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Heintiedig Cymru

Wales Infected Blood
Support Scheme

RESULTS OF THE WALES INFECTED BLOOD SUPPORT SCHEME CUSTOMER SATISFACTION SURVEY

The purpose of this report is to report the results of the Wales Infected Blood Support Scheme (WIBSS) Customer Satisfaction Survey.

INTRODUCTION

Following a discussion at the WIBSS Governance Group in 2020, a “WIBSS Satisfaction Survey” was developed and sent to all our beneficiaries in May 2021. The purpose was to gain insight and feedback on the services that WIBSS provide.

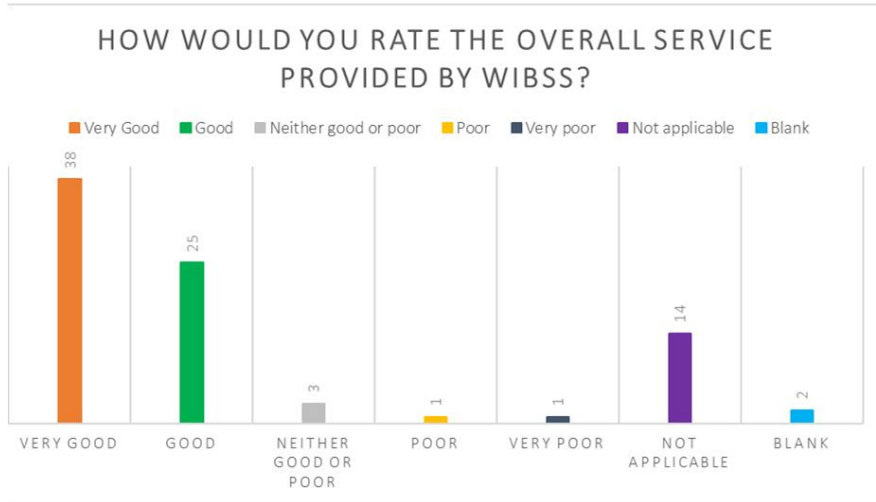
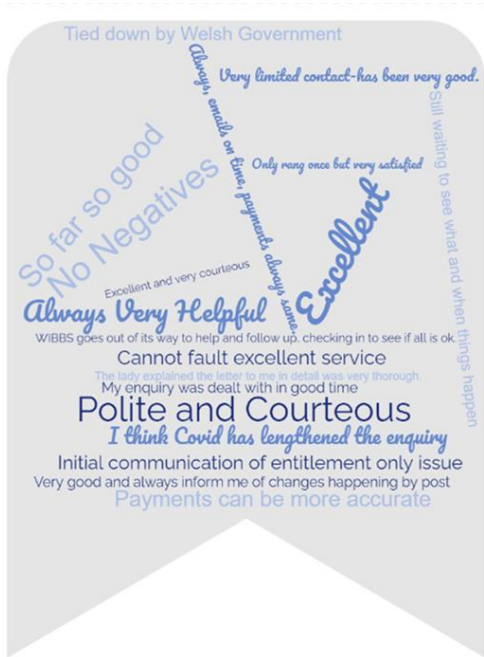
The WIBSS service is currently in a unique position. It is the only devolved UK scheme to directly provide a holistic welfare rights service and an emotional well-being service to the service users, in addition to the payment function.

It was important to seek opinions for each specific area and on the service as a whole. The survey was issued in May 2021. All replies were anonymous. 200 Satisfaction surveys were issued and 84 were returned, a 42% response rate. We have been advised that this is a good response rate.

Below are the survey findings. Some initial thoughts for consideration have also been noted under analysis/commentary.

FINDINGS

There is clear evidence that WIBSS service is highly regarded by those who use it, with 75% of respondents, stating that the overall service provided by WIBSS was ‘Very Good’ or ‘Good’, with staff ‘*always very helpful*’, ‘*polite and courteous*’, and the service being described as excellent (‘*Cannot fault [the] excellent service*’).



However, areas for improvement were also evident including raising awareness of the services WIBSS provide and communication with service users.

