

Cynllun Cynorthwyo Gwaed
Heintiedig Cymru

Wales Infected Blood
Support Scheme

WIBSS
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Heol y Goron / Crown Way
Caerdydd / Cardiff
CF14 3UB

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FFÔN / TELEPHONE: 02920 902280
EIN CYFEIRNOD / OUR REF:

DYDDIAD / DATE: 23rd November 2018

Mr Thomas Powell
Senior Inquiry Lawyer
Infected Blood Inquiry
Fleetbank House
1st Floor, 2-6 Salisbury Square
London
EC4Y

Dear Mr. Powell,

Request for the production of information under Rule 9(2) of the Inquiry Rules 2006.

In response to your request, I have replicated all the questions below with our response underneath each. Where there are attachments, I have referenced these in each section.

A – Materials held by the scheme

1. The IBI will require the scheme to provide it with copies of or access to materials relating to its establishment, the formation of its policies, its financial records, and its records of applications made by and payments made to beneficiaries. Please provide:
 - a) An explanation of the form in which you currently hold these materials, whether in electronic or hard copy, and how those materials are presently organised.

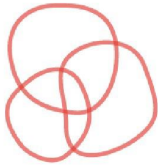
The records are kept in a locked cabinet in the WIBSS section of NWSSP based in Companies House, Cardiff, and a locked filing cabinet in the WIBSS Office in VCC.

Papers relating to the establishment of the scheme and the formation of its policies are stored electronically on a server in access controlled folders.

Applications forms are stored in folders in locked filing cabinet; electronically in the WIBSS, WROSES database and NWSSP Finance system.

Data transferred from the previous schemes is stored electronically on a NWSSP secure server in access controlled folders and also in the WIBSS WROSES database and NWSSP Finance system. We received only electronic data from the previous schemes, no hard copies of applications or medical notes has been transferred.

- b) A schedule of this material.



- Beneficiary payment data for transferring and new beneficiaries
- All beneficiary correspondence since the inception of the scheme
- Application requests and supporting information for new applicants to join the scheme
- Applications for “ad-hoc” grants
- Appeals panel supporting evidence

All stored as described in 1a.

c) Please indicate the volume of this material.

One full draw of a standard filing cabinet. Note: paper records kept to a minimum as most beneficiary data is kept on our secure (backed-up) server.

B – Setting up and operation of the scheme

2. Please provide a narrative account of the establishment of the scheme and outline its functions. In doing so, please:

The Wales Infected Blood Support Scheme (WIBSS) is a new service, managed jointly, on behalf of Welsh Government, by NHS Shared Services Partnership (NWSSP) and Velindre Cancer Centre (VCC). VCC is a core Service and NWSSP is a hosted organisation within Velindre University NHS Trust

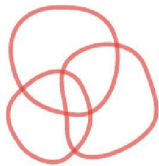
Established in October 2017, WIBSS provides support to people who have been infected with Hepatitis C and/or HIV following treatment with NHS blood, blood products or tissue in the 1980s and 1990s. Having taken over from the previous UK schemes (Eileen Trust, Macfarlane Trust, MFET Ltd, Skipton Fund and Caxton Foundation), WIBSS provides the following:

- A reliable, responsive, and accurate Payments Process;
- A dedicated support service operated by experienced Welfare Rights Advisors;
- A dedicated website that is maintained with useful information and signposting;
- a sensitive and dignified service, ensuring beneficiaries circumstances are understood;
- A key worker to support beneficiaries with navigating the healthcare system;
- A single point of contact for beneficiaries;
- An independent Appeals Process

Note that the Welfare Support element of the WIBSS scheme is unique to beneficiaries infected in Wales and this support mechanism is only prevalent within the Welsh scheme.

WIBSS also has close links to many external stakeholders and organisations, ensuring strong partnership networks for referrals, signposting and fair representation across the sector. The team has received much positive feedback from service users.

<https://wibss.wales.nhs.uk/>



Welsh Government written statement re: Reform of financial support for those affected by NHS supplied contaminated blood

<https://gov.wales/topics/health/publications/health/guidance/contamination/?lang=en>

Welsh Government Written Statement - Future support for those affected by contaminated blood following NHS treatment:

<https://gov.wales/about/cabinet/cabinetstatements/2017/contaminatedblood/?lang=en>

The Terms of Reference of the Management Group explains the governance in more detail. They are embedded in the document below.



