

Cynllun Cynorthwyo Gwaed
wedi'i haentio Cymru

Wales Infected Blood
Support Scheme



Report

WALES INFECTED
BLOOD SUPPORT
SCHEME (WIBSS)

ANNUAL REPORT
2020/2021

WALES INFECTED BLOOD SUPPORT SCHEME (WIBSS)

VELINDRE UNIVERSITY NHS TRUST

THROUGH

NHS WALES SHARED SERVICE PARTNERSHIP
AND
VELINDRE CANCER CENTRE

ANNUAL REPORT 2020/2021



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Introduction

Established in October 2017, the Wales Infected Blood Support Scheme (WIBSS) aims to provide support to people who have been infected with Hepatitis C and/or HIV following treatment with NHS blood, blood products or tissue.

Taking over from the existing UK schemes (Eileen Trust, Macfarlane Trust, MFET Ltd, Skipton Fund and Caxton Foundation), now referred to as the Alliance House Organisations (AHOs), WIBSS aims to provide both a streamlined financial payment service and personalised support for Welsh beneficiaries. WIBSS also offers a dedicated Welfare Rights Service and a Psychology and Well-being Service.

WIBSS currently supports 213 beneficiaries, including bereaved spouses and partners. However, the welfare and psychological support is also provided to wider family members of our beneficiaries.



Purpose of Report

The purpose of this report is:

- **to provide an update on the finance and support services during 2020-21 as part of the Wales Infected Blood Support Scheme;**
 - **to detail the work carried out by WIBSS during 2020-21;**
- and**
- **to look ahead to WIBSS priorities relating to 2021-22.**

Key issues arising during 2020-21

COVID-19 – The Pandemic

In March 2020 the UK entered its first lockdown, as a result of the global COVID-19 pandemic. Everybody who could work at home, was told to work at home, this included the staff at WIBSS. We successfully made this transition and operated on a “business as usual” basis.

We continued to make regular payments and to offer help and support to all our beneficiaries, many of whom were shielding as a result of their condition. We provided updates and advice on the website and were available throughout to help with any queries, provide benefit checks etc. Whilst we did need to stop home visits, we adapted to offer the well-being and counselling services, albeit remotely, over the telephone, on teams or skype calls.

Public Inquiry – The Infected Blood Inquiry

This is an independent public statutory inquiry established to examine the circumstances in which men, women and children treated by the National Health Service in the United Kingdom were given infected blood and infected blood products, in particular since 1970.

In 2020/2021 we responded to a further three Rule 9 requests from the Infected Blood Inquiry. The third request received in September 2020 was the most detailed request and was for a witness statement from Alison Ramsey, Director of Planning, Performance and Informatics at NWSSP, prior to her appearance before the inquiry in May 2021.

<https://www.infectedbloodinquiry.org.uk/evidence/transcript-london-thursday-20-may-2021-vaughan-gething-and-alison-ramsey>

Researching the information for inclusion in the witness statement, provided WIBSS with the opportunity to take stock, to review all our procedures, documentation, communication channels etc. This review identified a few areas where we needed to update our advice and guidance to better reflect the service and some ways we could improve the service we provide.

These included ensuring all documentation was consistent and, all new procedures were incorporated into the staff guidance. We have drawn up a list of items we will address and are currently work through it to revise and edit all documentation.

Key issues arising during 2020-21

Parity across the four UK nations

When the four devolved infected blood schemes were established in 2017, three of the four operated largely to similar terms and payment rates. Scotland adopted a slightly different model. WIBSS introduced a welfare rights service, which the other schemes did not have, but the payment rates were similar to those in England and Northern Ireland.

However, on 1 April 2019, the UK Government announced additional funding for the English scheme, which allowed them to significantly increase the payments rates for their beneficiaries'. As the Welsh Government did not receive any additional funding, they were not able to increase the payments rates for WIBSS.

In July 2020 we were asked by Welsh Government to provide detailed costings of what parity would cost. We provided costings for a range of scenarios.

In March 2021 Welsh Government asked us to provide updated figures urgently. We also attended a number of meetings with officials from the four nations and from the other UK schemes in which the potential detail of a parity agreement was discussed. On 25th March 2021 Vaughan Gething announced agreement on parity had been reached and payments would be made by the end of the calendar year (December 2021).

