action Plan:

- Although there are currently links in the body of the newsletter to the website and any services discussed we will add a specific section which makes these more prominent.
- We will review the ease of finding information on the website, along with the clarity of the advice provided.
- We will send an update to GP practices and NHS Health Boards to encourage them to make their patients who are infected or affected aware of the support available through SIBSS.

## Payments

- It would be helpful to know when payments increase and by how much
- Why is the payment level different to England?
- Are grants available to help improve my quality of life?
- Helpful if there was confirmation once the eligibility criteria are updated during the payment review

## ***Our response***

2020 was the first year where the inflationary uplift was applied to increase all annual payments by the Consumer Price Index (CPI); this was communicated to all members who receive regular payments by post and via the Newsletter. The Scottish Government has agreed that these payments will rise in line with inflation in future years as well so you will get an increase in April each year.

As an interim step in advance of any recommendations in the Infected Blood Inquiry's final report, the governments of the four UK nations are working towards increasing parity in financial support across the four UK schemes, taking account of local circumstances and beneficiaries' needs. However, the Scottish Government, acknowledging how well received SIBSS is, is keen to ensure any increase in parity still ensures sufficient flexibility to allow SIBSS to respond to beneficiaries' needs and Scottish circumstances, as well as making sure that no beneficiary is worse off as a result of any changes. These discussions around parity are still ongoing and an update will be provided on any progress made.

The website contains detailed guidance on the [grants](#) that are available in relation to improving quality of life, what they cover and how you can apply for these. If you require further assistance with these or feel you need a grant for something linked to your or your partner's infection, but cannot find information about it in the guidance, please contact the team who will be happy to advise.

## **Action Plan:**

- We will review the process for notification of uplifts to ensure members are aware of the increase each year.
- We will add a link to the grant section of the website in the next newsletter.
- We will provide an update to members as soon as further information is available regarding any potential changes to increase parity with other UK schemes.

## **Scheme Criteria**

- All stage 1s (those with chronic HCV) should be categorised as the highest section for payment
- Remove the different stages
- Sense that the process is designed to prevent one-off grant applications rather than facilitate them

## ***Our response***

SIBSS make payments on behalf of the Scottish Government using the criteria set out in the [Scheme document](#), a copy of which is available on our website or we can send you a hard copy on request. The 2018 [Clinical Review on the Impacts of Chronic Hepatitis C](#) recommended we have a distinction for those with Advanced Hepatitis C, but that at stage 1 we implement a self-assessment to better reflect the differing impacts of infection on members with Chronic Hepatitis C. We followed this guidance.

The [grant](#) section on the website provides guidance on how to apply, but should you need further assistance please contact the team who will be able to advise. We have sought to make the process as easy as possible and don't require members' income details for some grants – such as for counselling or psychological support. However,

while SIBSS has increased regular payments to reduce the need for means-tested grants, to ensure fairness some one-off grants do still need to be targeted at those on lower incomes to help those in the greatest financial need.

**Action Plan:**

- We will add an FAQ section to the website to help members and their families understand the different options within the scheme

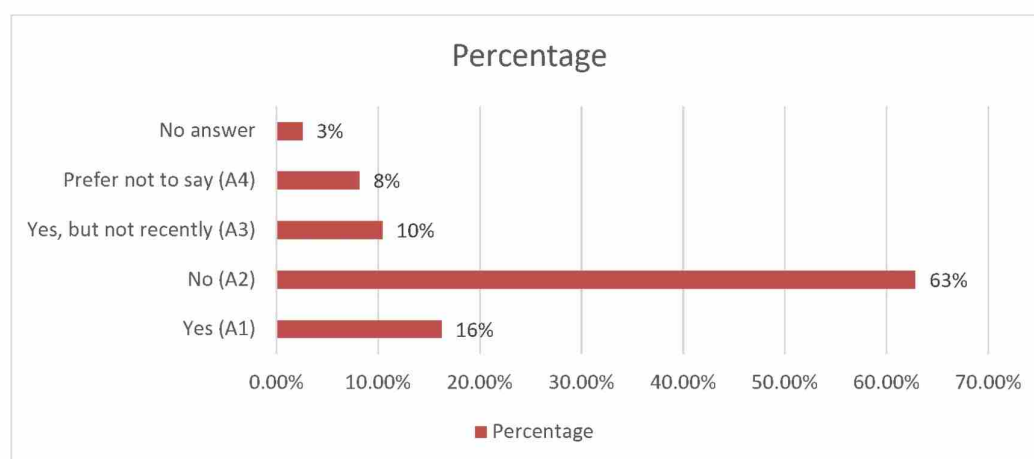
## Survey Results Relating to 3-Year Review

