

Witness Name: ALISON RAMSEY  
Statement No.: WITN4506029  
Exhibits: WITN4506030 - WITN4506035  
Dated: 27 September 2022

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF ALISON RAMSEY**

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I provide this statement on behalf of WIBSS in response to the request under Rule 9 of the Inquiry Rules 2006 dated 08 September 2022.

I, Alison Ramsey, will say as follows: -

#### **Section 1: Customer satisfaction**

1. A WIBSS Customer Satisfaction Survey was developed and sent to all beneficiaries (including bereaved partners) in May 2021.
2. The main purpose of the survey was to gain insight and feedback on the services that WIBSS provide. The survey covered the whole range of services provided by WIBSS and was broken down into five areas:
  - i. Overall service
  - ii. Payments made to you
  - iii. Welfare Rights and Advocacy Evaluation
  - iv. Emotional and Wellbeing Service Evaluation; and
  - v. Summary Questions.
3. The survey was issued in May 2021 with a return date of June 2021. All replies were anonymous. The survey was issued in both English and Welsh.
4. WIBSS already held a record of the preferred correspondence method indicated by beneficiaries. And so, the survey was issued either electronically via email or as a hard copy

by post, in line with their preferences.

5. The data analysis was not undertaken by the WIBSS staff team. The data from the returned surveys was collated by the NHS Wales Shared Services Partnership (NWSSP) Head of Performance and a data analyst from NWSSP. The interpretation of responses was undertaken by a Velindre NHS Trust clinical auditor.

6. A copy of the survey is enclosed with this Witness Statement – WITN4506030.

7. 200 surveys were issued by email with hard copies provided on request. 84 were returned. A response rate of 42%.

8. There was clear evidence that WIBSS is highly regarded by those who use it, with 75% of responses stating that the overall service provided by WIBSS was 'Very Good' or 'Good', with staff 'always helpful', 'polite and courteous' and the service being described as 'excellent'. However, areas for improvement were also evident including the need to raise awareness of the services WIBSS provides and strengthen communication with service users.

9. In response to the findings the WIBSS Manager produced an action plan. These were approved by the WIBSS Governance Group and are included within the published Survey Report in a format of 'You Said – We Did (or shall Do)'.

10. The Governance Group monitors progress against these agreed actions.

11. A copy of the survey findings including the action plan is enclosed with this Witness Statement – WITN4506031. The document is published on the WIBSS website.

## **Section 2: Support for psychological needs**

12. The Emotional Well-being and Psychology service continues to provide specialist one to one psychological support to those infected and affected. The service is delivered by one clinical psychologist and a counsellor.

13. To date, over 80 people have accessed the service. The split between those infected and affected who have accessed the service is 49% infected and 51% affected. The current caseload is 34.

14. For most of 2021/22 therapy was delivered virtually or via telephone due to the restrictions in place because of the COVID-19 pandemic. When the restrictions were eased, face-to-face appointments were reintroduced. Where possible, upon request, the team also provide home visits for those with mobility issues and/or chronic comorbidities commonly related to Hepatitis C, and HIV, or the treatments received such as Interferon.

15. Therapy is heavily focussed on developing the therapeutic relationship with the client. It strives to deliver consistency and to promote trust and reliability, in a support service that is allied with the NHS system that provided the infected blood and blood products that have had such a devastating effect on their lives. Feedback from those accessing the service would suggest that the approach adopted is successful. The Counsellor in the team has provided me with the following information:

- a. The team have been able to offer effective therapeutic interventions around a raft of themes including trauma such as panic attacks and flashbacks, hypervigilance, loss and bereavement, carrier status, stigma (living with secrecy), fear and isolation, self-imposed infertility from the fear of passing on HIV or hepatitis C, relationship difficulties, anxiety and depression, misplaced guilt and responsibility, living with related life -limiting health issues, anger, mistrust and distress caused by a lack of empathy from NHS staff regarding the causes of Hepatitis C chronic health conditions e.g., the presumption that someone with Hepatitis C is an alcoholic and the implication that they are lying about the causal factor of a cirrhosis diagnosis.
- b. The issue of parity of financial payments across the four schemes was contentious in the run-up to resolution and for a period thereafter. Whilst the disparity has not been forgotten, it is no longer a primary issue for most.
- c. The ongoing proceedings of the Infected Blood Inquiry, and the contentious evidence presented by some of those who have participated, and the proposed creation of the Compensation Framework, have complicated the trauma responses of many. It has caused secondary and continued psychological trauma. Consequently, therapy is having to address the immediate psychological and emotional responses to minimise further psychological harm, rather than addressing historical trauma.
- d. A common theme is that people want to draw a line and get on with their lives. They feel like they have been in limbo for a long time, and this is causing significant levels of distress. It is felt by the team that meaningful resolution focussed therapy to address historic trauma might be more effective once the Inquiry is concluded and the proposed Compensation Framework has been agreed.