<https://gov.wales/written-statement-infected-blood-update-financial-parity>

It stated, UK Treasury has announced that they will fund a number of changes to the 4 UK schemes to work towards parity. This funding will be backdated to April 2019.

beneficiaries

For our beneficiaries who currently receive ex-gratia payments delivered through our partners at the Welsh Infected Blood Support Scheme (WIBSS) the scheme will be amended as follows:

- Our regular annual ex-gratia payments will be increased to the rates currently paid in England/Scotland;
- Payments for bereaved partners will be increased to 100% of the beneficiaries payment in year 1, and 75% in year 2 and subsequent years in line with the position in Scotland;
- All the above payments are to be back dated to April 2019
- Lump sum payment to a Hepatitis C Stage1 beneficiary will increase from £20,000 to £50,000, with the additional £20,000 payable if a stage 1 beneficiary moves to stage 2. The total lump sum payable for Hepatitis C beneficiaries remains at £70,000. This is in line with Scotland and will be backdated to April 2017
- Lump sum payments for HIV (£80.5K), will change in line with England and be backdated to April 2017
- Winter fuel payments are to be paid in addition from April 2021

The other UK schemes will now follow our lead by paying the £10,000 death benefit on the death of a beneficiary.

WIBSS are currently waiting for revised Directions from Welsh Government to allow us to pay the revised rates and to introduce on-going payment for our bereaved spouses/partners.



Governance Group

The Governance Group monitors the operational management of WIBSS and provides governance, leadership and accountability for the scheme, on behalf of Welsh Government (WG) through Velindre NHS Trust.

The WIBSS Governance Group (VCC and NWSSP) is authorised to:

- Investigate or have investigated any activity within its Terms of Reference, and in performing these duties, shall have the right, at all reasonable times, to inspect any books, records or documents of the Trust, relevant to the Governance Teams remit, subject to any restrictions imposed by General Data Protection Regulations (GDPR). It can seek any relevant information it requires from any employee, and all employees are directed to co-operate with any reasonable request made by the Board.

It is empowered with the responsibility for:

- Reviewing and advising on the management of the WIBSS budgets, including running costs, the annual beneficiaries budgets and provisions
- Advising Welsh Government on rate changes and the potential financial and service implications of policy changes, both within Wales and other areas within the UK
- Implementation of Welsh Government policy
- Ongoing negotiation and partnership with Welsh Government to ensure the smooth running of the service.

Governance Group

The membership of the WIBSS Governance Group is as follows:-

- Director of Corporate Governance,
Velindre NHS Trust (Chair)
- Head of Operational Service & Delivery,
VCC
- Director of Planning, Performance and
Informatics
 - WIBSS Service Manager
 - Welsh Government Finance
Representative
- Welsh Government Policy Representative
 - Senior Welfare Rights Manager
 - Consultant Psychologist
 - Service User



Financial Support

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. Financial support is available for:

- New Applicants to the scheme
- Members of previous legacy schemes

There are varying levels of financial support available to beneficiaries of the scheme:



Financial Support

Hepatitis C Stage 1

for those infected with hepatitis C as a result of treatment with NHS blood, blood products or tissue

Enhanced Stage 1+ payments

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, but is not Stage 2

Hepatitis C Stage 2

For those beneficiaries who have developed

- cirrhosis
- Primary liver cancer
- B-cell non-Hodgkin's lymphoma
- Have received a liver transplant or are on the waiting list to receive one

HIV and co-infected payments

for those infected with HIV as a result of NHS treatment before October 1985 or are co-infected with HIV and Hepatitis C Stage 1 or 2

Bereaved spouses'/partners payments

for those who are the bereaved spouse/partner of a deceased beneficiary who met one of the criteria above

Bereavement payments

paid to the bereaved spouse/partner or estate of a beneficiary, on the death of the beneficiary to assist with funeral costs etc

Discretionary Small Grant Payments

financial support the beneficiaries and bereaved spouses/partners can apply for assist with the cost of essential items or services. The grants will normally only be available to cover costs of items or services which are needed, at least indirectly, as a result of the impacts of a beneficiary's Hepatitis C or HIV infection

Financial Support

Application Process

Applications for each of the financial support elements can be made by downloading the appropriate application form at [Home - WIBSS \(wales.nhs.uk\)](https://www.wales.nhs.uk) or by contacting WIBSS support team, who will send an application form if preferred.

On receipt of an application it is recorded in our register of application, it will be checked to ensure that all required sections are completed by the relevant person. We also check whether the required evidence of treatment with blood products has been provided. Where it has not, the welfare team would contact the applicant and seek permission to undertake a search of clinical coding, to see if that can provide the necessary evidence.

The welfare support team will also offer help and guidance on completing the forms if this is required.