The comments and insight provided by service users will ensure that WIBSS continues to offer and provide the best service possible going forward.

DATA ANALYSIS

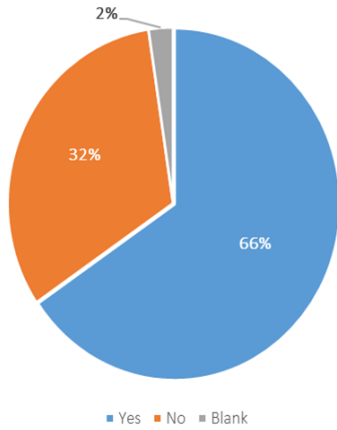
The survey was broken down into five areas:

- ▶ Overall service
- ▶ Payments made to you
- ▶ Welfare Rights and Advocacy Evaluation
- ▶ Emotional and Wellbeing Service Evaluation; and
- ▶ Summary Questions.

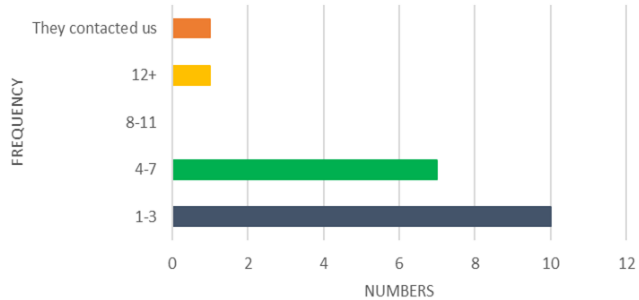
1. OVERALL SERVICE

Of the 84 respondents to the survey, 66% noted that they had contacted the WIBSS service, with the highest **frequency of contact** of these respondents being 1-3 times (10 respondents).

Have you contacted the Wales Infected Blood Support Scheme?

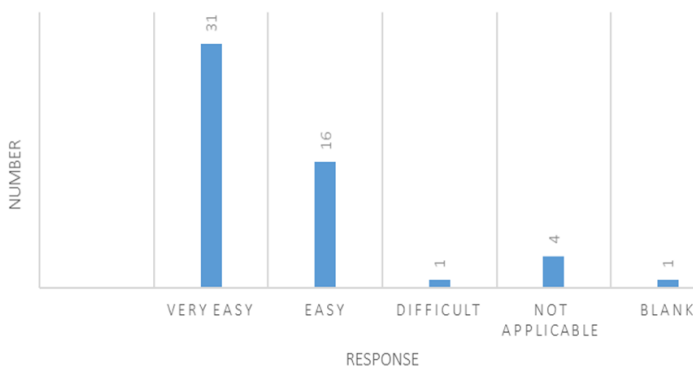


How many times have you contacted WIBBS in the last 12 months?



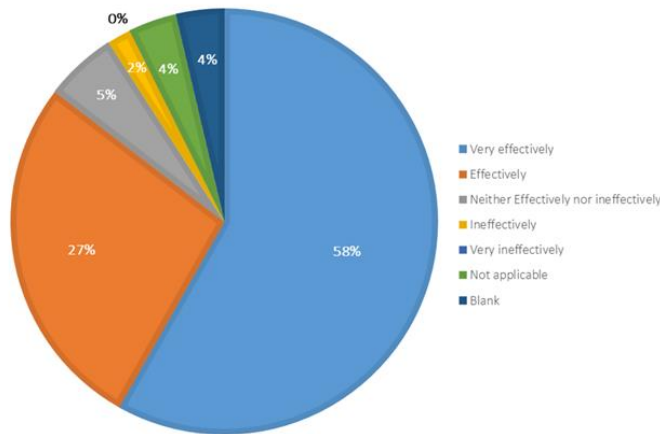
In terms of **ease of contact** 85.4% of those that had contacted the service found this 'Very Easy' or 'Easy'. The word cloud below shows comments provided in respect of ease of contact:

DO YOU FIND IT EASY OR DIFFICULT TO CONTACT WIBBS?