WIBSS
Management Group

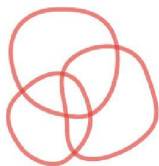
- a) Please name the individuals who have been and continue to be involved in the setting up, daily operation and oversight of the scheme, listing their roles and relevant dates;

WIBSS Implementation Board: October 2016 – October 2017

Martin Riley (Chair) – Head of Finance, NWSSP
Janet Davies – Head of Healthcare Policy, Welsh Government
Jenny Thorne – Healthcare Quality Division, Welsh Government
Catherine Cody - Healthcare Quality Division, Welsh Government
Gareth Haven – NHS & Social Care Finance Division, Welsh Government
Peter Elliott – Project Manager, NWSSP
Lisa Miller – Director of Operations, Velindre Cancer Centre
Georgina Galletly – Board Secretary, Velindre University NHS Trust
Cath O'Brien – Director, Welsh Blood Service
Lynne Kelly – Haemophilia Wales
Hayley Price – Welfare Rights Advisor, Velindre Cancer Centre

Daily Operation: October 2017 to date:

Martin Riley (Chair) – Head of Finance, NWSSP
Lisa Miller – Director of Operations, Velindre Cancer Centre
Mary Swiffen-Walker – Head of WIBSS, NWSSP
Rishi Rai, Management Accountant, NWSSP
Hayley Price – Welfare Rights Advisor, Velindre Cancer Centre
Rebecca O'Callaghan – Welfare Rights Advisor, Velindre Cancer Centre
Sarah Ferrier – Welfare Rights Advisor, Velindre Cancer Centre



Ryan Clappe – Team Support, Velindre Cancer Centre

WIBSS Management Group January 2018 to date:

Georgina Galletly (Chair) – Board Secretary, Velindre University NHS Trust

Martin Riley – Head of Finance, NWSSP

Mary Swiffen-Walker – Head of WIBSS, NWSSP

Janet Davies – Head of Healthcare Policy, Welsh Government

Andrew Holmes – Healthcare Quality Division, Welsh Government

Catherine Cody - Healthcare Quality Division, Welsh Government

Gareth Haven – Health & Social Care Finance, Welsh Government

Lisa Miller – Director of Operations, Velindre Cancer Centre

Lynne Kelly – Haemophilia Wales

GRO-A – Lay representative

- b) Outline your understanding of the degree to which the scheme is the remit of your relevant devolved administration. In particular, are the policies, levels of payments, methods of administration entirely devolved?

The Wales Infected Blood Support Scheme 2017, made by Welsh Ministers in exercise of the powers conferred on them by section 19(1), 203(9) and 204(1) of The National Health Service (Wales) Act 2006, came into force on 1st November 2017 and was amended on 18th June 2018. Decisions regarding the policies, levels of payments and methods of administration are devolved matters and so fall within the remit of the Welsh Government.

The Directions are embedded below:



20171101 - PHD -
Regs - BLOOD - Infe



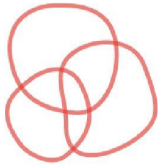
20171102 - PHD -
Regs - BLOOD - Infe

Amended Directions setting out revised rates:

<https://gov.wales/legislation/subordinate/nonsi/nhswales/2018/2018direct54/?lang=en>

It is important to note that the Welsh scheme provides a Welfare rights support service. This is unique to Wales and whilst this does not directly lead to additional payments to beneficiaries this certainly adds value to the Welsh scheme. The value will be evaluated and quantified.

- c) To what degree are your policies, and or levels of payment, influenced by those made in other devolved administrations, and is there any mechanism of oversight or comparison to monitor the consistency of policy and awards made across the devolved administrations?



The Welsh Government sets the policies and levels of payments for the Wales Infected Blood Support Scheme based on advice from WIBSS staff.

Rates of payments are not influenced by levels in other devolved administrations, although WIBSS staff do keep a watching brief on what is happening in other schemes, to ensure we can notify Welsh Government of any changes we think they should consider for WIBSS beneficiaries.

Regular meetings between Welsh Government and WIBSS staff are scheduled to discuss financial options and the implications.

- d) Outline any reviews or consultations which the scheme has undertaken about its policies or levels of payment;

WIBSS has recommended and had Welsh Government approval on the process for annual uplifts. This is based on the January release of the CPIH rate for the upcoming financial year.

WIBSS are in regular contact with the other devolved nations schemes and update the Welsh Government accordingly of any other scheme that has more beneficial terms than the WIBSS scheme. These are costed for Welsh Government consideration.

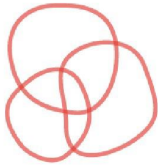
The Welsh Government set the rates and Directions and any amendments to rates will be communicated in writing to WIBSS. These are then actioned by WIBSS.

