

Witness Name: Alison Ramsey
Statement No: WITN4506001
Exhibits: WITN4506002 -
WITN4506009
Dated: April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALISON RAMSEY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 September 2020.

I, Alison Ramsey, will say as follows: -

Section 1: Introduction

Please set out your name, address, date of birth and any relevant professional qualifications relevant to your work at the Wales Infected Blood Support Scheme (“WIBSS”).

1. Alison Ramsey
NHS Wales Shared Services Partnership (“NWSSP”)
4-5 Charnwood Court
Parc Nantgarw
Rhondda Cynon Taf
CF15 7QZ
2. Fellow of the Institute of Chartered Accountants in England and Wales (FCA)

Please describe your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates. In particular please set out whether you had any role in the Alliance House Organisations (“AHOs”) and if so please describe that role and your responsibilities within it.

3. Please find an enclosed summarised resume [WITN4506002]. I confirm I have not had any role in the Alliance House Organisations.

Please set out the positions you have held, and currently hold, at WIBSS, including with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, and describe how you came to be appointed to those positions.

4. I have been Deputy Director of Finance and Corporate Services at NWSSP since June 2019. This followed an open recruitment exercise.
5. NWSSP is an independent organisation, owned and directed by NHS Wales. NWSSP supports NHS Wales through the provision of a comprehensive range of high quality, customer focused support functions and services.
6. NWSSP administers the WIBSS on behalf of the Welsh Government, in partnership with Velindre University NHS Trust. The WIBSS Manager is Mary Swiffen-Walker who works for NWSSP.
7. Martin Riley had previously held the role of Head of Finance and line manager for the WIBSS Manager and budget holder before leaving to take up a new role in another NHS organisation in Wales. He was also in post during the conception of the WIBSS.

Please describe your role and responsibilities in the above positions.

8. I am the line manager for the WIBSS Manager Mary Swiffen-Walker. I have professional responsibility for Stefan Dakovic, WIBSS Finance Officer.
9. I am the nominated budget holder within NWSSP for the WIBSS budget. I have been a member of the WIBSS Governance Group since I took up this role.

What induction, training and information did you receive from WIBSS as to its functions, aims and objectives?

10. A handover meeting with Martin Riley, the previous line manager for the WIBSS Manager.

11. A series of regular 1:1 meetings with the WIBSS Manager during my first few months in the role. This included going through the Directions, the team structure and processes.
12. I attended a meeting of the WIBSS Governance Group during the first week in the role to meet with other key parties including Velindre University NHS Trust staff and the key policy lead at the Welsh Government - Catherine Cody.

Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

13. None.

Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports which you provided.

14. None.

Section 2: Establishment of the Devolved Schemes and Transitional arrangements

Were you personally involved in any consultation by the DHSC or any other Government department or the Welsh Government about the establishment of WIBSS, its functions, aims and objectives? If so, please:

- a. Describe that process.
- b. Set out the contribution you made to the consultation.

15. No. I took up my post on 3 June 2019.

What did you understand the aims and objectives of WIBSS to be? What principles or philosophy underpin it?

16. The WIBSS aims to provide support to people who are infected with Hepatitis C and/or HIV following treatment with NHS blood, blood products or tissue in the late 1980s/early 1990s.

Please describe the extent of your involvement, if any, in the transitional arrangements from the AHOs to WIBSS.

17. None. I took up my post on 3 June 2019.

Are you aware of the criteria the AHOs applied to identifying whether a beneficiary should be referred to WIBSS – in particular, was it based on place of infection or place of residence?

18. I took up post on 3 June 2019, however through discussion with Mary Swiffen-Walker the WIBSS Manager, I understand that AHOs used the place of infection as the criteria to determine which scheme a beneficiary should be referred to i.e. if infected in a Welsh hospital; they would be referred to WIBSS.

Further to the first rule 9 response dated 23 November 2018 [WITN4506006] (especially at questions 2(e) and 5(b)):

- a. Were any attempts made by WIBSS to obtain more detailed information about beneficiaries from the AHOs so as to avoid beneficiaries having to submit information to WIBSS that had already been provided to the AHOs? If so, please give details. If not, why not?**

19. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, I understand the following: WIBSS asked all beneficiaries to confirm the details that transferred across to WIBSS at the start. The only additional information WIBSS asked beneficiaries to provide was their language preferences for ongoing communication and correspondence.

- b. Did the AHOs share any of their policy documentation or eligibility criteria with WIBSS? Please give details. Did WIBSS request this information? If not, why not?**

20. We did not request this information as WIBSS does not have a decision making role

in terms of setting eligibility criteria. WIBSS only received a summary of the appeals process from the Skipton Fund [WITN4506003].

c. Has WIBSS been disadvantaged in any way as a result of a lack of information provided to it by the AHOs? If so, please provide details.

21. No, as far as I am aware WIBSS operates according to the directions set down by Welsh Government.

What steps, if any, were taken to ensure that unsuccessful applicants to any of the AHOs were contacted about potential eligibility for support from WIBSS?

22. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, I understand the following:

- AHOs did not share the information of anyone who had been unsuccessful; therefore, WIBSS were not able to make contact with anyone;
- For all new applications, WIBSS does contact AHOs and/or Russell Cooke to establish if any previous application was made to any of the legacy schemes;
- Where an unsuccessful applicant has since applied to WIBSS, we would seek information from the AHO and/or Russell Cooke Solicitors, regarding the decision to reject the application at the time, but it would not affect our decision making process. We would apply the eligibility criteria of WIBSS to inform our decision.

To the extent not already addressed in previous rule 9 responses or above, what steps (to your knowledge) were taken by each of the AHOs and WIBSS to publicise each of the following:

23. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, I understand the following:

a. the establishment of WIBSS?

24. WIBSS created a website, which set out the criteria of the scheme, contact details, application forms and details of the service offered.

b. the date on which each of the AHOs would cease operations?

25. None that I am aware of.

c. methods of contacting or applying to WIBSS?

26. WIBSS contact details are set out on the website.

d. the general scope of support and other forms of assistance available from WIBSS, including (i) types of support and (ii) eligibility criteria?

27. Details are on the WIBSS website.

Do you consider that more could and/or should have been done (and, if so, what and by whom) to reach potential beneficiaries and offer them support and assistance through WIBSS?

28. I was not in post during the establishment period of the WIBSS and therefore do not know if more could/should have been done. Based on my discussions with the WIBSS Manager, the Welsh Government were working with key stakeholder groups in the establishment of WIBSS.

Did WIBSS have a website when it was first launched? If so, was it the same or similar to the current website? If not, please explain what information was available on it, and when this changed.

29. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, I understand the following:

- Yes a bilingual website was part of the launch;
- There have been additions and amendments made to the website since its initial launch. We keep the website under review and update it as required. Examples of additions and amendments made since its creation include:
 - a section on the psychology team has been added;
 - small grants scheme;
 - Stage 1+ payments;
 - information concerning COVID-19 pandemic;
 - the latest payment rates are updated regularly; and

- the appeals process was added.