Again, the comments from the service users are largely positive. Several respondents mentioned having to leave Answerphone messages. The survey was undertaken during the Global pandemic when staff were working from home. To ensure calls were not missed, an answerphone message was installed, one that would email the WIBSS Inbox to let us know a message had been received. Our aim was to return the call within an hour, if received during business hours, which in the majority of cases we achieved.

HOW HAVE YOUR ENQUIRIES BEEN DEALT WITH?



When considering the **quality of the service** and how effectively enquiries had been dealt with, there was again an overwhelming satisfaction with this (90.9% responded 'Very Effectively' or 'Effectively').

Similarly, 86% of those who had contacted the service were either 'Satisfied' or 'Very Satisfied' with the **speed with which they enquiry was dealt with**, with 5% stating they were either 'Dissatisfied' or 'Very Dissatisfied'.

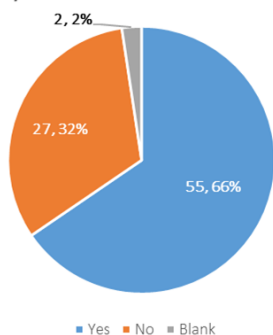
Many of the comments reflected the positive nature in which queries were managed, *'Very friendly and helpful staff'*, *'Three people I have spoken to have been extremely helpful'*, and the personalisation of the service delivered, e.g., *'Sarah and Ryan are the only ones I have anything to do with and they are 100%'*.

It was however recognised that where delays occurred these may have been as a result of COVID-19 and therefore were understood, *'It took a number of days, but with Covid understandable'*.

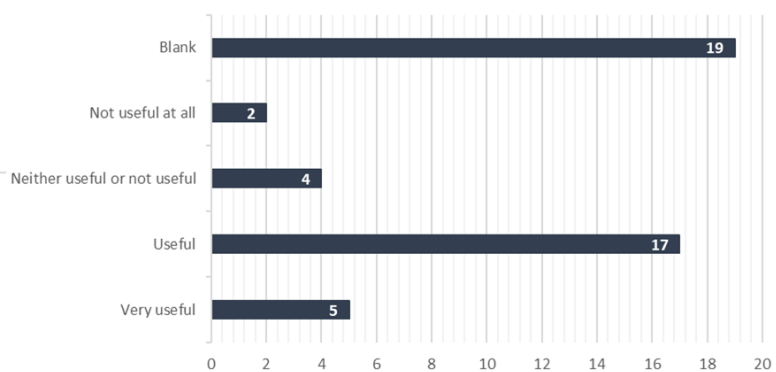
One respondent stated, *'Was only alerted by a friend to potential entitlement'*. This comment is in line with the later findings in relation to the need to raise awareness of WIBSS and the services that it offers.

Two thirds of those responding to the survey, noted that they had **visited the Services website**. Of the 55 that had, 22 (47%), found the site to 'Very useful' or 'Useful'; 4 (9%) were neutral in their response; with 2 (4%) stating that it was 'Not useful at all'. 40% of respondents to this question of **the usefulness of the site** provided no response.

Have you visited the WIBBS website?



If you have visited the WIBBS Website, how useful or not is it for finding information?



A review of the comments suggests more may need to be done for information to be available off-line as well as on-line, as many service users do not appear to access the information from the website. Comments such as *'Don't have a computer, not interested in having one'*; *'Not online'*; *'Not a computer person'*; and *'Don't own a computer'*, highlight this. Another suggested *'[It] would be better if we could print the forms for grants.'*

There are two comments suggesting more information could be provided on the website: *'Not enough information on Health and Welfare'*, and *'Other nation's websites are much more informative and all you have is the same information, very disappointed and dissatisfied'*.

Respondents were then asked about the **WIBSS newsletter**. A reliance on this was noted, with one respondent stating: *'As I am not online, I rely on paper communication to hear news etc'*. However, 30% of those responding were not aware of the Newsletter at all: *'How do I get this?'*; *'I need to find out about newsletter'*; *'Do not recall having one'*.