Additional questions were asked as part of the 3-year review on the scheme. These were numbered 13-19 in the survey and are summarised below:

- 5) Level of mental health support available to members
- 6) Awareness of SIBSS grants available for mental health support
- 7) Future SIBSS services not currently available
- 8) SIBSS services compared to the former UK-wide schemes
- 9) Appropriateness of level of payment

### 5 Level of mental health support available to members

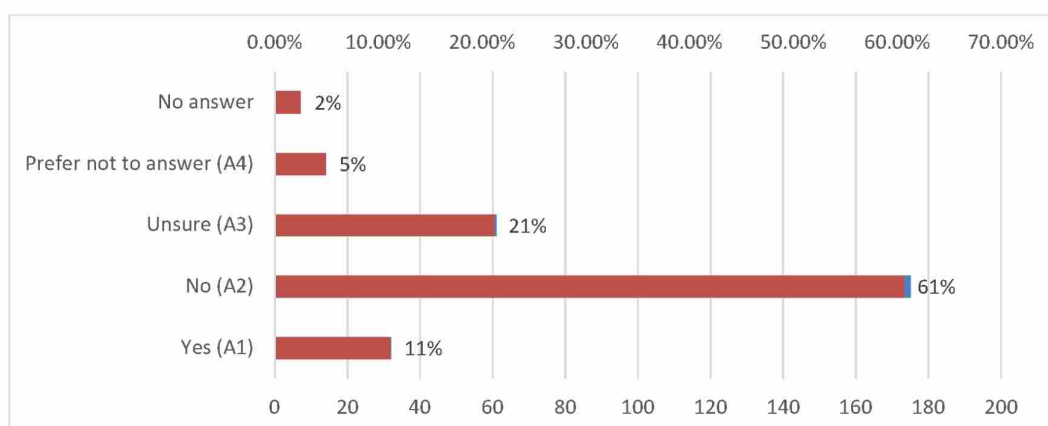
Scheme members were asked - Do you currently receive or have you recently received any psychological, counselling or other mental health support?



Members said:	Our response:
63% do not receive mental health support.	<p>It was clear from the results of the Clinical Review Report published in July 2018 that the mental health of many members is adversely affected by HCV. Whilst we have provided increased financial support in response to the Report and the 2015 Financial Review Group Report, we clearly could have done more to provide signposting for mental health support.</p> <p>Hopefully this survey has now highlighted the issue and when we publish the results we can update members on the services available.</p>

Additionally, we asked, if you don't currently receive support, would you or any of your family want to access some form of counselling, psychological therapy or other support linked to your infection or your partner's infection?





Members said:	Our response:
11% of members who do not receive support indicated that they or family members would like to while 60.6% of members responded that they did not want to access support.	The results show that 11% of members who are not currently receiving any support would like access to support for themselves or family members. There were also a further 28% of respondents that potentially could also look to access additional support, but either did not provide an answer or indicated that they were unsure. We recognise the importance of this service on people's lives and will be increasing the visibility of the services on offer along with the route to apply for grants. Increased visibility of the services could well translate into increased interest among those members who indicated they were unsure.

## Feedback from Scheme Members

In addition to the scored questions, members were asked to provide examples of what kind of support they currently have and what type of support they would find most helpful. Of the 16% accessing support currently and 10%, at some time in the past, support is being delivered by GPs, counsellors and a variety of specialist services e.g. the haemophilia psychological support service. There wasn't a clear consensus among those who were not receiving support, but would like to, as to which type of support they would prefer, but a number felt counselling would be helpful. A number of respondents felt it was particularly important to have support from someone with experience of infected blood and the Infected Blood Inquiry. Additionally, some respondents stated a preference for face to face consultations whilst others preferred telephone.