Section 3: Relationship with Government

Have you, or others within WIBSS to your knowledge, raised any concerns or issues with the Welsh Government about the funding, structure, organisation or running of WIBSS, or about the involvement of the Welsh Government, or about any other matter? If so, please explain what concerns and issues were raised. What was the response of the Welsh Government to those matters being raised?

30. The WIBSS team has raised with the Welsh Government Policy lead the increasing concerns raised in general terms with us by beneficiaries about the lack of parity between the rates paid across the four nations.
31. They have confirmed this matter has been shared with the relevant Welsh Government Minister, and that the issue of funding parity is being actively pursued at a UK level with the four nations.

Please describe the working relationship between WIBSS and the Velindre Trust, on the one hand, and the Welsh Government, on the other hand. Is there a particular point of contact? If so, who is that? Are you aware of any difficulties? If so, what are they, how do they impact on the running of WIBSS and how, if at all, have they been resolved?

32. Velindre University NHS Trust is the host organisation to NWSSP. NWSSP and Velindre Cancer Centre (also part of Velindre University NHS Trust) deliver the WIBSS in partnership on a day to day basis. The WIBSS Manager and Finance Officer are employed by NWSSP. The Welfare Team and Psychology service are employed by Velindre Cancer Centre. The team share electronic document drives and there is one main contact number for the team that diverts across members of the NWSSP staff and Welfare Team.
33. The main point of contact for the WIBSS team is Mary Swiffen-Walker of NWSSP. The main point of contact for the Welfare and Psychology teams is Lisa Miller for Velindre. The WIBSS Deputy Manager is Hayley Price.
34. The Board Secretary for Velindre University NHS Trust leads the Governance Group;

this is now Lauren Fear, previously Georgina Galletly.

35. The policy lead for Welsh Government is Catherine Cody and the finance lead for Welsh Government is Gareth Haven. Catherine Cody attends the Governance Group meetings and works closely with WIBSS when matters are raised by beneficiaries with WIBSS which are in respect of matters in the control of Welsh Government.
36. I am not aware of any difficulties.

Section 4: Funding/finances of WIBSS

Please explain what funding WIBSS receives from the English/UK Government. Is this limited to HIV allocation? Please explain what the HIV allocation is and how much it is.

37. WIBSS is funded directly by Welsh Government, any funding arrangement between UK Government and Welsh Government is a matter outside my knowledge.

Have problems arisen from the funding process? Is so, what were (or continue to be) the consequences?

In paragraph B(2)(d) of WIBSS' first rule 9 response Mr Riley [WITN4506006] stated that the Welsh Government had approved (on WIBSS' recommendation) annual uplifts to payments based on the CIPH rate. When was the first of these updates applied? Have those updates been applied annually since then?

38. There have been no problems with the funding process. Uplifts to payments were first applied in June 2018 and backdated to 1 April 2018. Since then the uplift has been agreed and applied annually.

The Inquiry understands that as well as lump sum payments and regular payments, beneficiaries can also apply for discretionary support and assistance. How is this part of the budget forecast? How are beneficiaries' needs for the forthcoming year anticipated? What was the size of this part of the budget in the last financial year?

39. We include in the budget a notional amount for discretionary support; based on uptake in prior years. There is however no set budget for discretionary support. Actual expenditure on discretionary support in 2019-20 was £27,490.

40. It is difficult to forecast the future needs of beneficiaries as the applications are varied, dependent on individual circumstances.
41. We keep the Welsh Government Finance team updated regularly on our forecast expenditure position, and would use this process to flag any emerging concerns about the call on discretionary support.

Does WIBSS hold any information about the financial needs of its beneficiary population? Is this information (or has it been), provided to the Welsh Government or English Department of Health? If so, how and when? If not, why not?

42. We do not hold this information as part of our standing data held on beneficiaries.
43. Where grant and benefit application forms have been completed, the Welfare Team may need to provide an income and expenditure summary for the beneficiary. Similarly, to complete a benefit check, the Welfare Team needs a financial snapshot. None of this information is provided to Welsh Government or English Department of Health, as the welfare rights process is confidential.

What mechanisms, if any, are in place to deal with budget overspends by, and/or additional and/or top-up funding for, WIBSS?

44. The WIBSS is 100% funded by the Welsh Government.
45. We submit an annual estimate of forecast costs prior to the beginning of the operational year and agree an estimated budget as part of our standard financial planning cycle. We work to this amount and provide regular updates throughout the year, highlighting any variances to the financial forecast. We report any expected variance whether an over or underspend.

In particular, if applicable:

a. Has WIBSS experienced a budget overspend (annual or quarterly)? If so, at what frequency?

46. We have not experienced any budget overspend to date.

b. Is there any mechanism for transferring an overspend into the next financial period? If so, what is the practical effect of transferring an overspend?

47. The need for such a mechanism has not arisen as WIBSS has not experienced a budget overspend and invoices Welsh Government for actual costs incurred.

c. Is there any other procedure for WIBSS to seek additional and/or top-up funding from the Welsh Government in the course of a financial year? If so, what is the procedure?

48. We would speak to the Welsh Government Finance lead if additional funding was required.

d. If available, to what extent has WIBSS used any such mechanisms?

49. We have not needed to seek additional funding to date.

Is there an absolute maximum amount in respect of any budget overspend, additional funding request and/or top-up funding request?

50. We do agree an estimated budget as part of our standard financial planning cycle; and we would work to this amount, reporting any expected variance whether an over or underspend.

How much funding (to your knowledge) has been provided to WIBSS each year since it was established?

51.	2017-18	£2,590,267
	2018-19	£4,330,640
	2019-20	£3,119,673

52. The above figures reflect actual expenditure.

53. The forecast for 2020-21 is £3,545,285.

54. The 2018-19 figure is higher due to Stage 1+ Enhanced payments paid out in Mar 2019.

In answer to question 2(c) in the first rule 9 response [WITN4506006] and question 5(c) in the second rule 9 response dated 16 January 2019 [WITN4506007], reference was made to regular meetings between the Welsh Government and WIBSS staff to discuss financial options and their implications. Please address the following:

- a. In what frequency are these meetings held? Has this changed over time?**
 - b. Who sets the agenda?**
 - c. Who attends the meetings?**
 - d. Please provide further details as to what is usually discussed.**
 - e. Are formal minutes, or any other written record, taken at these meetings? If so, by whom and who would be provided with copies?**
55. Now that WIBSS is fully established, the meetings between Welsh Government and WIBSS have moved to a more ad hoc basis to discuss specific matters as they arise, for example the latest update on forecast expenditure or to confirm the latest CPIH uplift.
56. There is no formal agenda or minutes.
57. The participants would usually be drawn from myself, Mary Swiffen-Walker, WIBSS Manager, Catherine Cody, Welsh Government Policy Lead, Gareth Haven, Welsh Government Finance lead, Sue Saunders NWSSP Principal Finance Manager or Stefan Dakovic, WIBSS Finance Officer.