Of those that were aware of the Newsletter (51, 61%) there were mixed reviews. Whilst it was felt the Newsletter *'Keeps us up to date with current situation of the whole case & services provided'*; *'... make[s] me aware of changes going on'*; that it was *'Easy to understand'*, and had *'Very clear information'*, it was found that it could be *'Quite difficult to read as it can be confusing'*, with respondents stating they would like things to be explained *'in a much simple[r] way'*.

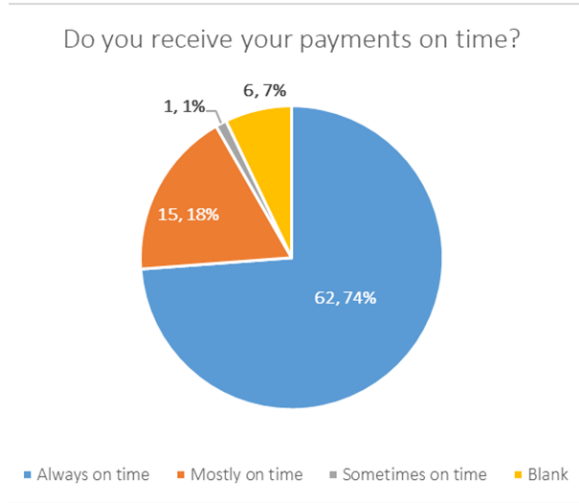
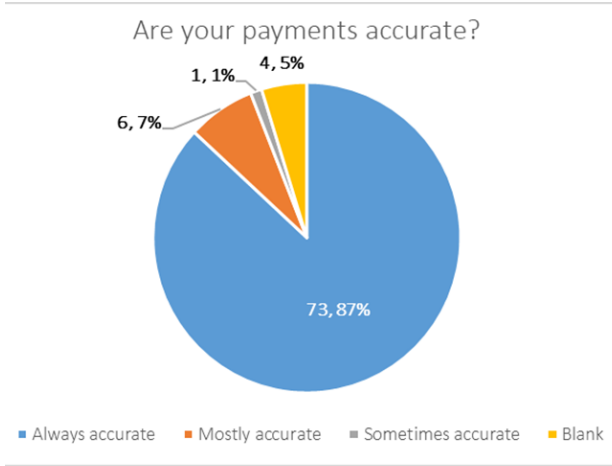
2. PAYMENTS MADE TO YOU

The scheme recognises that individuals living with hepatitis C and/or HIV face extra costs for things like insurance, travel insurance, care costs and travel costs to attend hospital appointments etc. and offers financial support to assist with this. The level of support varies dependant on what stage a person has. WIBSS also offers bereavement payments, bereaved spouse/partner payments and discretionary small grant payments.

In terms of **overall service provision for the payments**, an overwhelming 92% (77) felt the service relating to payments had been *'Very Effective'* or *'Effective'*. Of payments received 87% were *'Always accurate'*, with 8% being *'Mostly accurate'* or *'Sometimes accurate'*.

Some commentary made around the **accuracy of payments** provide for useful consideration on improvements that could be made:

- ▶ *'They are accurate but the parity calculations I feel should be done at a quicker pace seeing that Wales have been behind the rest of the country for some time and the new people need these payments to stay afloat.'*, and
- ▶ *'Whilst acknowledging payments accurately initially when WIBSS took over payments I found the form quite intimidating, particularly the emphasis on accepting payments when not entitled felt almost guilty at completing form.'*