Once the completed application is submitted, the WIBSS Manager will consider the application, based on criteria set out in staff guidance and provide a recommendation to the Director of Planning, Performance and Informatics in NWSSP on whether the application should be approved. In certain circumstances, the WIBSS Manager may seek a clarity on the medical opinion contained in the application form.

If the application is successful, the WIBSS Manager will write to the applicant informing them of the outcome and welcoming them to WIBSS.

Appeals Process

If an application to join the scheme is unsuccessful, an applicant can appeal if they disagree with the outcome of their application. Appeals are heard by a panel of independent medical experts with relevant clinical or similar experience in the field.

During the course of 2020-21, no appeals were submitted and therefore the appeals panel was not convened.

An appeal will not be considered in cases where it is acknowledged that the applicant is not eligible under the current eligibility criteria, but the applicant disagrees with those criteria (in such cases, the application could only be reconsidered if the Welsh Government agreed to amend the eligibility criteria).

The appeals panel process does not cover appeals regarding the Discretionary Small Grants process. To date we have not declined any small grant applications. At the inception of WIBSS we did not think a formal appeals process was proportionate given the value of these grants. This was queried during the Infected Blood Inquiry and we therefore intend to introduce a less formal system of reconsideration of declined applications for small grants.

The proposed approach would allow an applicant unhappy with the outcome of their grant application, to resubmit it to WIBSS for reconsideration. The WIBSS Manager would arrange for the decision to be considered by somebody independent of the original decision-making process. As part of our overall review of our documentation and guidance, we will amend the small grants section to reflect these changes.



Welfare Rights Service

Application Process

We recognise that beneficiary 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.

Key worker support includes:

- liaising with beneficiaries and wider family members to establish a trusting relationship and provide emotional support, outside of formal psychology and well-being referrals
- regular outbound check-ins with beneficiaries considered as vulnerable
- completion of paperwork and help to sort affairs for those unable to do so themselves.

The welfare rights service we offer is bespoke to the individual and their family. Although not exhaustive, below is a list of services we may be able to assist with:

- liaising with social workers to ensure complex beneficiary needs are met
- signposting free NHS dental care and prescription services for those eligible due to the new benefit entitlement
- chasing medical professionals seeking evidence to support applications to join WIBSS
- complete benefit and welfare checks, debt signposting, budgeting advice, navigating financial products etc.
- applying for a parking badge (Blue Badge), free bus travel and concessions.
- accessing health services, such as additional care requirements and health care transportation.

We also recognise a beneficiary's health not only impacts them, but it can also have a significant impact on those caring for them. Our welfare rights advisors can also consider the circumstances of immediate family and carers to check their entitlement to benefits which may help to improve overall financial circumstances and access to additional support requirements. The team have accreditation under Advice Quality Standards (AQS), and individually all advisors undertake continuing professional education with specialist welfare training providers.

In August 2020, the welfare rights team established a key contact within the Department of Work and Pension (DWP) policy team who has agreed to oversee DWP cases which are impacted by WIBSS funds.

The welfare rights team have intervened on behalf of several beneficiaries who had been interviewed under caution by the DWP Fraud Team. These beneficiaries had correctly, not declared their payments received from approved legacy infected blood schemes prior to WIBSS. The team has also intervened where new applications for benefits, such as pension credit and Universal Credit had been declined due to monies held from WIBSS and legacy schemes. All issues were resolved following intervention by the welfare rights advisors.

Welfare Rights Service

Case Study

Beneficiary C1

C1's late husband was a WIBSS beneficiary who sadly passed away. As a result, C1 was left managing the household finances for the first time and was struggling. She contacted the welfare rights team when she was told she could not claim Pension Credit, despite having an underlying entitlement, which had been revoked due to funds she received from WIBSS. The Welfare Rights Advisor escalated the matter to the Department of Works & Pensions (DWP) Policy Making team, detailing the legislation that allowed for WIBSS funds to be disregarded when calculating C1's entitlement.

As a result of this intervention, C1 was awarded her Pension Credit and it backdated to the date of her original claim. The Welfare Rights Advisor also identified that C1 was now also eligible for reduced council tax, free eye tests, dental care and travel concessions. C1 stated the welfare rights service had relieved some of her stress during her period of grief and was very thankful for the support.

This issue, and similar previous issues, led to the establishment of the key contact in DWP referenced above.

Psychology and Emotional Well-being Service

During 2019-20, a psychological and emotional wellbeing service specifically for WIBSS was established. 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.

Introduction of the psychology and emotional well-being team has allowed WIBSS to offer an additional level of support to beneficiaries.