Does WIBSS, including the Velindre Trust acting on its behalf, have ad hoc meetings with the Welsh Government? If so:

- a. How are these meetings arranged? Can WIBSS call for such meetings?**
- b. Who sets the agenda for these meetings?**
- c. Please describe any such meetings you know took place or which are planned, including dates where possible.**
- d. Who attends these meetings?**

e. Are formal minutes, or any other written record, taken at these meetings? If so, by whom and who would be provided with copies?

58. As per my answers in paras 54-57.

To your knowledge, does WIBSS have any other streams or sources of funding/income other than that provided by the Welsh Government and the English Department of Health? If so, from what source, how much funding/income was (or is) provided, and how are those funds managed/spent by WIBSS?

59. Not to my knowledge.

In your view, has WIBSS been underfunded at any point since it was established in 2017? If so, what was the impact on WIBSS? If so, was this due to (a) spikes in the number of applications, (b) an increase in the amounts applied for and/or (c) any other reason?

60. Not to my knowledge.

Does WIBSS maintain reserves? If so, who decides on the levels? Do/did you have involvement in those decisions? What is the justification for the level of reserves? Have reserve levels had any impact on discussions with the Welsh Government about increased or maintained levels of funding?

61. No.

As to WIBSS's operational costs:

a. Do these operational costs have to be met entirely from the money provided by the Welsh Government? In particular, is there any cost-sharing with other organisations under the Velindre Trust, i.e. NWSSP and the Velindre Cancer Centre (e.g. as to premises or staff)?

62. Most operational costs are met from money provided by Welsh Government including staff costs. Both NWSSP and Velindre Cancer Centre contribute indirectly to the supporting infrastructure such ICT support as an example.

b. What, if any, steps has WIBSS taken to manage its operational costs so as to maximise the monies available for beneficiaries?

63. The WIBSS was established with an efficient but effective management cost structure. The only additional running costs added to the operations of the scheme since inception have been the additional resource for the psychology support service.

Section 5: Communication and engagement with the beneficiary community

What steps, if any, has WIBSS taken to ensure that staff communicate appropriately with beneficiaries, applicants for support or assistance, and their families? Please include a description of any training or internal know-how practices, including mentorship or other networks.

64. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, I understand the following:
65. All beneficiaries were sent an introductory letter, welcoming them to WIBSS and setting out what the service offered and where they could access additional information.
66. As part of this letter WIBSS asked beneficiaries to confirm all the details we had received from the legacy schemes, and to identify how they would like to be contacted in future e.g. by email or by post, and in what language.
67. WIBSS offers a number of communications options including telephone consultations, Skype, face to face in an office or home visits across the UK, email and postal correspondence.
68. Members of the team attend and receive regular correspondence from DWP/HMRC and welfare forums to maintain a professional standard of service. We also offer our service bilingually.
69. The WIBSS Manager and Deputy Manager supervise the day to day operations of the team. The Welfare Team is experienced in benefit matters and are accredited and two members of the administrative support team have also attended Welfare Benefits training. All staff complete the NHS Wales statutory and mandatory training

packages.

To what extent, if at all, has WIBSS responded to, and acted on, any complaints in relation to its working methods or in relation to the way in which it communicates with beneficiaries, applicants and their families? Please give details of any cases within your knowledge, in particular as to:

- a. Complaints about lack of empathy from staff;**
- b. The wording of application forms;**
- c. The wording of information provided on WIBSS's website.**

70. WIBSS has not received any complaints in relation to our working methods or in relation to the way we communicate with beneficiaries, applicants and their families.
71. The team has received written notes of thanks from a number of beneficiaries and their families for their support and empathy in handling enquiries.

Please provide a detailed account of the steps taken by WIBSS to engage with and understand the beneficiary community. The Inquiry is aware of the engagement exercise undertaken in 2016. What further steps have been taken since then? In particular, has WIBSS set up any groups or meetings involving the beneficiary community, or continued such arrangements from the AHOs? If so:

- a. Please describe and name the groups/meetings;**
- b. What is the purpose of the groups/meetings?**
- c. How often do they meet or interact by other methods?**
- d. Who sets the agenda for meetings?**
- e. Who typically attends the meetings and how are beneficiaries selected for these meetings?**
- f. What impact, if any, do these have on the way WIBSS operates?**
- g. Have any problems been encountered in the running of such groups or meetings? How were they handled?**

72. I took up post on 3 June 2019, however through discussion with the WIBSS Manager, the Welfare Rights Team and Psychology Service I understand the following:

73. In addition to the answers provided in para 65-69 above, the Welfare Rights and Psychology Service sent representation to a recent IBI update meeting in North Wales, to make people aware of our services and to provide support to WIBSS beneficiaries attending the Inquiry.
74. It is the intention to continue to send representatives to future meetings.
75. In May 2018, the Welfare Team canvassed our beneficiaries for interest in setting up a WIBSS specific support group. 15 individuals registered their interest. However, not long after, there were several meetings involving beneficiaries in short succession of the Senedd Cross Party Groups, the IBI and with solicitors. Following a number of telephone calls from beneficiaries saying it was all getting too much for them, and after discussions at a WIBSS team meeting, it was agreed we would place the support group concept on hold while the Inquiry was on-going. The Welfare Team contacted all the individuals who had requested a support group to make them aware of the decision. We have received no further contact regarding this issue from any beneficiary, but would be happy to revisit this in the future, if beneficiaries feel it would be helpful to them.
76. It is worth noting that we have since 2019 introduced the Psychology Service which does also provide emotional support to beneficiaries.

What is the relationship between the senior management of WIBSS and the beneficiary community? Could this be improved, in your view? What steps have been taken to improve this relationship? What further steps could be taken in your view, and why?

77. I have had no direct contact with the beneficiaries; this would only usually arise if the WIBSS Manager or members of the Welfare Team were unavailable.
78. The senior manager who leads the service is Mary Swiffen-Walker, who has regular contact with the beneficiaries. To the best of my knowledge Mary has developed an appropriate rapport with the beneficiaries and their family members. She is empathetic, responds to queries promptly, and aims to be helpful when seeking information from them to support applications and queries.
79. Other consistent points of contact with beneficiaries are members of the Welfare Team. The Psychology Service also speak with beneficiaries with their agreement.

80. The WIBSS team has received a number of thank you cards and letters reflecting the help provided to beneficiaries and their family.
81. We are currently considering the appropriateness of conducting a service quality survey with beneficiaries.