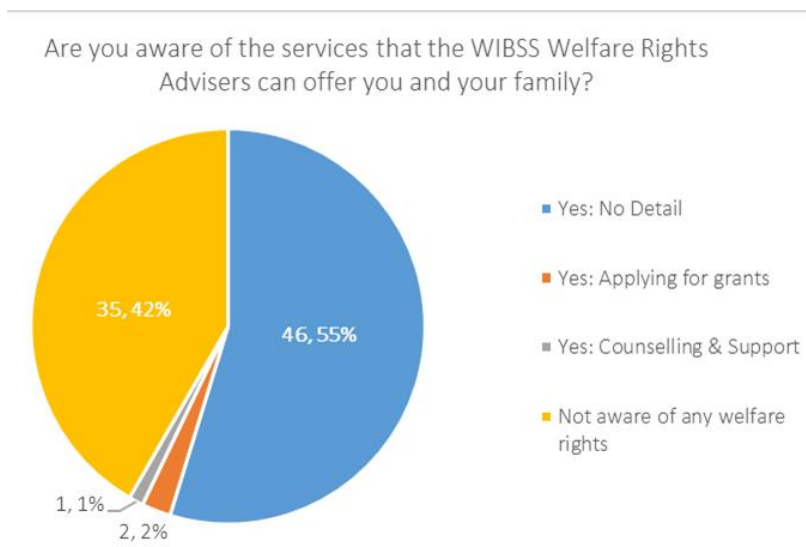


In terms of **timeliness**, three quarters (62) of payments were noted as being received ‘*Always on time*’; with 19% either being received ‘*Mostly on time*’ or ‘*Sometimes on time*’.

Some comments provided, enable some quick improvement wins if these can be managed e.g., one comment was that ‘*Dates can vary*’ and that ‘*Dates are all over the place*’. One suggestion that came through was that ‘*It would be nice to have the money paid on the same date every month*’.

3. WELFARE RIGHTS AND ADVOCACY SERVICE EVALUATION

We recognise that service users’ needs may extend further than just financial assistance and therefore offer a specialist welfare rights service. This has evolved into 2 distinct areas, key worker support and the welfare rights role.



58% of the 84 respondents noted that they were **aware of the services** that the WIBSS Welfare Rights Advisers can offer.

However, 42% (35) stated they were not aware of the service: ‘*Didn’t know about this service*’; ‘*Didn’t know but will enquire*’; ‘*I need to research this*’.

Of the 8% (7) that had accessed the WIBSS Welfare Rights Service, two had contacted to check their entitlement; one accessed counselling; and four to help with completion of the benefits form. A third of those receiving support stated that they saw changes/improvements to their circumstances because of the support and advice you received from the welfare rights team:

‘WIBSS has been a fantastic support supporting and understanding the worrying times I have filling in forms I don’t understand and with no other support’
‘The support received from WIBSS helped my stress levels and helped me make my PIP assessment’
‘I received my blue badge’
‘Reassurance regarding part payments with England’

4. EMOTIONAL WELLBEING SERVICE

From January 2020, individuals registered with WIBSS, their family members and bereaved family members have been able to access psychological assessment and treatment concerning the emotional difficulties of being given and living with a diagnosis of hepatitis C and/or HIV.

The team are aware of the historical context and have experience of working with the emotional difficulties that have occurred as a result. This specialist psychology service, acknowledges and recognises the physical and psychological complexity and the impact on quality of life and relationships.

Of the 84 survey respondents, 48 (57%) were **aware** of the specialist emotional wellbeing support available to them and their families from WIBSS.

For those that had accessed support from the service, a series of questions were posed to assess whether the support had been **helpful**:

	Yes	No
The counselling sessions have helped me better understand the difficulties I have experienced.	12	6
The counselling sessions have helped me to talk about the specific experiences related to being given infected blood products.	15	3
The counselling sessions have helped me to voice complex feelings.	15	3
It has been important to talk to someone who is aware of the circumstances surrounding infected blood products and the inquiry.	15	3
I have felt listened to in the sessions.	14	3
I have felt less burdened by my feelings and difficulties, from being able to talk to a specialist person.	14	2

When asked about **potential changes** that could be made to the sessions, or **other ways** in which beneficiaries of the service **could receive support** from the counselling and psychology service, respondents considered:

- ▶ Counselling sessions via the phone
- ▶ Group sessions
- ▶ Access to service locally
- ▶ Just knowing that someone is there to help or talk to is a safety net when you feel low

It is worth noting that one respondent stated that they had never been offered counselling.

14 of those completing the survey, responded to the questions regarding a network or group being set up with WIBSS beneficiaries to provide support to each other. 50% (7) felt this would be good, 2 were unsure and five were more comfortable with a more personal, one to one approach. Zoom and web platforms were the most commonly suggested tools, with the idea of a workshop, also being put forward.