### Action Plan:

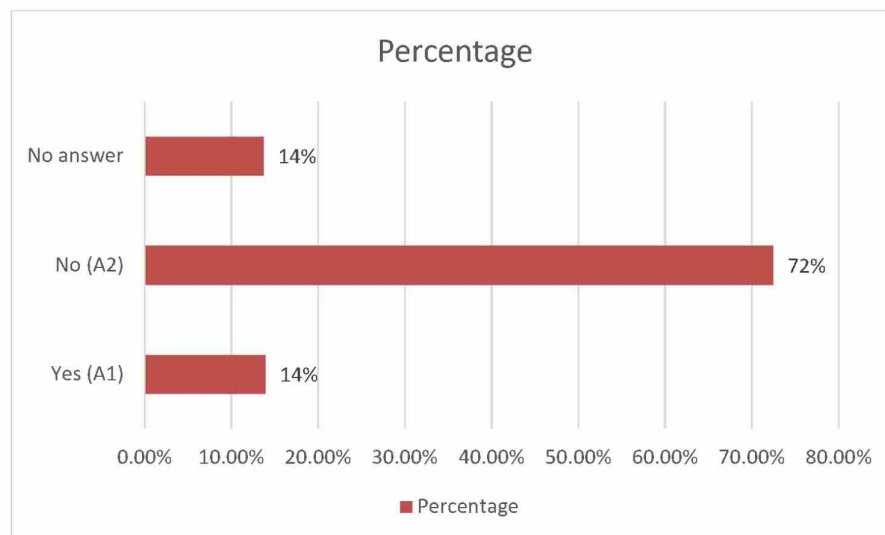
- We will include a feature in the next newsletter highlighting the support organisations available who members may wish to seek support from.
- We will review how easy it is for members to obtain information on mental health support from the SIBSS website.
- In addition, the Scottish Government is looking at how best to provide bespoke psychological or counselling support for those members and their families who said they do not receive support, but would or may want to. This is expected to build on the existing psychological support service for patients with bleeding disorders and



their families by ensuring equivalent support is also available for those who were infected via a blood transfusion or tissue transplant.

## 6 Awareness of SIBSS grants available for mental health support

Members were asked - Are you aware one-off grants are available to help with the cost of counselling or other health services, where you find it difficult to access it through the NHS?



Members said:	Our response:
72% were unaware that one-off grants are available for counselling or other health services.	We added this question to our survey to raise awareness of the financial support available as so few members have applied for this support in the past. Hopefully this will change going forward as we have had such a successful response rate to our survey. The increased signposting through the newsletter is intended to further increase the awareness.

## Feedback from Scheme Members

In addition to the scored question members were asked why they found it difficult to access support and, although the feedback was relatively low, it appears lack of awareness of services and the cost of private services were the main barriers to access. There was also a lack of awareness that the grants for counselling can be used for family members as well as infected people so we will seek to improve awareness around this.

From the comments it was apparent that many people felt they either did not need counselling or that it wouldn't be of help to them. Additionally, numerous members noted that they preferred to get support from friends or family. While most of those who were receiving some form of mental health support were happy with this, a small number raised concerns about receiving counselling or psychological support through the NHS or their local

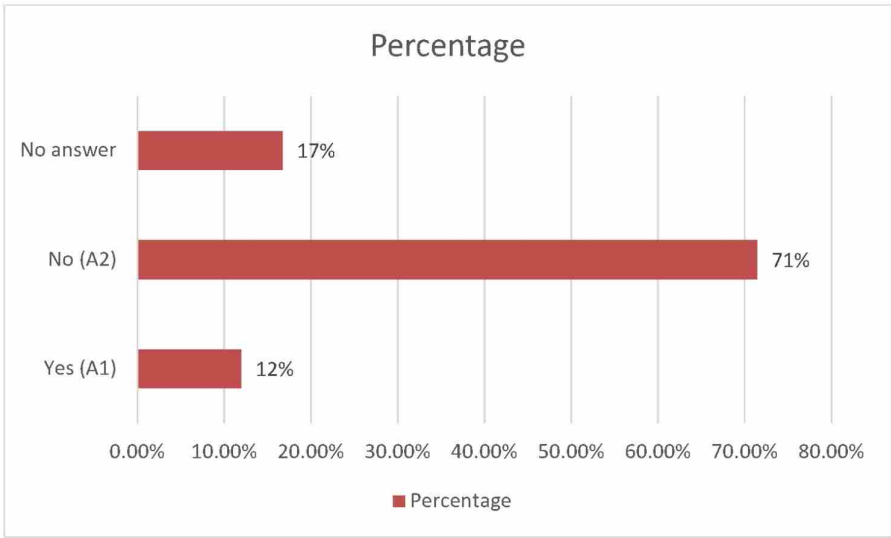
haemophilia centre. Therefore, even if a bespoke psychological support service becomes available, there may still be some people who would prefer using a private counsellor.

Action Plan:

- We will include further information on eligibility and applying for grants as well as clear signposts to our website information in the next newsletter.
- We will review the application process to make it as straightforward as possible. We have already ensured that applications for counselling or psychological support are not means-tested, so members don't need to provide income details, and we also don't require members to have tried to access support through the NHS first. However, we will do more to make members aware of this.

