Witness Name: Dr Chris Jones Statement No.: WITN4065004

Exhibits: WITN4065005 -

WITN4065008

Dated: May 2021

# INFECTED BLOOD INQUIRY

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# WRITTEN STATEMENT OF DR CHRIS JONES ON BEHALF OF THE WELSH GOVERNMENT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules

Catherine Cody, Senior Policy Official and Gareth Haven, Head of Financial Planning and Management within the Welsh Government's Department of Health and Social Services (DHSS) have been involved in providing advice and information to me in

I, Dr Chris Jones, will say as follows: -

respect of the issues set out below.

2006 dated 8 April 2021.

# Section 1: Establishment of and initial funding and budgeting for the Scheme

1. The Welsh Government has a very good working relationship with the Wales Infected Blood Support Scheme (WIBSS). The main strength of this working relationship is that the Welsh Government policy lead and WIBSS scheme manager have been in post since work began on the scheme and have built up a large knowledge base of both the Wales scheme and the schemes in the other nations. The relationship is open and transparent.

- 2. WIBSS Governance meetings take place on a quarterly basis and regular discussions are had between the scheme manager and policy lead as necessary.
  - (a) The team at Welsh Government past and present is as follows:

Name	Job Title	Dates involved
Rhian Pound-McCarthy	Policy Manager, Blood Safety and Healthcare Associated Infections	January 2015 – September 2016, May 2019 – December 2019
Jenny Thorne	Head, Blood Safety PolicyWelsh Government	2011 – December 2017
Janet Davies	Head of Healthcare Quality	July 2016 - April 2019
Andrew Holmes	Head of Antimicrobial Resistance, Healthcare Associated Infections and Blood Safety Policy	Mid 2017 – end 2018
Debbie Tynen	Head of Antimicrobial Resistance, Healthcare Associated Infections and Blood Safety Policy	June 2019 - ongoing
Catherine Cody (main point of contact)	Policy Lead, Blood Safety and Healthcare Associated Infections	July 2016 - ongoing
Angela Jermyn	Policy Manager, Blood Safety and Healthcare Associated Infections	November 2020 - ongoing
Dr Chris Jones	Deputy Chief Medical Officer/Head of Population Health Care	July 2016 – ongoing
Gareth Haven	Head of Financial Planning and Management (Health)	July 2016 - ongoing

(b) The process by which original policies and budget of WIBSS were agreed is as follows:

It was accepted by the 4 nations that the schemes should be broadly similar whilst reflecting the requirements of their own beneficiaries. Welsh Government undertook a consultation with beneficiaries along with a series of stakeholder

engagement workshops held in both north and south Wales. It was the outcome of both these activities that assisted policy officials shape the WIBSS via a series of internal meetings both at official and Ministerial level. It was agreed that at that time the main ex-gratia payments i.e. HIV, Hep C stage 1 & 2 should be broadly in line with those proposed by the Department of Health and Social Care (DHSC) and the Scottish Government who had already set up their support scheme.

- (c) At a meeting with Alliance House Organisations (AHO) on 16 June 2017 the following information was requested to aid the setup of WIBSS:Desk instructions for the general ex-gratia payments and appeals panels.Data transfer of beneficiaries' details and payments made to date.
- (d) Very little information was shared by AHOs when setting up WIBSS. We have not received the hard copy files of the beneficiaries previously on an AHO scheme, only the data payment files. No desk instructions were shared.
- (e) The DHSC had no direct link in setting the policies and the budget for WIBSS at the time it was being set up. The DHSC took part in the discussions, along with the other health departments, with HMRC and DWP to ensure that the revised ex-gratia payments under the new schemes would not be taken into consideration when assessing for tax and/or benefits.

#### Section 2: Funding for the Scheme

- The budget allocated to WIBSS is considered as part of the annual budget setting
  process of the Welsh Government. Forecast of expected costs are received
  regularly from WIBSS, with specific revisions where any change in policy is being
  proposed.
- 4. This will include an estimate of costs in relation to HIV cases which can be taken into account when setting the Welsh Government budget for WIBSS. The additional budget for the HIV cases is transferred to Wales at the second supplementary

budget\* each year. This is because it was recognised that no funding flow to Wales had taken place in relation to the historical HIV cases.