There are approximately 60 clients currently accessing psychological intervention from WIBSS. To date we have been able to offer an assessment and intervention to all beneficiaries and family members who have self-referred or been referred to the service. There is currently no set number of sessions offered. We operate a flexible service which reflects the need to the specific client.

The feedback we have received about the service has been overwhelmingly positive. People have been impressed with the flexibility of the service and have found talking to a therapist who is aware of the specialist context and specific issues they face is helpful and containing.

During the pandemic, the team have continued to offer the service via telephone/ video calls or face to face as preferred. The team highlighted that the theme of lack of parity was common in their clinical work and not only due to the difference in financial payments across the schemes.

Psychology and Emotional Well-being Service

There was growing awareness that the lack of parity was provoking and reinforcing feelings of anger and mistrust of the government and NHS and doubts about how the Infected Blood cases/inquiry were being managed. The psychology and emotional well-being team were noticing that such issues were causing some people secondary and continued psychological injury, and there was some evidence that some were being held within a trauma response and unable to engage in meaningful therapy relating to their infected blood experience while the issue of parity remained unresolved.

Clinical Psychologist, Caroline Coffey wrote to Welsh Government highlighting the degree of stress the issue of parity was causing beneficiaries, highlighting that the stress caused by this issue was preventing people from being able to deal effectively with other related issues they were facing. This letter was also read out during the Infected Blood Inquiry and proved to be a very powerful piece of evidence demonstrating the impact on beneficiaries.

The psychology and emotional well-being team plan to host an online event for all beneficiaries and family members to openly discuss the desire to offer a community/group level support/intervention if required, but the team would like direct input from service users on what would be appropriate and helpful. Themes of isolation, separation and difference from others often are discussed in the clinical work which supports the idea for group/community involvement but how to offer this approach is complex and needs thought and planning.

The psychology and emotional well-being team discussed the possibility of beneficiaries/clients writing testimonials about their experience of engaging in the specialist service and the impact of the therapeutic work. Several clients were keen to write and found the process of expressing their experience also therapeutic.

Beneficiaries activity

2020-21

There are 213 beneficiaries & bereaved partners registered for support through the scheme. This is broken down into the following groups. (Valid as at 31 March 2021).

Beneficiary Group	Number of registered Beneficiaries
Hepatitis C Stage 1	36
Hepatitis C Enhanced Stage 1+	79
Hepatitis C Stage 2	41
Hepatitis C Stage 2 Widow	2*
HIV	2
HIV & Hep C Stage 1 (Co-infected)	3
HIV & Enhanced Stage 1+ (Co-infected)	11
HIV & Hep C Stage 2	2
Bereaved spouse/partner	37

2* bereaved partners are classified under both our existing scheme of beneficiaries receiving ongoing widow's payments and under the bereaved total.

beneficiaries

Payments Rates 2020-21

The levels of payments available to beneficiaries in 2020/21 are set out in the table below.

Beneficiary Group	Annual Payments
Hepatitis C Stage 1	£4,790
Hepatitis C Enhanced Stage 1+	£19,172
Hepatitis C Stage 2	£19,172
HIV	£19,172
HIV & Hep C Stage 1 (Co-infected)	£23,317
HIV & Enhanced Stage 1+ (Co-infected)	£37,826
HIV & Hep C Stage 2 (Co-infected)	£37,826

WIBSS pay annual payments on a monthly or quarterly basis, depending on beneficiary preference. Payments are made on the 20th of the month. Where the 20th falls on a bank holiday or weekend, payment will be the nearest working day prior to the 20th.

One-off non-discretionary lump sum payments are also paid to successful new applicants to the scheme. A new applicant who is Hep C Stage 1 or HIV would be entitled to a £20,000 lump sum payment. A beneficiary who moves from Hep C Stage 1 to Hep C Stage 2 would receive an additional £50,000 lump sum payment. A new applicant who has already developed to Hepatitis C Stage 2 would receive a £70,000.

A one-off non-discretionary lump sum payment of £10,000 is also paid to the bereaved spouse/partner/dependant relative or estate of a deceased beneficiary to assist with funeral costs.

WIBSS also make regular non-discretionary payments to bereaved spouses/partners/dependant relatives, equal to 75% of the rate the deceased beneficiary was on at time of death. These payments are paid for 3 years from date of death.

WIBSS Structure

The main WIBSS team consists of eight members of staff, led by the WIBSS Manager.