7) Future SIBSS services not currently available

We asked scheme members: Are there any services that SIBSS does not currently provide which you would like SIBSS to make available in future?



Members said:	Our response:
71% are happy with the current level of support from SIBSS and did not think there were other services which should be available. However, 12% would like SIBSS to provide additional services.	The majority of members are content with the level of services SIBSS offers. However there are those who would like for more services to be made available and a number of suggestions are being taken forward as a result of the feedback

## Feedback from Scheme Members

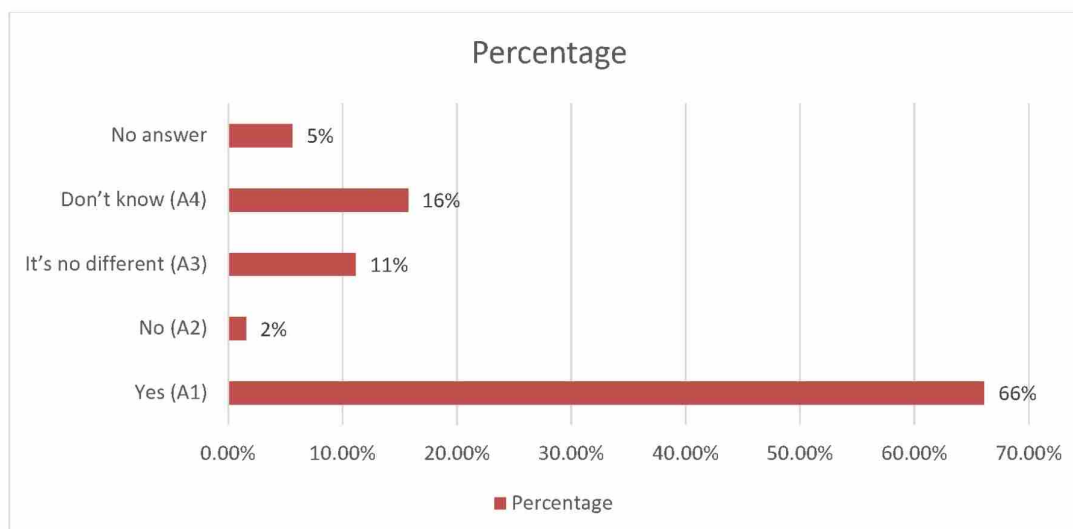
Although the feedback was overwhelmingly positive, services that members indicated that they would like to see in the future included: help with insurance costs, funeral costs, carers costs, prescription prepayment certificates for those members living in England, support groups, mortgage support, HCV-related private or overseas health costs and benefits advisors.

### Action Plan:

- The survey report will raise awareness of support available; additional information will be provided through subsequent newsletters
- Mortgage support – for members applying for a mortgage we provide a letter to lenders on request to give them reassurance that members receive regular payments. We will highlight this service in our newsletter.
- English residents can apply for a one off grant to cover the cost of prescription prepayment certificates where some of the prescriptions are HCV or HIV-related.
- Support groups – our website lists the support groups that are currently available. The website review will ensure information is as accessible, well signposted and up to date as possible.
- Help with insurance costs. Current payment levels take into account higher insurance costs; however, for those HCV members being charged higher rates despite having been successfully treated – along with those with HIV with an undetectable viral load - we will explore this issue with insurance suppliers to ensure that members are being treated fairly.
- Funeral costs and pre-paid funeral plans, costs for employing a carer(s) and HCV or HIV-related health costs are already covered by our one-off grants scheme - <https://nhsnss.org/media/4152/sibss-guidance-on-support-and-assistance-grants-v1-7.pdf> - We will include information on eligibility and applying for grants in the next newsletter and encourage members to speak to the team about these.
- Benefits Adviser(s) – the Scottish Government will explore whether there are suitable benefits advisers available who can support those members who would like help with their benefits applications or appeals and who need more bespoke support than the general support available from Citizens Advice Scotland/ local Citizens Advice Bureaux. If suitable advisers can be identified, we will update members through the newsletter, but in the meantime if you are having any problems accessing benefits, please get in touch with the SIBSS team or with Citizens Advice Scotland directly.

## 8) SIBSS services compared to the former UK-wide schemes

We asked: Do you think it is better to have support from SIBSS compared to the former UK-wide schemes (Skipton Fund, Caxton Foundation, Macfarlane Trust, Eileen Trust, MFET)?