Section 6: Eligibility requirements for WIBSS

As to substantive eligibility requirements:

- a. **Please explain why the cut-off date for treatment for a person suffering from Hepatitis C is 1 September 1991. In particular did WIBWS make any enquiries (and if so what) as to whether all blood/plasma/blood products collected prior to this date and so not subject to HCV screening, were taken out of circulation and destroyed?**
82. This is a matter outside my knowledge.
- b. **Have there been any issues, difficulties or concerns arising out of the application of cut-off dates of infection as an eligibility requirement? If so, what are they and how were they (or are they being) addressed?**
83. Not to my knowledge.
- c. **Confirm whether it is correct that a person must have been infected by a Welsh health body to receive support from WIBSS, even if they now live in another part of the UK?**
84. Under the directions of the scheme, I can confirm that it is correct that a person must have been infected by a Welsh health body to receive support from WIBSS.

Have WIBSS had to refer a question about the interpretation of the eligibility criteria to the Welsh Government? If so, please give details.

85. I took up post on 3 June 2019, however through discussion with Mary Swiffen-Walker

the WIBSS Manager, I understand the following:

86. WIBSS sought advice from Welsh Government in June 2018 in relation to the possibility of acquiring Hep C infection from treatment with Anti-D products.
87. We understand that Welsh Government consulted with the other devolved administrations and the Welsh Blood Service. Welsh Government responded that the position was that Anti-D was considered safe and not a possible route of infection for Hepatitis C.

In what circumstances, if any, would WIBSS seek the view or opinion of a medical assessor or professional when determining eligibility?

88. Determining eligibility is part of the job role of the WIBSS Manager. She would seek the view or opinion of a medical assessor where guidance is not clear, or where the WIBSS Manager wants to sense check her understanding of the medical factors of the application.

As to the procedural requirements for an application to become a beneficiary of WIBSS:

- a. **What is the standard of proof which an applicant must satisfy?**
- b. **How does the burden and standard of proof operate in practice?**
- c. **Are there any differences on the burden and standard of proof depending on the application being made? If so, why?**

89. Answering a) to c):

When assessing an application, WIBSS staff refer to the WIBSS Staff Guidance document [WIBS0000001] and the Assessment of Chronic (Stage 1) Hepatitis C Infection Applications document [WIBS0000002].

- d. **Is there a requirement for an applicant to have evidence of receipt of blood/blood products in their medical records (even where relevant records (i) have been lost/destroyed by the NHS, (ii) are otherwise unavailable through no fault of the applicant or (iii) where there is evidence of poor record keeping such that there is a reasonable suspicion that a record of the use of blood/blood products would not have been made and/or (iv) where there is**

evidence that the procedure carried out would ordinarily require blood/blood products despite there being no such record)? If so, why?

90. Yes there is a requirement for an applicant to have evidence of receipt of blood/blood products in their medical records. The WIBSS is only open to individuals who have been infected through NHS treatment with infected blood/blood products.

91. However, we consider each application carefully and do take into account, by seeking medical advice, the balance of probability based on the evidence applicants are able to submit.

e. Have applicants been accepted as eligible despite not having medical records showing the treatment they alleged to have caused the infection? If not, please explain why.

92. No. The rules of the scheme, set out by Welsh Government require evidence of medical treatment and/or blood transfusion having taken place. Where an applicant has been unable to provide the required evidence, the Welfare Team have contacted the NHS Information Service Department, and asked them to check clinical coding, to ascertain whether this could provide the evidence needed.

93. Clinical Coding is the use of standardised statistical codes to transform descriptions of medical diagnoses or procedures to produce a medical classification.

f. Where an application by a family member is made, is there a requirement to have evidence of the cause of death in a death certificate? If so, why?

94. There is no requirement to have evidence of the cause of death in a death certificate. The death certificate may be helpful in determining that the person had Hepatitis C or HIV, but evidence of the method of transmission would still be required.

g. Does WIBSS provide for exemptions or waivers to documentary record requirements and, if so, what are the exemptions/waivers?

95. Not that I am aware.

As to these procedural requirements:

a. **In what form and how are they provided to registrants or applicants for support from WIBSS? To the extent that this is not done, why not?**

96. WIBSS documentation is available on line and we will also post hard copies to home addresses.

b. **To the extent that these requirements are only available with internet access, what adjustments exist to provide them in other formats?**

97. We also provide hard copies on request.

c. **What are the views, insofar as you are aware, of the Welsh Government about making these requirements accessible?**

98. Matter outside my knowledge.

d. **What role does WIBSS have in keeping them under review and notifying concerns or proposals to the Welsh Government? Please specify how, by whom and in what frequency this is done, if at all.**

99. WIBSS does not have a formal role in keeping the procedural requirements under review. In practice however, where the WIBSS team may identify an issue arising from the processing of applications, we would raise them either directly with Welsh Government or through the Governance Group.

Are you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for WIBSS? If so, which concerns have been identified and what did you/WIBSS do in response?

100. None that I am aware of.

Section 7: Decisions on support applications within WIBSS

Different types of support:

Please provide the most up to date figures as to:

a. The number of WIBSS beneficiaries.

101. There are currently 176 beneficiaries; this includes 175 live beneficiaries and 1 widow of a deceased beneficiary.

b. The number of WIBSS beneficiaries receiving regular payments (and at what level).

102. See table:

Beneficiary Stage	Beneficiary Total	Annual Amount
Hep C Stage 1	36	£4,790
Hep C Stage 1+	79	£19,172
Hep C Stage 2	42	£19,172
Hep C Stage 2 Widow	1	£14,379
HIV	2	£19,172
HIV & Hep C Stage 1	3	£23,317
HIV & Hep C Stage 1+	11	£37,826
HIV & Hep C Stage 2	2	£37,826
Total	176	

c. The number of WIBSS beneficiaries who have received HCV stage 1 payments, enhanced payments and stage 2 payments.

103. 173 beneficiaries, this includes those co-infected individuals who have received HCV Stage 1, Stage 1+ and Stage 2.

d. The number of discretionary grant applications which have been approved.

104. See table:

Year	Amount
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17-18	2
18-19	12
19-20	10
20-21	3*
Total	27

* this is from April to September 2020 i.e. year to date.

e. An update on the number of applications refused (including as to which type of application it was).

105. See table:

Year of application	Number	Context
2017-18		
Hep C Stage 1	1	New application (successfully appealed)
2018-19		
Hep C Stage 1	7	New applications (2 appealed. Accepted onto scheme following receipt of additional information).
2019-20		
Hep C Stage 1	5	New applications
HIV & Hep C Stage 1	1	New application
Hep C Stage 1 to Stage 2	1	Current Beneficiary
2020-21*		
Hep C Stage 1 to Stage 2	1	Current Beneficiary
	16	

* this is from April to September 2020 i.e. year to date.

In the answer to question 2(e) in the first rule 9 response dated 23 November 2018 [WITN4506006], WIBSS commented that it continued to pay regular discretionary

payments to beneficiaries who had previously been in receipt of them pending a review by the Welsh Government. Has the Welsh Government carried out the review of these payments? If so, what was the outcome? If not, when is the review due to take place to your knowledge? Further:

106. I took up my role on 3 June 2019. I understand from my discussion with the WIBSS Manager that the review is on hold pending the outcome of discussions on parity of payments across the four nations.

a. Are these discretionary regular payments still being made?