- e. Preparatory therapy is underway around people's expectations of the Inquiry's findings and outcome, to minimise future psychological harm, e.g., realistic versus unrealistic, what would justice look like etc,

16. The team hosted an online focus group event in February this year. The event was online due to COVID-19 restrictions. All WIBSS beneficiaries were invited, and a small (eight attendees) but lively group attended. Attendees were asked for their ideas to help develop the Emotional Well-being and Psychology service, as the team believe that it is important the service users have a say in shaping the service to meet their needs.

17. There was a consensus amongst those who attended around creating peer support opportunities and bringing together people as a community, through shared experience. As a result, a few ideas have been shared with the wider WIBSS beneficiary group for their input and views. This work is ongoing.

18. The team have established the Infected Blood Psychology Network with colleagues from the Scottish and Northern Ireland psychology services. The group meet bimonthly to share ideas, information, best practice, common themes and potential opportunities for research and cross border work. This network has also been consulted to help shape the English Infected Blood Support Scheme (EIBSS) psychology service with the emphasis on the importance of delivering a specialist service.

### **Section 3: Provision between the four nations**

19. Following the announcement made by the Welsh Minister for Health and Social Care on 25 March 2021 and parity discussions between government officials of the four nations that followed, changes were made to the financial payments made to WIBSS beneficiaries. These changes were enabled through Directions issued by Welsh Ministers on 13 August 2021.

20. A copy of the revised WIBSS Directions is enclosed – WITN4506032.

21. The parity payments were processed on 18 August 2021. The only exceptions to this were where WIBSS did not already hold the bank account details for bereaved partners and/or estates. This information was promptly sought, and the relevant parity payments then made as soon as practicable.

22. WIBSS already provided a welfare service and an emotional and psychological service to

WIBSS beneficiaries. There were no changes made to these services.

23. WIBSS has made payments in respect of Winter Fuel allowance to Bereaved Partners. This was enabled by Directions issued on 18 March 2022 and payments processed on 24 March 2022.

24. A copy of the revised WIBSS Directions is enclosed – WITN4506033.

25. A summary of the current WIBSS payment rates is set out in the tables below and can be found on the WIBSS website:

<b>One off Lump Sum Payments</b>	<b>Before parity amount</b>	<b>Current amount</b>
Hepatitis C Stage 1	£20,000	£50,000
Hep. C Enhanced Stage 1	Nil	Nil
Hepatitis C Stage 2	£50,000	Additional £20,000
HIV	Varied but up to £80,500	£80,500
Co-infected (HIV and Stage 1)	Varied but up to £80,500	£80,500 plus £50,000  A total lump sum of £130,500
Co-infected (HIV and Enhanced Stage 1+)	£20,000	Nil
Co-infected (HIV and Stage 2)	£20,000 plus £50,000	£80,500 plus £70,000  A total lump sum of £150,500

<b>Regular Payments</b>	<b>Pre-Parity 2021/22 rates</b>	<b>Revised rates from April 2022/23</b>	<b>Revised rate at 75% for Bereaved partners</b>
Hep. C Stage 1	£4,833	£19,498	£14,629

Enhanced Stage 1+	£19,344	£29,569	£22,177
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Hep. C Stage 2	£19,344	£29,569	£22,177
HIV	£19,344	£29,569	£22,177
Co-Infected (HIV and Stage 1)	£23,527	£40,135	£30,103
Co-Infected (HIV and Stage 1+)	£38,166	£46,469	£34,852
Co-Infected (HIV and Stage 2)	£38,166	£46,469	£34,852
Winter Fuel*	*	£561	£561

*\* Under the original scheme arrangements WIBSS did not pay a separate winter fuel payment. However, because of the parity agreement a winter fuel payment of £544 was subsequently made to our core beneficiaries in October 2021. Following agreement from Welsh Government, a winter fuel payment of £544 was also made to our bereaved spouses/partners in March 2022.*

26. We have also made a few changes to our WIBSS website to improve the layout and accessibility of information.

27. We have made a change to the One-Off Discretionary Grant form. WIBSS has clarified the position regarding provision of household income information. This followed my evidence session to the Inquiry on May 2021. The form now states *'We assess all applications on a case-by-case basis. Although we ask for information regarding your household income, this is not taken into consideration when assessing a claim. By providing this information, you enable WIBSS to assess whether you may be entitled to any additional benefits, you are not currently claiming'*.