- \* This is the process that takes place between UK Governments where they agree additional transfers of budget during a financial year. There are normally two supplementary budget exercises each financial year, one in early summer May/June and one in Dec/Jan.
- 5. Funding is paid to WIBSS via a regular invoicing arrangement with their host body, Velindre NHS Trust, and all annual costs are reimbursed on an 'actuals' basis. This arrangement includes the funding for HIV cases.
  - (a) This process has remained the same since the inception of WIBSS.
  - (b) For the process between Welsh Government and WIBSS there have been no major problems in how this has worked. WIBSS staff and Welsh Government officials work closely together to manage any issues as they arise.
- 6. In terms of the ongoing annual process for the transfer of HIV funding, it would be desirable that this arrangement is regularised and that Wales receives a permanent transfer of funding.
- 7. Funding levels for WIBSS are reviewed annually and during the financial year, if required. A WIBSS budget forecast is compiled based on the most recent levels of payments combined with the number of recipients. In addition to this, we include the running costs for the WIBSS administrative team, as well as the additional support services offered by WIBSS.
- 8. The levels of regular payments and lump sums were initially set in 2016-17 after consideration of the Scottish and English schemes; coupled with the wider consideration of overall affordability. The exact make-up of the WIBSS scheme and each of its payments were compiled after careful consideration of the elements of the schemes introduced in Scotland and England in 2016 and also following an engagement process with those affected in Wales.

- 9. Each year, the WIBSS regular payment amounts are increased by the Consumer Prices Index, to take account of inflation. There have been other changes made in the required level of funding for WIBSS, for example, in March 2019 when the Hep C Stage 1 + category was introduced (Minister's statement WITN4065002). Welsh Government has not matched the increase in ex gratia payments announced by the UK Government on the opening day of the Infected Blood Inquiry in 2019. Welsh Government Officials and their counterparts in the other UK health departments, have been working hard to address the range of parity issues since then. This includes work on a further financial settlement from the UK Government to fully secure funding levels for the future. A bid on behalf of all 4 health departments has been put to the UK Treasury by the Cabinet Office.
- 10. Prior to the parity announcement on 25th March 2021 (Minister's statement WITN5665006), Welsh Government had received many representations in the form of correspondence both from beneficiaries, their families and Senedd members. Whilst all correspondence is given due consideration, the fact remained that Welsh Government were unable to meet the financial implications of these requests. Since the announcement on 25th March 2021, Welsh Government are working with their counterparts in the DHSC and the other nations to agree a funding formula and transfer of funds for the coming financial year.
- 11. There is no ongoing minimum funding commitment by the UK Government or DHSC towards the Welsh Government's funding for WIBSS.
- 12. It would be preferable if a permanent budget transfer to Welsh Government, from 21-22 onwards, could be agreed with the UK Government. This would cover the difference between the existing commitment level for WIBSS payments and the new levels agreed under the parity arrangements.
- 13. Moving away from 'in-year' budget transfers and time limited proposals from the UK Government would ensure there is continuity and security for the levels of payments required to achieve parity across all UK nations.

- 14. There is an annual commitment for DHSC to provide funding to cover the costs of payments made to those who were infected with HIV. This has arisen as there has been no permanent transfer of funding made to Wales to cover the costs of those with HIV unlike the arrangement made under the old schemes (Skipton / Caxton) for those infected with Hepatitis.
- 15. Each year at the second supplementary budget estimate, DHSC informs Welsh Government of the level of funding it will receive (in-year) in relation to the costs for those with HIV. The budget transfer occurs in Dec/Jan and is allocated to the Health & Social Care Group (HSS) in Welsh Government and into the WIBSS budget line.
- 16. This process does not affect the timing of funding flows to WIBSS for those with HIV as the HSS budgets underwrite this element until the transfer from the UK Government is received.

### Section 3: The Department's role in eligibility and payment levels

- 17. In 2017 WIBSS was established via an Establishment Order (WITN4065005) and the Welsh Government "Direct" WIBSS as to how they would operate. The Directions are updated each time there are changes to the payment levels or revisions to the scheme. The Operational Agreement is attached (WITN4065006).
- 18.A Memorandum of Understanding (MoU) has been developed between WIBSS and Welsh Government and is attached (WITN4065007).
- 19.A Governance Group is in place to oversee the running of WIBSS. The Group is made up of officials from WIBSS/WG and Velindre NHS which meet on a quarterly basis. At these meetings information is shared on the general running of the scheme including funding aspects, updates on the psychological service and the benefit/welfare support provided. It is also an opportunity for Welsh Government to update on potential policy changes and discussions on parity.
- 20. Eligibility criteria is set by Welsh Government. There is a common eligibility criteria for HIV and/or Hep C stage 1 & 2 across all 4 schemes.