Members said:	Our response:
<p>66% of members prefer the support provided by SIBSS to the former UK-wide schemes.</p> <p>Only 2% indicated they felt SIBSS was not better than the previous schemes.</p>	<p>To have such a low percentage indicate they preferred the old schemes highlights that the services offered by SIBSS are valued and are an improvement over what came before.</p> <p>Through the feedback we received regarding additional services we will look to see what improvements can be made to further enhance the scheme.</p>

## Feedback from Scheme Members

Members liked that the service is based in Scotland and felt that communication with the service was easier. Of those who had had experience of the previous schemes, some had had good experiences and so were more likely to feel the support between SIBSS and the previous schemes was equitable. However, the majority felt SIBSS staff are more helpful and the scheme provides more information than its predecessors. A number of people also felt it was much better to receive all their support from one scheme, rather than several different schemes.

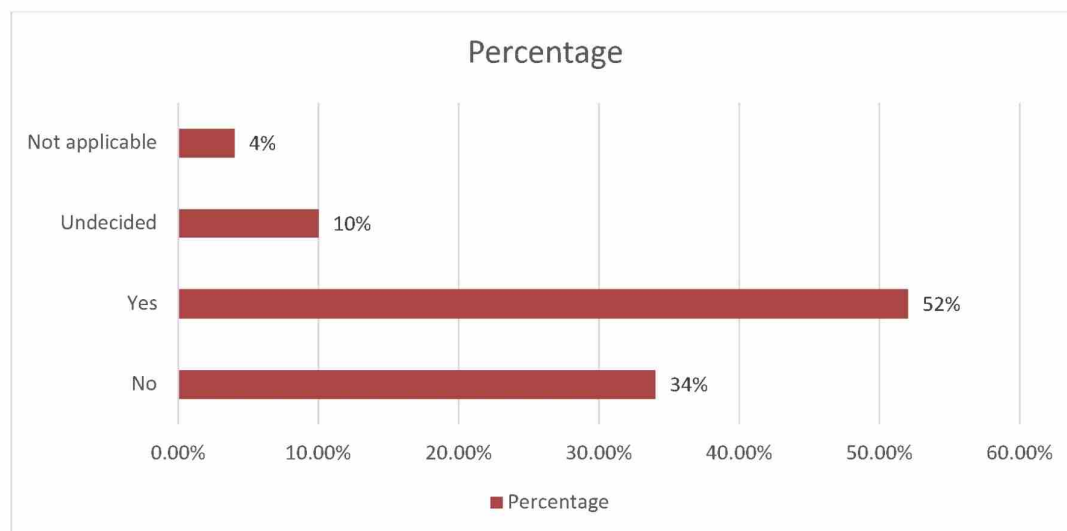
### Action Plan:

- Regular service reviews to ensure we continue provide the best possible service meeting members changing needs



## 9) Appropriate level of payment

We asked: If you receive a monthly payment, do you feel your current payment level is appropriate based on the impact of your infection (or for those who are bereaved, your spouse or partner's infection) on your daily life?



Members said:	Our response:
Despite a technical flaw which meant there was not a 'no' option, members were able to overcome this through the use of the comments section. We received 200 comments out of 395 responders - 51%. We reviewed each comment and were able to extrapolate the number of 'no' responses. By doing this we saw 52% of members who responded to the question feel that the payment is reasonable, while 34% thought it was insufficient. Although this error makes it more difficult to understand everyone's views, 51% is still a relatively good response rate that helps us to gauge the feeling of members.	<p>We can only apologise for the technical flaw which meant the 'no' option was missing. This was only brought to the attention of the SIBSS team after the survey had run. We have gone through all responses to try to identify those that would have selected no and published the results based on this.</p> <p>The purpose of the question is to help inform the service going forward, based on what members think. We would not wish to misrepresent the results as this works counter to this approach and therefore renders the survey and the action plan based on it less reliable.</p>

## Feedback from Scheme Members

For many members the payment level was seen as appropriate for their needs. For some members there was a general acknowledgment that you could not put a price on the loss of loved ones, career or wellbeing suffered as a result of being infected and so it was not really about money. However, others felt they should receive more money due to the impact on their life or that of their spouse or partner. Parity with other UK schemes' payment levels was seen as desirable by a small number of respondents.



One person seemed to think they were only going to receive their payments for three years. We should clarify that all annual payments for both infected people and widows, widowers, civil partners and long-term partners are expected to be paid for the rest of members' lives so members should be reassured by this.