107. The regular discretionary payments are still being made to those that were in receipt of them when they transferred over.

b. If not, does this mean that some beneficiaries are worse off under WIBSS than they were under the AHOs?

108. N/A following response to a) above.

c. If so, how does this sit with the assurances made by the Government that no one would be worse off under the devolved schemes?

109. Matter outside my knowledge.

To the extent that discretionary payments or grants for specific expenses/items were or continue to be provided by WIBSS:

a. Where is this publicised by WIBSS? (In particular please set out where on the WIBSS website it is made clear that such an application can be made).

110. We have now made information available on the WIBSS website. Prior to this, my understanding is that the Welfare Team would have made beneficiaries aware of it when they were speaking with beneficiaries and assist them with completing the forms, and continue to do so.

b. Why is it not possible to download an application form (Form J) from the website? Please provide a copy of Form J.

111. Form J is now available on the website for download.
- c. The Staff Guidelines state that these grants will only be awarded for certain items. Is this information publicised? If so, where? If not, why not?**
112. The criteria have now been included on the WIBSS website.
- d. Are these grants/payments means tested? If so, why? Are the income brackets publicised? If so, where? If not, why not?**
113. No. We may ask for income and expenditure information when requesting a grant as part of an overall benefit check. This is to identify other sources of income/benefits the applicant may be entitled to apply for.
- e. Does WIBSS consider the amount of money previously given to an applicant from (a) WIBSS, (b) the previous AHOs and/or (c) income from benefits when determining each application? If so, why?**
114. We do not take this into consideration.
- f. Was or is prior authorisation required (including by reference to quotes)?**
115. The WIBSS team advises applicants not to purchase items prior to receiving notification of whether the grant application has been successful. We do ask for copies of quotes and receipts to support grant claims and payments.
- g. Was or is there a policy or practice of always granting the application in the sum of the lowest quote provided? If so, why?**
116. As with the use of all public money, it would be considered good practice, unless there was a justifiable reason not to.
- h. Does the success or otherwise of an application depend on the number of applications made per year or is each application considered on its merits, irrespective of the overall demand on WIBSS? If the latter, please explain any safeguards in place to ensure individual consideration.**

117. No, every application is considered on its merit.

Further to the third rule 9 response dated 14 May 2019 (questions 1-2) [WITN4506008] and the fourth rule 9 response dated 14 November 2019 (questions C(i)-(ii)) [WITN4506009] regarding the Enhanced Hepatitis 1+ Payment Scheme:

a. What input did WIBSS have into the formation of the criteria for this payment?

118. I took up post on 3 June 2019, but I understand from the WIBSS Manager that WIBSS did not have input into the decision making concerning the criteria for this payment.

b. Has any guidance been incorporated into the WIBSS Staff Guidance for the determination of such applications? Please indicate in what sections and provide a copy.

119. Yes – a copy of the guidance is enclosed [**WIBS000001**].

c. What guidance has been made available to applicants or potential beneficiaries about the existence of this payment? By what method (including whether only by digital means and/or on request)? Is it publicised on the WIBSS website? If so, where?

120. I took up my role on 3 June 2019. I understand from my discussion with the WIBSS Manager that WIBSS wrote to all the beneficiaries and made them aware of the new scheme and attached the application form.

121. When we have had new Stage 1 applicants, we have made them aware of the Stage 1+ payment when we write to welcome them to the scheme.

d. How many applications have been made for this payment?

122. 90 applications.

e. Have all applications been successful? If not, why not?

123. Yes

f. Please provide any other updates on the enhanced payment scheme.

124. There are no further updates.

Other than regarding the Enhanced Hepatitis 1+ Payment Scheme addressed in answer to question C(ii) to the fourth rule 9 response [WITN4506009], to what extent, if at all, does WIBSS allow payments to be backdated (such as to cover a period prior to first registration with WIBSS or the specific application date)?

125. Yes, where for example an applicant who has successfully applied to join WIBSS, is identified during our checking process as having been a member of one of the legacy schemes, but who did not receive regular payments from them, and did not transfer to WIBSS when the majority of beneficiaries transferred.

126. We have backdated payments to include the amount of regular payments they should have received from the legacy scheme. We have also backdated the payments they would have been receiving from WIBSS from 1 April 2017 to the date of application.

The Inquiry understands from the responses to the previous rule 9s that regular payments and lump sum payments are not means-tested? Is that correct?

127. That is correct.

If that is not correct, please explain the mechanism for means-testing. Specifically:

a. What income brackets apply?

b. To what extent and in what circumstances do income brackets take into account household income rather than that of the applicant? If so, why?

c. Are relevant income brackets published? If so, where and how can beneficiaries or applicants access this information?

d. Are income brackets kept under review? If so, how and at what intervals?

128. Not applicable as I have stated that regular payments and lump sum payments are

not means-tested.

Please provide your view on the consistency and fairness of decision-making by WIBSS when assessing applications. Please include details as to:

- a. any improvements during your time at WIBSS; and**
- b. the extent to which new applications are compared with applications with similar fact patterns or claims.**

129. The WIBSS Finance and Welfare teams work together well and use each other's knowledge and experience to ensure consistency and fairness. There has been low staff turnover in the team.
130. An internal audit was completed in 2018-19 and all recommendations have been implemented.
131. The volume of new applications is fairly low, so it is difficult to reasonably look at patterns in applications.

The process

Are you aware of beneficiaries who were unable to satisfy the procedural requirements for payments from WIBSS after successful registration? Please comment in particular on requirements to produce the following and, where they are required, why this is necessary:

- a. historic medical records, particularly on blood transfusions;**
- b. supporting letters, notes and other documentation from GPs and/or specialist consultants.**

132. No, I am not aware of beneficiaries unable to satisfy the procedural requirements for payments from WIBSS after successful registration.

Are you aware of beneficiaries making an application for a discretionary grant who were unable to satisfy the procedural requirements for payments from WIBSS after successful registration?

133. WIBSS only administers a small grant scheme. To date, all small grant applications submitted to WIBSS, who meet the required criteria, have been successful. I am not aware of any beneficiaries who were unable to satisfy the procedural requirements.

Please comment in particular on requirements to produce the following and, where they are required, why this is necessary:

a. details of household income (past and present);

134. Not a requirement for a small grant application, but information is asked for to determine if the beneficiary might be able to access additional support from other sources.

b. full itemised details of monthly income and expenditure;

135. Not a requirement for a small grant application, but information is asked for to determine if the beneficiary might be able to access additional support from other sources.

c. two quotes for a particular product or service;

136. We do seek quotes to support a small grant application, to ensure value for money.

d. proof of marital status, cohabitation or dependency of a child, including through historic bank statements.

137. Not a requirement for a small grant application.

To what extent are beneficiaries given the opportunity to re-submit revised reports or further documents before a final determination of their application (e.g. if the WIBSS Manager considers there are likely to be evidential deficiencies or gaps)?