WIBSS recommended that the £10,000 Bereavement payment available to bereaved spouses and partners and dependant relatives, should also be available to the estate of the deceased beneficiary. This recommendation was accepted by Welsh government and has now been implemented.

WIBSS are currently in advanced negotiations with Welsh Government relating to the establishment of a new psychological support service, within WIBSS, for the beneficiaries and their families. The service would be an All-Wales service aimed at haemophilia and whole blood beneficiaries, their families and bereaved families to include spouses, children, parents, siblings and grandparents. The service would be delivered via a 4 tier, stratified model based on need. Beneficiaries, family members and bereaved family members will be able to access any of the services available within the model according to need.

The Welsh Scheme has a sophisticated welfare support model unique to Wales and, if approved, this new Psychological Support Service would integrate into the holistic package delivered in Wales.

Welsh Government are also developing, in collaboration with WIBSS, a scheme to provide additional support to beneficiaries at stage 1 via a "Mental Health Wellbeing



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Impact Evaluation". This is currently being progressed and will be a Welsh solution to the "SCM" process set up in England.

- e) Outline the processes by which the scheme has facilitated the transition from Alliance House Organisation model of trusts and scheme to the current arrangements;

The Legacy Schemes contacted the beneficiaries and sought permission to transfer their data to the relevant scheme. They then supplied us with the minimum personal data required (in the form of excel spreadsheets) to allow us to categorise, contact and set up payments for the transferring beneficiaries.

The data was collated onto one composite spreadsheet. The composite spreadsheet was checked for accuracy, a gap analysis was undertaken to establish if any of our beneficiaries would be worse off under our scheme.

As the Cabinet Secretary for Health had issued a statement that no one would be worse off under our scheme, we notified Welsh Government of what action it would need to take to ensure this statement was honoured. This resulted in WIBSS continuing to pay regular discretionary payments to those beneficiaries who had previously been in receipt of them; until Welsh Government could review the position.

A welcome letter was sent to all transferring beneficiaries asking them to confirm their contact details, bank details, language preference, etc. We also notified them what their revised payments would be.

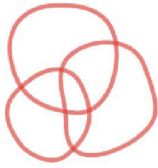
3. Please explain:

- a) The position of your scheme within the structure of the NHS Business Services Authority for your devolved administration. To whom does the scheme report? What is the scheme's relationship with that authority?

The NHS Business Services Authority hosts the English Infected Blood Support Scheme. The NHS BSA does not host the WIBSS. WIBSS reports to the Welsh Government, via the Velindre University NHS Trust. The structure of this is set out in the response provided in B2 above.

- b) What provisions and policies are in place for funding your scheme? Who determines the level of funding, how is this determined, and what level of funding is presently

guaranteed, or



The Wales Infected Blood Support Scheme is funded by the Welsh Government, with the Department of Health currently contributing some funding to the Welsh Government towards costs of payments for those beneficiaries with HIV. The Welsh Government therefore determines the level of funding for WIBSS. Levels of funding are considered in each annual spending review.

The current budget for WIBSS is set at £2.3 million for 2018-19.

Based on the rates issued in the Welsh Government Directions, NWSSP Finance cost the implications for each individual beneficiary and inform the Welsh Government of the total cost. This is fully funded via the allocation provided to NWSSP via the allocation letter from Welsh Government.

Therefore, the current agreed levels of payments are guaranteed and fully funded.

i. anticipated for the future?

Provisions for future payments are calculated annually and updates are sent quarterly to Welsh Government. The costs associated with beneficiary payments for the next financial year (April to March) are sent to Welsh Government for approval by the middle of February.

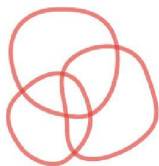
The Welsh Government are best placed to answer this question but from my perspective the Directions are owned by the Welsh Government and the Service is currently fully funded. I believe the Welsh Government are fully committed to their financial obligations under the scheme and I do not foresee any issues with the scheme being fully funded in future. The Welsh Government's annual budgets are subject to the agreement of the UK Government and therefore funding levels for future years cannot be guaranteed by the Welsh Government. However, the current Welsh Government administration is committed to maintaining the levels of financial support set out in the Wales Infected Blood Support Scheme 2017 (as amended). Whilst no government can guarantee what future administrations may recommend or what budget the UK Government may approve, it is likely that future administrations would wish to continue to ensure sufficient financial support is available through WIBSS.