- (a) Welsh Government working with WIBSS set out the procedural requirements.
- (b) WIBSS makes the decisions on whether or not an applicant meets the eligibility requirements, it is they who have day to day management of the scheme.
- (c) Welsh Government set the payment levels.
- (d) Applications for assistance are not routinely referred to Welsh Government for consideration. WIBSS have a very small budget for a small grant scheme and where there are applications for novel or contentious issues these are sometimes discussed between the WIBSS scheme manager and WG policy lead to ensure that we are applying the guidelines in an open and fair manner. The guidelines of the other schemes are also considered in these situations to ensure fairness. Following deliberation the final decision is made by WIBSS.
- 21. The Hepatitis C virus was formally identified in May 1988. Advice on the introduction of the Hepatitis C screening test in the UK was given by the Advisory Committee on Virological Safety of Blood. In November 1990, following evaluation of the test by the blood service it was agreed to introduce screening. The UK was one of the last European Countries to introduce screening that began in September 1991.
- 22. On checking our files we are unable to locate information relating to enquiries about the withdrawal/destruction of blood and or blood products collected prior to September 1991.
- 23. Welsh Government do not review the decisions made by WIBSS on beneficiary eligibility. There are clear guidelines which set out the criteria and WIBSS work within these, referring to medical experts when necessary.
- 24. Welsh Government policy manager meets with counterparts in the other health departments on a regular basis. At these meetings policies and payment rates are discussed and where appropriate action is taken to implement/revise the scheme at WIBSS.

- 25. Each of the schemes are different, WIBSS was set up to reflect the needs/wishes of our beneficiaries at that time within the financial envelope available. In 2017 when WIBSS was set up the payment rates were consistent across all 4 schemes, changes have occurred since then which due to our financial position we have not been able to commit to.
- 26. Following the Ministerial announcement on 26 March 2021, there is greater monetary parity across the 4 schemes. Eligibility criteria to join the schemes remains the same however all the schemes differ slightly in the way that they are administered.

#### Section 4: The Department's role in outreach and publicity by the Scheme

- 27. The Welsh Government has not taken steps since WIBSS has been in existence to identify potential beneficiaries.
- 28. However in 2014, the then CMO wrote out to GPs in Wales asking them to identify patients who may have risk factors or historic factors in relation to Hep C (WITN4506008). It is not known if any of our current beneficiaries were identified through this route.
- 29. Welsh Government do not have a role in deciding whether WIBSS discloses information to the public. Welsh Government and WIBSS have always operated in an open and transparent manner. The WIBSS website provides details of its eligibility criteria.

# Section 5: The Department's role in reviews and consultations

30. Welsh Government consulted with its beneficiaries in 2016 (WITN5665002) on the setting up of WIBSS and what they sought from the scheme. As the scheme has evolved we have worked towards including additional areas of support such as the Hep C stage 1+ and the psychological support. Although no formal consultation

process took place, we received correspondence from beneficiaries and these changes were discussed internally at Welsh Government. We have been mindful of our budget constraints and having to work within these whilst developing revisions which meet the needs of our beneficiaries. We did consult with medical experts during the policy discussions.

# Section 6: Other

- 31. Copies of the WIBSS Operational Agreement are attached.
- 32. Welsh Government and WIBSS scheme representatives do not have meetings where formal records are kept. If particular issues are raised a follow-up decision email is often sent.

# **Statement of Truth**

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

GRO-C

Signed

Dated 5 May 2021

#### Table of exhibits:

Date	Notes/ Description	Exhibit number
6 March 2019	Minister's Written Statement –	WITN4065002

	Introduction of the Hep C Stage 1+ and psychological support service.	
25 March 2021	Minister's Written Statement – Parity Update	WITN5665006
November 2017	WIBSS Establishment Order	WITN4065005
November 2017	WIBSS Operational Agreement	WITN4065006
April 2012	MOU – Welsh Government and WIBSS	WITN4065007
29 August 2014	CMO letter to GPs – Identifying those with Hep C	WITN4065008
2016	Welsh Government Consultation with Beneficiaries	WITN5665002