Action Plan:

- The Scottish Government is discussing with the other UK governments the potential for increasing parity between the four UK schemes, but, as reflected in responses to the previous question, wishes to retain a separate Scottish scheme that has the flexibility to reflect its members' needs. It will also take account of any recommendations from the Infected Blood Inquiry when the Inquiry reports to look at further improvements in the support people need.
- SIBSS payment levels are based on recommendations from the 2015 Financial Review Group and the 2018 Clinical Review Group. While infected people do now receive higher regular payment levels on the English scheme, in most cases SIBSS members have received higher payments overall when the £30,000 additional payment made in Scotland for those in Stage 1 and the higher payments which began in 2016 for those at Stage 2 or with HIV or coinfecting are taken into account.

## Appendix 1

### Action Plan Summary:

#### Communication

- We will include a specific section in the newsletter that contains links to both the website and support organisations discussed to make them more visible and increase the ease of members accessing services.

Target Completion Date – Next newsletter publication September 2020

- Review the ease of finding and navigating the website, along with the clarity of advice provided. We will do this via testing with those unaware of the service or what to look for.

Target Completion Date – September 2020

- We will issue an update to GP practices and NHS Health Boards reminding them of the support offered by SIBSS. This will help raise awareness of the scheme and mean it is more likely that a patient presenting with HCV or HIV from infected blood will be pointed towards the support available.

Target Completion Date – September 2020

#### Payments

- We will review the process for notification of the annual uplift following feedback that some members were unaware of it so that it is rectified for the uplift next April.

Target Completion Date – March 2021

- We will add a link to the grant section within the newsletter to assist members in quickly accessing relevant information.

Target Completion Date – September 2021

- We will provide an update from the Scottish Government regarding the discussions on parity as soon as we receive notification of this.

Target Completion Date – To be confirmed

#### Criteria

- Add an FAQ section to the website to help address the queries we receive and provide members and their families with more clarity as to what is available through the scheme.

Target Completion Date – October 2020

## **Mental Health**

- A feature in the next newsletter highlighting the support organisations who specialise in mental health and can support those affected by infected blood.
- Review the ease with which members can obtain information on mental health support from the SIBSS website.
- Include information on eligibility and applying for grants in the next newsletter.

Target Completion Date: September 2020

## **Applications**

- Review the application process to make it as straightforward as possible.

Target Completion Date: November 2020

## **Future Services**

- Identify any suggested improvements that are appropriate and feasible for SIBSS to provide.

Target Completion Date: Ongoing review of service with any improvements implemented as soon as possible

## **Payment Level**

- Update members on discussions between SG and the other UK Governments regarding the outcome of the Infected Blood Inquiry and impact upon payments.

Target Completion Date: TBC

## Appendix 2

### Survey Questions

Each member was asked to rate the following questions on a scale of Very Poor to Very Good