Alison Ramsey
Director of Planning,
Performance and Informatics
NWSSP

Lisa Miller
Head of Operational Service and
Delivery
Velindre Cancer Centre

Mary Swiffen-Walker
WIBSS Manager

Psychology and Well-being

Caroline Coffey
Clinical Psychologist

Julie Armytage
Counsellor

Finance

Stefan Dakovic
Finance Officer

Welfare

Hayley Price
Welfare Rights Manager,
Deputy WIBSS Manager

Rebecca O'Callaghan
Welfare Rights Advisor

Sarah Ferrier
Welfare Rights Advisor

Admin Support

Ryan Clappe
Support Officer

Finance Report

The table below summarises the claims expenditure for 2020-21 with the 2019-20 comparatives. These costs include ad-hoc, widows and small grants payments.

WIBSS Claims Expenditure	2020/21	2019-20 Comparative
No. of Beneficiaries	176	175
Total Payments to Beneficiaries	£3,382,927	£2,919,251

Please note the figures above have been subject to in year movements i.e. new applications, deaths in year, moves from one stage to another, ad hoc requests etc.

NWSSP provide the NHS Wales Finance Team within Welsh Government with regular updates on forecasts throughout the year. The administration of the scheme is cost neutral to both NWSSP and Velindre Cancer Centre, with Welsh Government funding the scheme in full.

Finance Report

A summary of the running costs for 2020-21 is set out below with a 2019-20 comparative:

WIBSS Running Costs	2020/21	2019-20 Comparative
Pay	£218,749	£194,152*
Expenditure	£10,372	£6,270
Total	£229,121	£200,422

*Note the 2019-20 running cost spend is not a full comparative to 2020-21 due to the introduction of the Well-being Psychology team towards the end of 2019. 4 months of pay costs are included within the 2019/20 compared to a full year spend in 2020/21.

New Applications for Financial Support

WIBSS received 4 applications in 2020/21.

Application Type	Applications received	Outcome
Hepatitis C Stage 1	1	Accepted
Enhanced Stage 1+	1	Accepted
Hepatitis C Stage 2	1	Accepted
HIV payments	0	N/A
Move from Stage 1 to Stage 2	0	N/A
Widows application	1	Declined but accepted on receipt of additional information
Total	4	4 Accepted

Performance Report

WIBSS performance against Key Performance Indicators is set out below.

Description of key performance indicator	20/21 Target	Status
Responding to correspondence within set time limits	Within 4 working days	100%
Responding to Freedom of Information requests within required deadlines	In line with Trust policy	100%
Dealing with applications within required timescales	Within 28 days from receipt of complete information	100%
Dealing with appeals within set time limits timely basis	Once all information received, provided is 10 working days before the next Appeals Panel, 100% to be submitted to the next panel	No appeals
Payments made on a timely basis	100% of payments to be made 0-2 days before the due date	100%
Advising WG on CPIH Uplifts and the cost implications for the next financial year	In February each year	100%

Performance Report

Description of key welfare rights indicator (no formal KPI set)	Status
Total Welfare Rights cases opened in previous 12 months	62
No of Key Worker Advice Only	34
No of welfare rights casework	28
Income Generated (Nov 17 – July 2021)	£357,091.92
Outstanding outcomes July 2021	<ul style="list-style-type: none">·1 PIP renewal·1 PIP mandatory reconsideration·1 ESA claim·1 Housing Benefit Claim·1 Council Tax Reduction claim

performance

Support and Assistance Grants Scheme

In 2020-21 we received 6 applications for a support and assistance grant. This is lower than in previous years. From speaking to beneficiaries, it seems that beneficiaries had more pressing worries and concerns regarding their health and wellbeing related to the pandemic. Also in practical terms many were shielding or isolating and may well have not wanted trades people into their homes.

The next Newsletter will contain details of the support and assistance grants that are available to beneficiaries.



Forward Look

2021 -2022

The main priority for WIBSS in 2021-2022 will be to implement the changes announced in the parity agreement made on 25th March 2021.

In addition to this, the workplan will also include the following –

- Agree a Memorandum of Understanding between Welsh Government and Velindre University NHS Trust which sets out the aims and objectives of the WIBSS service and encompasses the current working practices in WIBSS.
- Review all WIBSS documentation and guidance to ensure consistency and accuracy and to ensure it reflects all the changes introduced as a result of the parity agreement.
- To review and update the WIBSS website to reflect the parity changes and to make it more user friendly.
- Issue a Customer Satisfaction Survey to all beneficiaries, including the bereaved spouses/partners, and act on the results.
- Work with our Psychology and Emotional Wellbeing team to identify additional opportunities to support WIBSS beneficiaries e.g., through support groups.