C – Number of beneficiaries

4. Please provide a table setting out the following:

a) How many beneficiaries are registered to receive support, how many are in the process of registering. Of these:

169 beneficiaries are registered with WIBSS and receive regular financial support.



The widows (not included in the 169 above) were provided with a “one-off” lump sum payment equivalent of 3 years funding. They receive no regular payments in the Welsh scheme.

One beneficiary is in the process of registering.

- i. How many were previously registered with the Alliance House Organisations, and which Alliance House Organisation in particular;

197 in total. This comprised 166 live beneficiaries and 32 widows / partners. Please note that one beneficiary is also a widow therefore this totals 198 not 197.

Please note that some beneficiaries were registered with more than one scheme.

Skipton: 165
MFET : 18
Macfarlane : 15
Caxton : 9

- ii. How many were automatically transferred during the 2017 transition, and many have since registered (i.e., how many are new applicants);

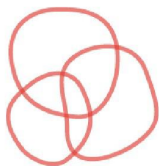
All 197 beneficiaries above transferred. The transfer was not automatic as each of the previous schemes had to seek authority from the individuals that they were content to transfer.

Since the original transfer (October 2017) other beneficiaries have subsequently given permission for their data to be shared and have subsequently transferred into the WIBSS.

Previous scheme beneficiaries that transferred after the initial transfer date: Three
New beneficiaries: Two
In year new widows and estate payments : Six

- b) Please indicate how many individuals are in each category of beneficiaries (i.e., HIV, HCV Stage 1, HCV Stage 2, family of deceased beneficiary (distinguishing spouse or children), etc.).

HCV Stage 1 : 108
HCV Stage 2 : 43



HIV : 2

HCV Stage 1 and HIV : 14

HCV Stage 2 and HIV : 2

169 in total – balancing to response in C 4a)

- c) Please indicate how many receive lump-sum payments, on-going payments, discretionary payments, and/or some combination of these.

169 beneficiaries receive regular financial support.

- d) Please state what if any steps you take to identify those who may be eligible for payments.

This is made explicit on the WIBSS website. There is an application and eligibility section which explains how to apply, all the relevant forms and where and how to submit them. Link below:

<https://wibss.wales.nhs.uk/apply/>

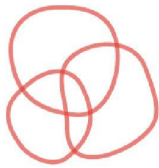
Details of WIBSS were widely distributed to key third party organisations to facilitate the transition, including but not limited to Haemophilia Wales, Haemophilia UK and Hep C Trust.

D – Determining eligibility

5. Please explain how claimants' eligibility is determined, including change of circumstances, setting out:

- a. Who is the decision maker;

Application Type	Role of Decision Maker	Name	Signed off by	Name
New applications/ High value grants	Scheme Manager	Mary Swiffen-Walker	NWSSP Head of Finance or VCC Director of Operations	Martin Riley or Lisa Miller
Income Top Up/Low value grants	Scheme Manager or Finance Officer	Mary Swiffen-Walker or Rishi Rai	NWSSP Head of Finance or VCC Director of Operations	Martin Riley or Lisa Miller



In addition a Scheme of Delegation has been developed to ensure payments are correct:

NHS Wales Shared Services Partnership

Scheme of Delegation for inclusion within Velindre Scheme of Delegation

Wales Infected Blood Support Scheme (WIBSS)

Scheme Designation	Post	NWSSP Revenue Requisition and Invoice £000	Travel Expenses	Vacancy Approval Forms	Payroll Documentation	Adv Over App
Director	Director of Shared Services	90	✓	✓	✓	✓
Director of Finance and Corporate Services	Director of Finance and Corporate Services	60	✓	✓	✓	✓
Heads of Services (within own area)	Head of Finance	10	✓	✓	✓	✓
Heads of Function (within own area)	WIBSS Manager	5	✓	x	x	x
Head of Financial Management	Head of Financial Management	5	x	x	x	x

- b. How eligibility deriving from previous registration with the Alliance House Organisations has been determined;

We accepted all transferring members as qualifying eligible members.

Identification & Data Sharing

Alliance House organisations contacted beneficiaries, for consent to be given allowing their data to be shared with WIBSS. In addition, Welsh Government & Skipton Trust worked in partnership to identify, then pay, those eligible for a new £10,000 bereavement payment offered by WIBSS.

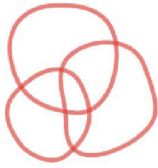
All beneficiary data was received from Alliance House organisations. It was collated by WIBSS and a gap-analysis report was prepared, to ensure no beneficiaries were financially worse off post-transfer.

Communication

WIBSS provided contact details and a website URL to the former Alliance House organisations, to include on their website to redirect beneficiaries to the new scheme.