Overall, feedback on the emotional support received was positive:

*'Would like to say how comfortable and informal the sessions were'
'I have found these sessions to be extremely valuable. I really hope that this service continues.'*

5. SUMMARY QUESTIONS

When asked if there was anything WIBSS could do to **improve respondent's experience**, 18 (51%) of the 35 comments stated they were satisfied with the service, having received a positive experience:

*'I am well satisfied with the service and cannot think of any way to improve it.'
'I think WIBSS does a great job looking after us who were affected.'
'No, I think WIBSS provide a good service'
'None at the moment it has been a positive experience when attending meetings.'
'Nothing, as I have been extremely satisfied with 'WIBSS' overall.'
'WIBSS has been very professional and very helpful.'
'WIBSS provide a very good service.'*

When thinking about improvements, **communication and awareness** raising was mentioned – communication in relation to timelines for the outstanding monies due, receiving updates (via e-mail): *'Widowers to be kept up to date with information. Bring your website up to the same standards as EIBSS'*, updates with regard to what is going on with Government and how the Enquiry is progressing; and awareness

raising of services on offer. As noted earlier, some respondents were not aware of the help available from WIBSS or of counselling opportunities.

For **payments**, Remittance Advice Payments via e-mail was commonly noted, as well as the monthly payment being paid on the same date each month. i.e., 10th or 15th.

Of help would also be **Mortgage information** of companies willing to accept the payments.

Some of the feedback related to reason that WIBSS had been set up in the first place. One respondent has asked: *'Can I get an apology from those responsible for my experience?'*, with others seeking back pay to the date they or their family members became affected, an example provided was 1983.

The final question within the survey, **'Is there anything else that WIBSS could offer you as part of the service?'** provided a sense of the value and importance placed on the service by its beneficiaries:

'Don't let it stop. The right people are obviously doing the right job'

'Just ensure nothing like this ever happens again. Other than that, no you are doing a great job.'

'In general, I have no complaints to make towards WIBSS, but the length of time it has taken to compensate the victims is outrageous. The people who have stood in the way of compensating the victims should be named and shamed publicly and should be made to apologise publicly.'

Other thoughts noted were:

- ▶ Someway to remember those no longer with us.
- ▶ A government top up for those nearing pension age
- ▶ A phone call after letters are sent out which are long winded, just to check they are understood.
- ▶ Death Benefits - who can have the benefits of our payments?
- ▶ A structure of communication or a recognition of support from GPs
- ▶ More Money.

'Thank you to the support you have provided to myself and others in my situation, keep up the good work.'

'WIBSS and the staff do a fantastic job and I'm grateful for the help they give me.'

YOU SAID, WE DID (OR SHALL DO)

COMMUNICATIONS & AWARENESS	
YOU SAID	WE DID (OR SHALL DO)
Other Nations websites have more information. Why don't you bring it up to standard of EIBSS?	<p>We recognised that our website was sometimes difficult to navigate, so we have spent time reviewing all the information contained on it, updating it to reflect the latest changes to the schemes and retitled the headings to make it easier to find things and more user friendly.</p> <p>We are also looking at additional content and as part of that, we will review websites for other schemes.</p> <p>If there is specific information people would want included, they can contact us at VCC.WIBSS@wales.nhs.uk or by telephone on 029 2090 2280 and we will consider adding the content.</p>
It would be helpful if we could print forms from the internet.	It is possible to download and print the forms from the internet. However, if people prefer, they can contact us at VCC.WIBSS@wales.nhs.uk or by telephone on 029 2090 2280 and we will post a hard copy of the forms to them.
<p>I was not aware of the Newsletter.</p> <p>The Newsletter is too complex.</p>	<p>The Newsletter will be issued quarterly. We will send it to all beneficiaries and ask those who do not want to receive it to "opt out".</p> <p>We will also ensure the Newsletter is written in simple terms and we will ask a Patient Liaison Officer to proof-read it, prior to issue.</p>
Complicated letters should be followed up with a telephone call, to ensure the recipients understand the letter.	<p>WIBSS recognises that some letters we must issue contain a lot of information to take on board. In particular, we recognise the letter detailing parity payments was quite complex, even though we did try to keep it as simple as possible.</p> <p>We would encourage anyone who does not understand any correspondence we issue to contact us, and we will take the time to explain things to them.</p>
Bereaved spouses/partners should be kept up to date.	Any correspondence/leaflets/newsletters issued by WIBSS to beneficiaries, are issued to all beneficiaries. This includes bereaved spouses/partners.