28. One residual matter relating to parity that has not yet been fully resolved relates to child payments. WIBSS does not make financial payments for children under the current terms of the scheme. The Welsh Government is still considering this matter and has not yet issued WIBSS with any directions to make such payments.

#### **Section 4: Advice and advocacy services**

29. WIBSS provides a Welfare Rights and Support Service. Whilst we do not call this an advocacy service, it could be considered as such in form and function. This accredited team would make applicants aware that we offer free of charge, confidential advice and support when applying to the WIBSS scheme. This includes assistance with completing forms, guidance on obtaining medical evidence, contacting medical professionals, and pursuing all

other avenues of obtaining supporting documentation, such as clinical coding.

30. I have interpreted the term 'registrant' to mean an individual who is a member of WIBSS, which we refer to as beneficiaries. The WIBSS Welfare Team would assist beneficiaries and their families with accessing medical care and support and/or social care and support. Examples include applying for grants for house adaptations, obtaining specialist mobility aids, signposting specialist dental care, applications for Attendance Allowance and Carers Allowance. Where authorisation is given by the beneficiary, the Welfare Team can liaise directly with social workers to ensure a beneficiary's complex situation is recognised and the best possible provisions are provided to our beneficiaries.

31. Further to my evidence as set out in WITN4506001 paras 69, 143 – 146 as to the role of the Welfare Rights Team, they continue to specialise in benefit matters, are accredited and maintain professional training. The Team also offer advice on contemporary issues, such as targeted campaigns relating to the increasing consumer energy costs. The Welfare Team aim to work in partnership with the Department of Work and Pensions for the benefit of WIBSS beneficiaries, with a named DWP contact in place for escalation of any issues or concerns.

32. WIBSS does not currently provide an advice and/or advocacy service to assist beneficiaries with access to financial products and/or advice on what to do with any lump sum payments (including the £100,000 interim payment recommended by the Inquiry). We do offer advice and guidance relating to access to benefits and income tax and social care financial assessments. WIBSS recommends beneficiaries contact an independent financial advisor, regulated by the Financial Conduct Authority (FCA) to assess their individual circumstances.

33. WIBSS has no current plans to offer this in future. We would continue to advise they contact an independent financial advisor, regulated by the Financial Conduct Authority (FCA) to assess their individual circumstances, and can offer independent specialist advice.

34. WIBSS does already provide all beneficiaries with confirmation of their annual payments each year. The timing of this coincides with when the annual uplift is confirmed by the Welsh Government. On occasion we have been asked to provide a specific letter confirming annual income for mortgage purposes. A copy of a template letter WIBSS uses to respond to such request is enclosed – WITN4506034.

35. The Welfare Team does offer support to beneficiaries in the completion of forms and gathering other relevant information when applying for mortgages.

## **Section 5: Accountability**

36. The nature of the relationship between WIBSS and the Welsh Government is set out in the Memorandum of Understanding. A copy of the signed Memorandum of Understanding is enclosed – WITN4506035.

### **Statement of Truth**

I believe that the facts stated in this witness statement are true.

Signed \_\_\_\_\_ 

**GRO-C**

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Dated \_\_\_\_\_ 06/10/2022 \_\_\_\_\_

#### **Table of exhibits:**

<b>Date</b>	<b>Notes/ Description</b>	<b>Exhibit number</b>
May 2021	A copy of the Customer Satisfaction Survey	WITN4506030
Undated	A copy of the Customer Satisfaction Survey findings	WITN4506031
13 August 2021	A copy of the Directions in respect of changes to WIBSS financial payments	WITN4506032
18 March 2022	A copy of the Directions in respect of Winter Fuel allowance to Bereaved Partners	WITN4506033
Undated	A copy of the template mortgage letter	WITN4506034
May 2021	A copy of the signed Memorandum of Understanding	WITN4506035