Details of the transition were communicated on <https://wibss.wales.nhs.uk/existing/> advising beneficiaries of the implications of the transition to WIBSS, new payment criteria and what to do in the event their details were not transferred.

Beneficiary Contact



In order to establish accurate records were transferred by Alliance House, each beneficiary was contacted to confirm their bank details, personal details, contact and language preferences, addresses and payment frequencies prior to first payment being made on 20th November 2017.

All WIBSS beneficiaries were contacted, within the initial 6 weeks, and offered individual welfare rights assistance to ease the financial and emotional impact relating to the transition from the former schemes.

- c. Your policies in respect of standards, and burden of proof required of applicants for various entitlements;

See Directions embedded in response to question B 2b).

- d. Your statistics as to how many applications have been granted and how many have been refused or amended;

Applications Approved – 16
Applications Declined – 8
Applications Pending – 1

- e. Provide a schedule of all applications received since the establishment of your service, indicating what entitlement was claimed and whether the award was granted, declined, or is under consideration / review;

As above

- f. Please explain your appeals and complaints procedure.

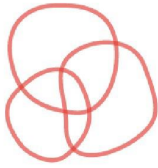
Appeals process embedded below:



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Complaints procedure

It is important that we welcome comments and learn from people's experiences, good or bad about our services. The vast majority of people are happy with the service they receive. Sometimes though, things might not go as well as expected. When that happens, we



need to look at what went wrong so we can try to make it better. Velindre NHS Trust has a clear policy in place if you wish to raise a concern, details of which are found here.

<http://www.velindre-tr.wales.nhs.uk/raising-a-concern>

E – Payments made

6. Please provide:

- a. A spread-sheet illustrating what payments can be made to beneficiaries and at what level, commenting where appropriate on these where they require additional explanation, for example, where these are means-tested set out the applicable threshold; where they are index-linked (or similar) please explain.

Rates are attached from link in our website below. Please note our rates include Winter Fuel:

<https://wibss.wales.nhs.uk/wibss-payments/>

- b. To the extent that this is not reflected in your schedule, an explanation to what degree a beneficiary's circumstances and household income affects the payments they receive.

Currently this is not relevant however, on our advice Welsh Government are considering this. If approved this information will be forwarded to the IBI.

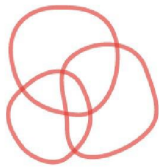
- c. An explanation as how to the policies for quantum for payments to beneficiaries (fixed, on-going, discretionary) has been determined. Did you receive expert medical evidence and or consult the beneficiary community in setting the level of payments? Did you receive any other external advice?

Payments have been set by Welsh Government. Currently WIBSS are honouring the regular discretionary payments made by the legacy schemes, while Welsh Government consider options for regular discretionary payments going forward.

- d. Please set out the amount paid by your scheme on a quarterly basis and any projections for payments to be made in the future.

Annual payments forecast to be £2.298m.

Quarterly payments £575k



18/19 beneficiary payments

	Hep C Stage 1	Hep C Stage 2	HIV	HIV and Hep C Stage 1	HIV and Hep C Stage 2	Total
No of beneficiaries	108	43	2	14	2	169
Regular annual payments (18/19)	£4,622	£18,500	£18,500	£22,500	£36,500	
Total Annual payments	£499,176	£795,500	£37,000	£315,000	£73,000	£1,719,676
No of beneficiaries receiving discretionary payments	10	0	1	12	2	25
Total annual discretionary payments	£27,000	£0	£5,748	£45,780	£7,284	£85,812
Total Payment	£526,176	£795,500	£42,748	£360,780	£80,284	£1,805,488

Ad-hocs

To P07

Estimated P08-P12

accrued in 17/18

£338,195

£200,000

-£45,854

£2,297,829

F - Applications refused

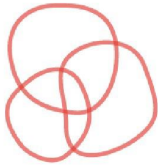
7. Please provide:

- a. A spread-sheet setting out all the applications that have been refused, together with the reason for the refusal.



Item WIBSS F7a.xlsx

- b. A spread-sheet setting out which of those applications have been appealed and the outcome of that appeal.



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Item WIBSS F7b.xlsx

If you require any further clarification or information, please contact me and I will be happy to engage.

GRO-C

Martin G. Riley

Pennaeth Cyllid • Head of Finance

Partneriaeth Cydwasanaethau GIG Cymru - Cyllid a Gwasanaethau Corfforaethol

NHS Wales Shared Services Partnership - Finance and Corporate Services

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