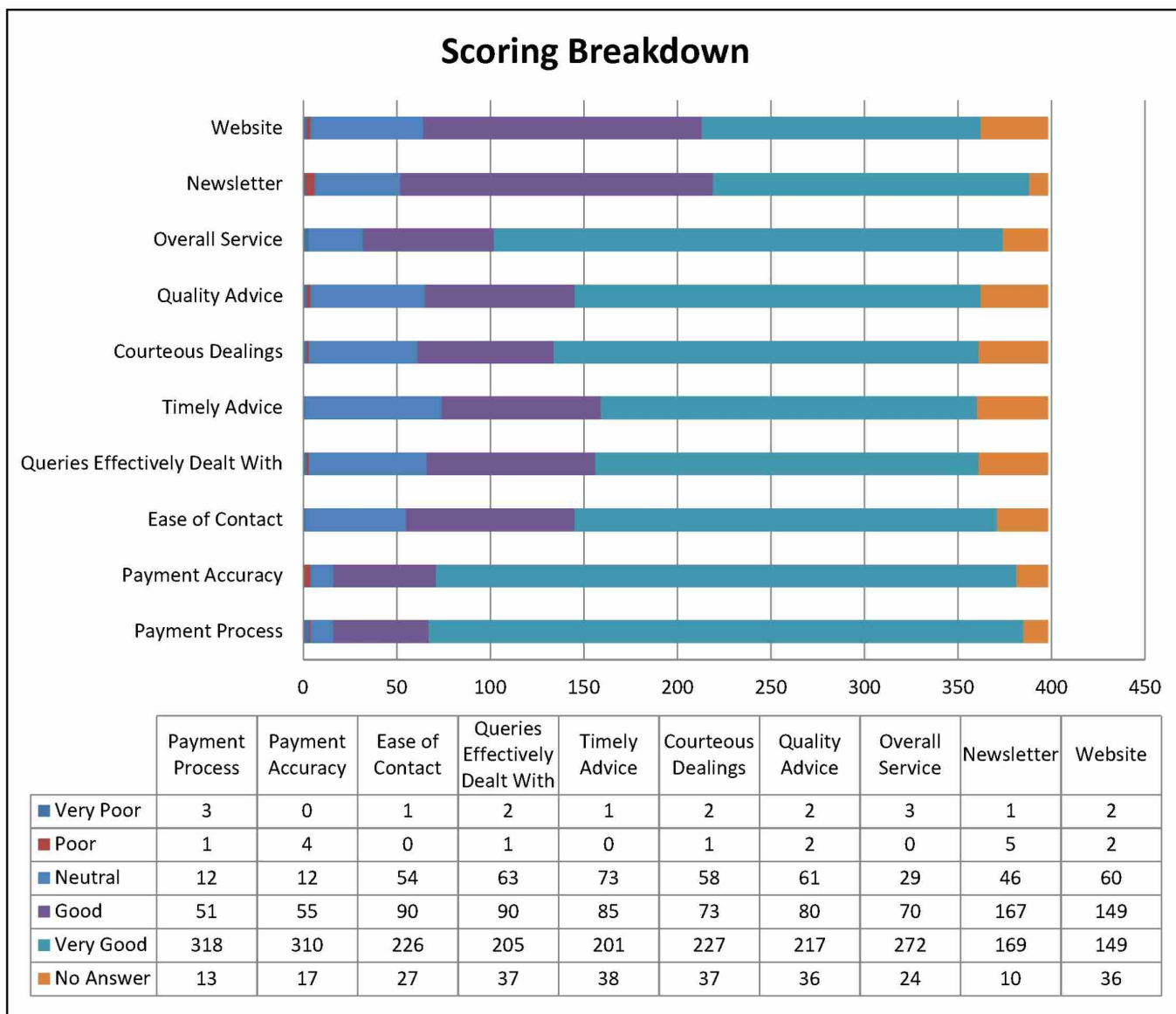
- Q1.** How well SIBSS processes any payments due to you?
- Q2.** The accuracy of your payment?
- Q3.** Ease of contacting SIBSS?
- Q4.** How effectively your queries are dealt with?
- Q5.** How timely advice is received on your queries?
- Q6.** How courteously your queries are dealt with?
- Q7.** The quality of the advice received?
- Q8.** The overall service provided by SIBSS?
- Q9.** How useful the bi-annual SIBSS newsletter is?
- Q10.** How useful is the SIBSS website?
  
- Q11.** Where you rated us 'Very good', can you tell us why so we can pass on your feedback to staff and we'll also then know what to do more of:
  
- Q12.** What do we currently do for you that doesn't add value and we could stop

#### Survey Questions in relation to 3-year review of service

- Q13.** Do you currently receive or have you recently received any psychological, counselling or other mental health support? If yes, please advise what type of support you receive in the box provided
  
- Q14.** If you don't currently receive support, would you or any of your family want to access some form of counselling, psychological therapy or other support linked to your infection or your partner's infection?
  
- Q15.** Are you aware one-off grants are available to help with the cost of counselling or other health services, where you find it difficult to access it through the NHS?
  
- Q16.** If you don't access any form of counselling or psychological support currently, but would like to what type of support would be most helpful and what difficulties have you experienced accessing support
  
- Q17.** Are there any services that SIBSS does not currently provide which you would like SIBSS to make available in future?
- Q18.** Do you think it is better to have support from SIBSS compared to the former UK-wide schemes (Skipton Fund, Caxton Foundation, Macfarlane Trust, Eileen Trust, MFET)?
  
- Q19.** If you receive a monthly payment, do you feel your current payment level is appropriate based on the impact of your infection (or for those who are bereaved, your spouse or partner's infection) on your daily life?