<p>Updates regarding the government and the Public Inquiry.</p>	<p>WIBSS is completely independent of the public inquiry and therefore, is not privy to the progress it is making on a regular basis. When updates are released by the Public Inquiry, we make our beneficiaries aware of them, by sharing a link on our website and by notifying them in the next Newsletter, or where necessary by writing to them e.g., if a consultation is taking place.</p> <p>Where Welsh Government advise us of any changes, or updates to the WIBSS scheme we put this information on the website and write direct to beneficiaries promptly.</p>
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<p>PAYMENTS</p>	
<p>YOU SAID</p>	<p>WE DID (OR SHALL DO)</p>
<p>Timeliness of the parity money due.</p>	<p>WIBSS was only able to process the parity payments once Directions from Welsh Government had been approved. We received the revised Directions on Friday 13th August 2021, and the parity payments, including the backdated elements, were made by 20th August 2021. WIBSS was the first UK scheme to implement all the parity changes.</p>
<p>It would be nice to have the money on the same day every month.</p>	<p>We are required to ensure that the money reaches your bank account by 20th of each calendar month. Sometimes the payment will reach you earlier, often due to the timing of weekends or bank holiday.</p> <p>On occasion, the money may be paid one or two days in advance of the 20th of the month where we are managing the overall volume of NHS Wales payments being paid in any one week. Crucially you should never receive payment after the 20th, as we recognise this could cause knock on issues with direct debits or standing orders going out of your accounts.</p>
<p>It would be helpful to have information about Mortgage Companies willing to accept WIBSS payments.</p>	<p>We have raised this issue with Welsh Government, and we understand it is being discussed at a UK level with all four schemes. As soon as we have any update information, we will include it on our website and notify beneficiaries in writing too.</p>

SERVICE ACCESS	
YOU SAID	WE DID (OR SHALL DO)
There should be access to service locally.	<p>COVID restrictions have prevented WIBSS from providing services at a local level, and from providing the home visits we previously provided. Once the COVID restrictions are lifted, and it is safe to do so, we intend to provide services locally and to reintroduce home visits for those who request them.</p> <p>WIBSS would like to stress that our services are available to all our beneficiaries, regardless of where they live. Even if a home visit was not possible, we would explore options for providing the service in other ways.</p>
Death benefits – who can have the benefits of our payments?	<p>Bereavement Payment – WIBSS pay a £10,000 Bereavement Payment to the bereaved spouse, dependent relative or estate of an infected beneficiary, when the beneficiary passes away.</p> <p>If there is a bereaved spouse or partner of an infected beneficiary, then they will receive regular bereavement payments following a beneficiary’s death. The payment is 100% of the beneficiary’s payment for the first year, and then 75% of the rate for subsequent years.</p> <p>WIBSS are currently drawing up a form, which will allow beneficiaries to indicate who should receive these payments following their death.</p>

FURTHER THOUGHTS	
YOU SAID	WE DID (OR SHALL DO)
A structure of communication or a recognition of support from GPs.	WIBSS issued an information leaflet about the service to all GPs in Wales in 2019. We are in the process of updating the leaflet to reflect the parity payment agreements and we will reissue it to all GP surgeries.
Pay us more money.	Alongside the Public Inquiry, the UK Government has announced a separate review to consider looking at a Compensation Framework. For more information visit https://www.gov.uk/government/publications/infected-blood-compensation-framework-study-terms-of-reference

Wales Infected Blood Support Scheme (WIBSS): Customer Satisfaction Survey Results



Survey- English
Version May2021.doc



Survey- Welsh
Version May2021.doc