Witness Name: Sally Richards
Statement No: WITN4508002
Exhibits: WITN4508013-016
Dated: 21/04/2021

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF SALLY RICHARDS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 19 December 2018.

I, Sally Richards, Scheme Manager within the National Services Scotland (NSS), Scottish Infected Blood Support Scheme (SIBSS) with responsibility for managing the scheme, will say as follows: -

1. **Your response at 2(b) states that SIBSS was established pursuant to section 28 of the Smoking, Health and Social Care (Scotland) Act 2005. That section empowers Scottish Ministers to create a scheme to make payments to people infected with hepatitis C as a result of NHS treatment prior to 1991. Please advise where the power to make payments in respect of HIV may be found.**

   This is a matter for the Scottish Government. The Scottish Government has advised as follows. The payments to those with HIV and the widows, widowers and partners of those with HIV who are deceased are made using common law powers.

2. **Your response at 2(c) states that the recommendations of Financial Review Group relating to payment levels form the basis of SIBSS' payments. Please provide further details about which of the Group's recommendations were and were not implemented. If recommendations were not implemented, please explain why.**

   The Scottish Government has provided the following information. The following recommendations of the Financial Review Group **[WITN4508014]** have been implemented:

   Proposal 1. Annual payments (page 10) – this has been implemented and is reflected within the Scheme document. In relation to bullet point 5, there is not a formal mechanism within the

Scheme document regarding payment of the annual payment upfront in the event of a terminal diagnoses, but SIBSS staff would consider this if a beneficiary requested a change to their normal monthly or quarterly payments.

Proposal 2. Supporting widows, widowers (page 10-11) – this has been implemented in full and is reflected within the Scheme document. In relation to the penultimate bullet point in this section, the criteria for establishing a direct causal link to death was considered as part of the 2018 Clinical Review of the Impacts of Chronic Hepatitis C.

Proposal 3. Increased lump sum payment for chronic hepatitis C infection (page 11) - this has been implemented in full and is reflected within the Scheme document.

Proposal 4. Support and Assistance Grants (page 11-12) - this has been implemented. Whilst up to £1 million per year was provisionally set aside for these grants the level of demand for grants was below this level. In light of the recent implementation of the Clinical Review group recommendations on annual payments for those with chronic hepatitis c and their widows, widowers or partners, SIBSS funding is now much more focused on annual payments, with less focus on grants as the need for income top-up support in particular has reduced. The £1000 per year living costs supplement has also been merged into the new annual payments. Whilst the demand for grants has been limited, they remain available – see the guidance on the SIBSS website (https://nhsnss.org/media/3191/sibss-guidance-on-support-and-assistance-grants-v1-5-final.pdf).

In relation to the final bullet point under proposal 4, Support and Assistance grants are available to fund the types of support listed, although as noted in the guidance referred to above, one-off grants are focused on providing support related to the impacts of the person's infection or, in the case of widows/partners or dependents of the deceased, on helping them with transitional costs following their spouse, partner or parent's death. Whilst one-off grants are not focused on items like household items, access to complementary therapies or tax assistance if these are not related to a person's infection, beneficiaries are encouraged to seek income top-up support if they need it in order to fund such costs (the levels of income top-up support available were increased compared to those provided by the Caxton Foundation in order to help ensure more beneficiaries would be eligible). Finally, as well as winter fuel costs, the living costs supplement is designed to cover additional costs for travel and life insurance.

Proposal 5. Further Work (page 13) – the status of these recommendations is as follows:
- one-off lump sum payments by way of final settlement. The Scottish Government is in discussion with Haemophilia Scotland about this. The Scottish Government is waiting for

greater clarity regarding whether or not the UK Inquiry plans to consider this point. If the Inquiry will not consider it, then further work on this will be taken forward by the Scottish Government with stakeholders and NHS National Services Scotland.

- access to insurance products. This is to be considered further, but has been discussed with Scotland and the Scottish Infected Blood Forum. The Scottish Government intends to take forward some work on this (although in light of the UK Inquiry and other work, it does not have the capacity to do so at the moment).

- periodic review of the Scheme. The Scheme's Advisory Group helps SIBSS staff to monitor the Scheme on a regular basis. The Scottish Government has agreed that there should be periodic reviews of the scheme and has been in discussion with stakeholders about this. However, given the significant recent changes to the scheme to implement the Clinical Review and the fact that the Inquiry is currently reviewing SIBSS and other UK schemes, no separate major review of the scheme is planned at the current time.

- Evidence-based review and attributing cause of death to hepatitis c – these two recommendations were both taken forward by the Clinical Review of the Impacts of Chronic Hepatitis C.

- Applicants rejected by the Skipton Fund – this recommendation has been implemented. Applicants are allowed to reapply if they were previously rejected by the Skipton Fund.

- Appeals – applicants are permitted to appear at the meeting of the appeals panel and to bring a representative with them if they wish. If their appeal is rejected they would receive an explanation from SIBSS regarding why it was rejected.