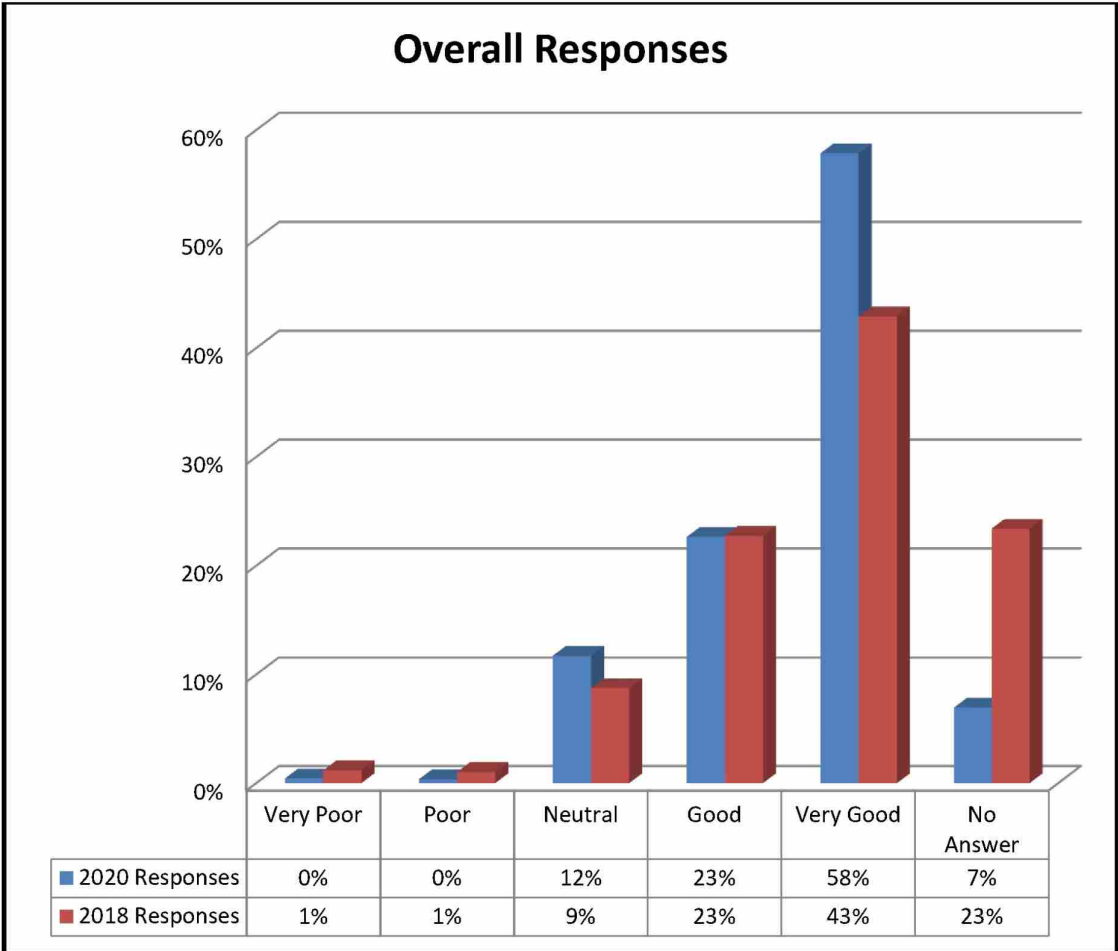
## Appendix 3

Graph 1: Scoring Breakdown





Graph 2: Total Response Summary Comparison



## Appendix 4

### SCOTTISH INFECTED BLOOD SUPPORT SCHEME CONTACT PREFERENCES FORM

#### SECTION 1 CONTACT DETAILS AND PREFERENCES

What is your SIBSS reference number?

X	S	B					
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If there are any methods you **do not** want us to contact you by, please let us know by ticking the boxes below:

**Do not** contact me by letter

✓  
☐

**Do not** contact me by  
telephone

☐

**Do not** contact me by e-mail

☐

If you are happy for us to contact you via telephone or e-mail, please provide those details here:

Home Telephone Number

Mobile Telephone Number

E-Mail Address

If you are happy for us to write to you, where would you like us to send any letters?

My home address

✓  
☐

An alternative address

☐

If you prefer us to write to you at an alternative address, please let us know that address here:

Alternative  
Correspondence  
Address

Post Code

If you are happy to receive letters or e-mails, would you like to receive occasional updates or newsletters from the scheme? (e.g. updates to funding or other support available, surveys to provide feedback on the scheme, etc)

Yes ☐

No ☐

If you would prefer not to receive such information, then we will only send you essential communications relating to your payments or applications. The occasional updates will also be made available on our website at <https://nhsnss.org/SIBSS>

## SECTION 2 SIGNATURE OF BENEFICIARY

Please sign below to confirm the details and preference provided on this form:

Name

Signature of  
Beneficiary

Date

Please note – if the beneficiary is unable to sign themselves due to serious illness or disability, please get in touch with us directly if you wish to act on their behalf – we may need to do some verification checks before we update our records.

You can change your preferences at any time by calling, e-mailing or writing to us using the details below:

Email: NSS.SIBSS@nhs.net

Telephone: 0131 275 6754

Post: Scottish Infected Blood Support Scheme  
Practitioner Services  
Gyle Square  
1 South Gyle Crescent  
Edinburgh EH12 9EB