138. The WIBSS Manager writes seeking additional information before making a final decision. If an application is rejected the response adds that WIBSS will reconsider the outcome if additional information is available and submitted.

How long from the receipt of an application is a decision typically made? Please distinguish between different types of application where necessary and specify the basis for reported timescales.

139. This would usually be within 25 days of receipt of all necessary information being received.

Is there a procedure in place to consider applications made on an urgent basis? If so, when does that procedure apply and how does it operate? If not, why not?

140. There is no specific procedure for urgent applications, but the volume of applications received means that all applications are actioned promptly.

What practical support or assistance is available to applicants to help them in making applications? What kind of support and assistance has been provided?

141. A Welfare Rights Advisor from the Welfare Team will help applicants to complete applications if necessary, and this offer of assistance is on the website. When required, members of the Welfare Team have undertaken home visits to help new applicants complete the application forms. As home visits are not advisable in the current COVID19 circumstances, a member of the welfare team may complete the form on behalf of the applicant, during a telephone/zoom consultation, and will then post the completed form to the beneficiary for signature.

Other sources of support

To what extent is the availability of other sources of support, including benefits and charitable support, taken into account when determining (a) eligibility for and (b) levels of support from WIBSS? Is this relationship explained in any written guidance? If so, where and how can beneficiaries or applicants access this information, if at all?

142. This is dependent on the nature of the application or support being sought. For example, if an application is made for a wheelchair via the discretionary grant scheme, then a member of the Welfare Team would make enquiries as to whether this can be accessed via local Appliance or Community Equipment services. The Welfare Team will also check, whether other grants are available from the local authority or other charitable sources.

Are there any particular arrangements between WIBSS and the Department of Work and Pensions (DWP) as to entitlements to benefits? Please describe any issues and steps taken to ensure that payments are not taken into account by the DWP.

143. The Welfare Team has established a key contact within the DWP policy team who has agreed to oversee DWP cases which are being impacted by WIBSS funds.

Are you aware of any beneficiaries having had problems with the DWP as a result of payments made to them by WIBSS? If so, please provide details.

144. The Welfare Team has confirmed to me that three beneficiaries who have been in receipt of benefits for a lengthy period have been investigated for fraudulent benefits claims for not declaring the income from the legacy schemes. They were not required to declare this income and the Welfare Team intervened and provided information to clarify this.

145. Two other beneficiaries who correctly declared their WIBSS income, then had it incorrectly taken into account as capital income and were turned down for benefit entitlement from DWP. The Welfare Team escalated this matter to the DWP policy team and established a contact who agreed to intervene if similar cases arise in the future.

146. All claims were resolved following the intervention of the Welfare Team.

Non-financial Support

The Inquiry has been given details of the psychological support provided by WIBSS in a written statement by Prof Chris Jones, Chief Medical Officer of the Welsh Government dated 11 February 2020, at paragraphs 2-10 [WITN4065001]. Please provide the numbers of those using the service, how many sessions are offered and any further relevant updating information.

147. The Psychology Service Team has confirmed to me that there are approximately 60 beneficiaries currently accessing psychological support from WIBSS.

148. The team has been able to offer an assessment and intervention to all beneficiaries

and family members who have self-referred or been referred to the service.

149. There is currently no set number of sessions offered so the numbers will fluctuate over time. The team operates a flexible service which allows for difference in what can be offered depending on presentation and need. The team has received positive feedback about the flexibility of the service and overwhelmingly that people have found talking to a therapist who is aware of the specialist context and specific issues helpful and psychologically contained.

In the response to the first rule 9 from Mr Riley he outlined two forms of non-financial support available to beneficiaries of WIBBS. As to the key worker to assist with negotiating the health system:

a. How many beneficiaries have taken up this offer?

150. Not recorded. All contact with the Welfare Team is recorded but only as part of the overall advisory service numbers. We do not record separately contact requesting assistance negotiating the health system.

b. Can you provide a narrative description of the kind of assistance provided?

151. Assistance provided includes signposting psychological support (prior to WIBSS own Psychological Service being offered), liaising with social workers to ensure complex beneficiaries needs are met, signposting NHS free dental care and prescription services for those eligible due to new benefit entitlement, chasing medical professionals for evidence to join the WIBSS scheme etc.

c. What kind of experience and qualifications does the key worker have?

152. Both advisors have worked in the advice sector for a minimum of 7 years.

d. Has there been an evaluation of the quantifiable value of the services to the beneficiary as suggested in the first rule 9 response? If so, what was the outcome?

153. The Welfare Team have estimated the value including benefits (backdated and

projected for the year) to be £333,390. This covers the period; Nov 2017 – Sept 2020.

154. The second service identified by Mr Riley is the benefits advisory service.

a. How many beneficiaries take up this offer?

155. Approximately 48 individuals, some of whom will have had repeat contact.

b. Can you provide a narrative description of the kind of assistance the benefits advisor can give? Does it extend to support in tribunals?

156. Complete benefit and welfare check, financial health check, debt signposting, budgeting advice, navigating financial products, guiding through applications such as mortgages, SMI, UC, council tax reduction etc.

157. Yes, the Welfare Team would represent at tribunal though not required to date, as decisions all overturned at mandatory reconsideration stage.

158. The service has raised awareness of benefit changes and welfare reforms, through creating and distributing newsletters. The information is also made available on the website.

159. A newsletter was put together explaining the measures that were introduced at the start of Covid, which had an impact on some benefit rules and procedures. Information was also provided on the schemes the government brought in to support self-employed workers etc. during the pandemic.

c. What kind of experience and qualifications do the benefits advisors have?

160. The Welfare Rights Advisors are Professional CMAP (Certificate Money Advice Practice) qualified, with a minimum of 7 years' experience, Velindre Cancer Centre also has the Advice Quality Standard accreditation. The WIBSS Welfare Rights Service work within these guidelines under the existing accreditation.

<https://advicequalitystandard.org.uk>

Are there any areas of unmet need? Please comment in particular on the need identified by the engagement process that concluded in March 2017 for support in accessing financial services such as insurance and other public services (see the written statement to the Welsh Government of Mr Gething dated 30 March 2017 [CVHB0000040]).

161. Not to my knowledge.

Section 8: Disparities between support under the Devolved Schemes

Are you aware of any disparities between WIBSS and the other Devolved Schemes in relation to any of the following? If so, please describe the disparities that exist. Are they justified in your view? What steps (if any) have been taken to end the disparities?:

a. The procedural eligibility requirements to apply to the scheme, such as providing medical records, supporting letters or proof of cohabitation.

162. Matter outside my knowledge.

b. The substantive eligibility requirements for different types of support (where the same or similar support is available under multiple Devolved Schemes), such as household income or qualifying marital or relationship status.

163. Matter outside my knowledge.

c. Payment levels and types of payment to beneficiaries, including to widows, widowers and other family members.

164. WIBSS payment rates are lower than all other UK nations schemes.

165. WIBSS however pay bereavement payments to the "estate" rather than only paying to the bereaved spouse or dependent relative, as the other schemes do.

166. WIBSS also pay widows payments of 75% of the beneficiaries' payment rate for 3

years from death. I understand that Scotland pays 100% for 1st year and then 75% until widows' death. England don't make widows payments, but their widows can apply for Income top-up.

d. The lack of particular types of support found in one or more of the other Devolved Schemes, such as continuing payments after the death of a primary beneficiary and the availability of discretionary grants.

167. Nothing to add to a) to c) above.

The Inquiry understands that WIBSS keeps a watching brief on the awards made by the other UK schemes to notify the Welsh Government of any changes that WIBSS considers should be made:

a. Please give details of all instances of such notifications by WIBSS.

168. None that I am aware of. Welsh Government informed us of changes made to Northern Ireland scheme via email on 28 January 2020 and 1 September 2020.

b. Please give details of the Welsh Government's response, explaining which proposals were (i) accepted or implemented (if any) and (ii) not acted on.

169. Not applicable given answer to a. above.

c. Please explain why WIBSS has not recommended changes being made to WIBSS when other schemes are more generous to beneficiaries.

170. WIBSS administers the scheme as determined by the Welsh Government.

Are you aware of any other mechanism by which information and existing practices are exchanged between any of the Devolved Schemes? If so, how are these coordinated and in what intervals? Have such exchanges led to any particular changes within WIBSS?

171. Not that I am aware of.

Section 9: Appeals and complaints process

Further to the third rule 9 response dated 14 May 2019 and the fourth rule 9 response dated 14 November 2019:

a. Has there been a sufficient number of appeal decisions for informal guidelines or precedent to emerge? Is there any other mechanism used to ensure consistency across appeals?

172. There have been no further appeals since the previous responses. We have only heard three appeals since the WIBSS was created, so insufficient numbers for informal guidelines or precedent to emerge.

b. Please provide any examples of appellants who have used procedural rights to (i) give evidence or make representations in person and/or (ii) be accompanied by a family member, friend or lay representative.

173. None

c. Why can't appellants attend with legal representatives?

174. Matter outside my knowledge.

Please clarify the response to question A(v) in the fourth rule 9 response that "WIBSS does not have an appeals procedure for non-medically based applications, such as discretionary grants and income top-up. WIBSS does not currently offer income top-up." Does this mean:

a. discretionary grants are available under the scheme but there is no right of appeal, while;

175. Correct, discretionary grants are available under the scheme but there is no right of appeal, however to date we have not rejected any requests.

b. income top-up support is not available and, therefore, there is no right of appeal?

176. Correct, income top-up support is not available, and therefore there is no right of

appeal.

Are there any updates to the details of appeal panel members provided in the fourth rule 9 response dated 14 November 2019 [WITN4506009]? Please also provide details for Helen Cook stated to follow in the fourth rule 9 response.

177. There are no updates to make to the appeal panel members. The details for Helen Cook are enclosed [WITN4506004].

Further as to the WIBSS appeals procedure:

a. Are there any time limits or fees for bringing an appeal? If so, what are they, and how are they made accessible to potential appellants?

178. There is a time limit of three months from the date of the letter rejecting the application to notifying WIBSS that someone wishes to launch an appeal, but no time limit on how long they take to provide additional information. The time limit is notified to the rejected applicant in the letter of the rejection.

b. What is the typical timeframe for determining an appeal? Please describe the steps or stages involved in the process, including time periods for each.

179. WIBSS would aim to convene an appeals panel within 3 months of receipt of the appeal. Appeals Panels would be planned to be held quarterly, if there were sufficient appeals to hear.

180. I understand from the WIBSS Manager that to date only one appeals panel has been held, because we have only received three appeals, and all were dealt with at the same panel. Details and all documentation were sent to the Inquiry with a previous Rule 9 request. See attached Appeals Panel Operational Process [WITN4506005].

What is the standard of review or appeal applied? To your knowledge, why and by whom was this standard chosen?

181. The role of the panel is to reach a judgement on whether or not the application meets the criteria set out for the relevant aspect of the Wales Infected Blood Support Scheme being applied for. An appeal will only be considered where it is made on the basis that

the appellant feels that WIBSS has incorrectly reached a view that they are not eligible for a payment in accordance with the scheme eligibility criteria.

182. An appeal would not be considered in cases where the appellant acknowledges they are not eligible under the current eligibility criteria, but they disagree with those criteria (in such cases, the application could only be reconsidered if the Welsh Government agreed to amend the eligibility criteria).
183. An appellant can only appeal once in relation to any individual application to WIBSS, although they can appeal again for example if they have submitted two different applications for different types of payments, of which both were refused.
184. With regard to the second part of the question, this matter is outside my knowledge.

d. Please comment on the extent to which written reasons are provided.

185. The Chair of the Appeals panel agrees a form of words with other panel members, and this is included in the letter. The WIBSS Manager would then send to the appellant giving the result of the appeal.

e. Does the appeal procedure provide for any right of further review or appeal? If so, in what form and under what conditions? If not, why not?

186. It does not set out any right of further review or appeal. I do not know why not, this is a matter outside my knowledge.

How common is it for decisions to be appealed? Please provide up to date statistics on the number of appeals launched since WIBSS was established.

187. My understanding from discussion with the WIBSS Manager is that since November 2017 we have received three appeals. There have been no additional appeals since previous Rule 9 responses were sent.

How frequently do appeals succeed? Please provide up to date statistics on success and failure since WIBSS was established. To your knowledge, what are typical grounds for (a) allowing and (b) refusing an appeal?

188. My understanding from discussion with the WIBSS Manager is that since November 2017 we have received only three appeals, so difficult to cite typical grounds with such low volumes.

189. One appeal was successful. The other two appeals were unsuccessful. However, the Panel members agreed they would reconsider the unsuccessful cases if additional information was submitted. Additional information was submitted, and the appeals were successful. Had the additional information been provided to WIBSS when the WIBSS Manager considered the initial applications, the applications would have been successful, and they would not have needed to appeal.

In relation to the complaints procedure managed by the Velindre Trust referred to in the first rule 9 response dated 23 November 2018 (question 5(f)) [WITN4506006], please provide any further details relevant to WIBSS complaints. In particular:

- a. What are typical complaints (as distinct from appeals) relating to WIBSS?**
- b. How often were such complaints (i) upheld or (ii) investigated further?**
- c. What, if any, redress is offered to successful complainants?**

190. Answering a to c, we have not received any complaints to date.

What information is provided to beneficiaries about (a) the WIBSS appeals procedure and (b) the above complaints procedure? How is this provided to potential appellants?

191. The appeals procedure is on the website. As stated above, when an application is rejected, the applicant is proactively notified of the appeals procedure.

192. Details of the complaints procedure is on the WIBSS website.

Section 10: Mechanisms for ongoing review and improvement

Please describe any mechanisms for ongoing review and improvement of WIBSS, including through the NHS or with the Department of Health, the UK Government and/or the Welsh Government.

193. The Governance Group would be the mechanism to discuss such matters.

194. We have discussed matters such as information to include on the website, the introduction of the psychology service and the appropriateness of conducting a service quality survey with beneficiaries.

Please comment on any reviews and/or reforms that have been conducted within WIBSS to your knowledge, including timescales, outcomes and costs involved.

195. None to my knowledge.

Section 11: Relationships with other organisations

What involvement or interactions does WIBSS have with the Haemophilia Society?

196. No formal involvement in the day to day running of the service. We respond to correspondence when received.

What are the advantages of Lynn Kelly being a member of the Implementation Board and the Management or Governance Group?

197. I took up post in June 2019, by which time Lynne Kelly had left the Governance Group, so a matter outside my knowledge.

How does WIBSS ensure that it also receives the perspective of those beneficiaries who do not have a bleeding disorder?

198. When we contact beneficiaries, we use a consistent approach and the information goes to all beneficiaries. We would not differentiate between those with a bleeding disorder and those who do not.

Please describe the working relationship between WIBSS and the Haemophilia Society. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of WIBSS and how if at all, were they (or are they being) resolved?

199. We do not have a formal working relationship with Haemophilia Wales but respond to

any ad hoc queries or questions where we are able to provide information or assistance.

What involvement or interactions does WIBSS have with the UK Haemophilia Centre Directors Organisation?

200. My understanding from discussion with the WIBSS Manager is that we have not received any correspondence, and have had no formal involvement with this organisation.

Please describe the working relationship between WIBSS and the UK Haemophilia Centre Directors Organisation. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of WIBSS and how if at all, were they (or are they being) resolved?

201. Not applicable given given that we have had no formal involvement with this organisation.

Please list any particular clinicians you have been/were in regular contact with during your work with WIBSS.

202. I have not had any direct contact, but the WIBSS Manager has confirmed contact with:

- Brendan Healey, Public Health Wales Microbiology
- Andrew Yeoman, Consultant Hepatologist Aneurin Bevan UHB, National Clinical Lead for Liver Disease Delivery Plan in Wales.
- Dr Chris Jones, Deputy Chief Medical Officer Welsh Government
- Dr Marion Lyons, Senior Medical Officer Welsh Government

Please describe the working relationship between WIBSS and the Hepatitis C Trust. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of WIBSS and how if at all, were they (or are they being) resolved?

203. We respond to correspondence when received but no formal involvement in the day to day running of the service.

204. No difficulties that I am aware of.

Section 12: Criticisms or observations

**The following criticisms or observations have been made to the Inquiry by witnesses:
How do you respond to each of these criticisms or observations?**

a. Low payment levels from the AHOs have been carried over to WIBSS.

205. WIBSS has no involvement in setting the levels of payment, however as far as I am aware the WIBSS rates are higher than the AHO rates.

b. It is uncertain whether top-up payments under WIBSS will be available on a continuous basis.

206. WIBSS does not make income top-up payments. WIBSS has however continued with the payments to those beneficiaries who were in receipt of top-up payments under the AHO arrangements.

c. The WIBSS system resembles the making of an application for welfare benefits which feels humiliating and demeaning. The term “begging” culture has been used.

207. I am very sorry that a witness has made this comment. If the witness would be willing for their name to be disclosed then we would gladly speak with them directly about their experience of engaging with the WIBSS team and consider any improvements we can make to our procedures.

d. The availability of information, such as in relation to travel expenses and winter fuel payments, has caused difficulties.

208. I am sorry to hear that as our winter fuel payments and travel expenses are included in the WIBSS rates we pay and are not paid separately. We do explain this in our correspondence with beneficiaries when they are notified of their payment. However, we will take on board the comment and revisit our wording.

e. Some potential beneficiaries were not aware WIBSS existed, i.e. there is insufficient publicity and dependence on word of mouth.

209. We rely upon the WIBSS website to promote awareness of the scheme. Information is also available on the main NWSSP website. WIBSS would be willing to consider suggestions as to how we could do more to promote awareness of the scheme.

f. There is no parity between the levels of support provided to WIBSS beneficiaries compared to the other Devolved Schemes, especially EIBSS.

210. WIBSS does not set the levels of support provided to beneficiaries, this is a matter for Welsh Government. WIBSS has raised with Welsh Government the concerns shared with us by beneficiaries about the current lack of parity between the schemes.

g. WIBSS support levels do not properly reflect lost earnings for those who were on higher incomes prior to infection with HIV and/or HCV.

211. WIBSS does not set the levels of support provided to beneficiaries, this is a matter for Welsh Government, as currently established WIBSS is not considered a loss of earnings compensation scheme.

Do you consider that WIBSS is well run? Do you consider that it achieves its aims and objectives? To the extent not commented on above, are there particular difficulties or shortcomings in the way in which WIBSS:

a. conducts its operations?

b. interacts with beneficiaries and/or applicants for support or assistance?

212. Yes I do consider that WIBSS is well run and that it achieves its aims and objectives.

213. The Team aims to listen, act promptly where we are able to offer support, and show empathy to those beneficiaries and family members who contact us.

214. The Team always strives to provide support but must operate within the Directions of the scheme.

215. We are achieving the aims of the scheme as currently established.

216. It can be difficult to strike the right balance between providing additional information and respecting that some beneficiaries may not wish to be contacted outside of matters relating to their core payment matters. The Team would gladly consider any additional ideas or suggestions on improvements we may be able to make to the day to day running of the service. The Team has considered the appropriateness of running a survey with beneficiaries to capture their experiences of WIBSS, and we are keen to proceed with such a survey as soon as possible.

Section 13: Other

Please provide any other information you may have that is relevant to our Terms of Reference.

217. As noted in the evidence above, enclosed with this statement:

- Alison Ramsey summarised employment history [WITN4506002]
- Skipton Scheme Appeals Advice Sheet [WITN4506003]
- WIBSS Staff Guidance document [WIBS0000001]
- Assessment of Chronic (Stage 1) Hepatitis C Infection Applications document [WIBS0000002]
- Enhanced Stage 1 Payment Process [WIBS0000003]
- Helen Cook details [WITN4506004]
- Appeals Panel Operational Process [WITN4506005]
- Response to the first Rule 9 request by Martin Riley on behalf of WIBSS, dated 23 November 2018 [WITN4506006]
- Response to the second Rule 9 request by Martin Riley on behalf of WIBSS, dated 16 January 2019 [WITN4506007]
- Response to the third Rule 9 request by Andy Butler on behalf of WIBSS, dated 14 May 2019 [WITN4506008]

- Response to the fourth Rule 9 request by Alison Ramsey on behalf of WIBSS, dated 14 November [WITN4506009]

Statement of Truth

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

Signed |  GRO-C

Dated 28/04/2021