Operation of the scheme – proposals (pages 13-14) – the great majority of these recommendations have been implemented, but with the following few exceptions. In relation to the third bullet point, whilst SIBSS payments are not taken into account by the Department for Work and Pensions (DWP) or Scottish local authorities in calculating entitlement to benefits, the DWP does now require benefits claimants to declare income from SIBSS and other UK schemes. This is a matter for the DWP and not something within the Scottish Government's control. In relation to income generated from the investment of payments, this is also a matter for DWP and not within the control of the Scottish Government. The Inquiry may wish to ask DWP about this.

In relation to the fifth bullet regarding appeals, NSS has put in place a credible and transparent appeals panel with the appropriate clinical expertise. This does include a lay member who can take account of the patient voice, although they are not an infected or affected patient. The

Scottish Government however decided that it was not appropriate to have an option of ultimate appeal to the Cabinet Secretary for Health and Sport; given most appeals relate to clinical matters, the Cabinet Secretary would not be well placed to reach decisions on appeals. If an applicant was dissatisfied with the outcome of an appeal, they would still have the opportunity to seek a judicial review where appropriate.

In relation to the sixth bullet point regarding accountability, given that NHS National Services Scotland is a large agency and the management of SIBSS is only one part of their work, it does not have affected patients on its Board (although they are of course able to apply to become Board members when positions become vacant). However, representatives of those affected are members of the SIBSS Advisory Group.

Finally, in relation to the final bullet point under this section, the new annual payments recommended by the Financial Review Group were backdated to 1 April 2016.
The Scottish Government has provided the following information. The following recommendations of the Financial Review Group **[WITN4508014]** have been implemented:

Proposal 1. Annual payments (page 10) – this has been implemented and is reflected within the Scheme document. In relation to bullet point 5, there is not a formal mechanism within the Scheme document regarding payment of the annual payment upfront in the event of a terminal diagnoses, but SIBSS staff would consider this if a beneficiary requested a change to their normal monthly or quarterly payments.

Proposal 2. Supporting widows, widowers (page 10-11) – this has been implemented in full and is reflected within the Scheme document. In relation to the penultimate bullet point in this section, the criteria for establishing a direct causal link to death was considered as part of the 2018 Clinical Review of the Impacts of Chronic Hepatitis C.

Proposal 3. Increased lump sum payment for chronic hepatitis C infection (page 11) - this has been implemented in full and is reflected within the Scheme document.

Proposal 4. Support and Assistance Grants (page 11-12) - this has been implemented. Whilst up to £1 million per year was provisionally set aside for these grants the level of demand for grants was below this level. In light of the recent implementation of the Clinical Review group recommendations on annual payments for those with chronic hepatitis c and their widows, widowers or partners, SIBSS funding is now much more focused on annual payments, with less focus on grants as the need for income top-up support in particular has reduced. The £1000 per year living costs supplement has also been merged into the new annual payments. Whilst the demand for grants has been limited, they remain available – see the guidance on the SIBSS website

(https://nhsnss.org/media/3191/sibss-guidance-on-support-and-assistance-grants-v1-5-final.pdf).

In relation to the final bullet point under proposal 4, Support and Assistance grants are available to fund the types of support listed, although as noted in the guidance referred to above, one-off grants are focused on providing support related to the impacts of the person's infection or, in the case of widows/partners or dependents of the deceased, on helping them with transitional costs following their spouse, partner or parent's death. Whilst one-off grants are not focused on items like household items, access to complementary therapies or tax assistance if these are not related to a person's infection, beneficiaries are encouraged to seek income top-up support if they need it in order to fund such costs (the levels of income top-up support available were increased compared to those provided by the Caxton Foundation in order to help ensure more beneficiaries would be eligible). Finally, as well as winter fuel costs, the living costs supplement is designed to cover additional costs for travel and life insurance.

Proposal 5. Further Work (page 13) – the status of these recommendations is as follows:

- one-off lump sum payments by way of final settlement. The Scottish Government is in discussion with Haemophilia Scotland about this. The Scottish Government is waiting for greater clarity regarding whether or not the UK Inquiry plans to consider this point. If the Inquiry will not consider it, then further work on this will be taken forward by the Scottish Government with stakeholders and NHS National Services Scotland.

access to insurance products. This is to be considered further, but has been discussed with Haemophilia Scotland and the Scottish Infected Blood Forum. The Scottish Government intends to take forward some work on this (although in light of the UK Inquiry and other work, it does not have the capacity to do so at the moment).

- periodic review of the Scheme. The Scheme's Advisory Group helps SIBSS staff to monitor the Scheme on a regular basis. The Scottish Government has agreed that there should be periodic reviews of the scheme and has been in discussion with stakeholders about this. However, given the significant recent changes to the scheme to implement the Clinical Review and the fact that the Inquiry is currently reviewing SIBSS and other UK schemes, no separate major review of the scheme is planned at the current time.

- Evidence-based review and attributing cause of death to hepatitis c – these two recommendations were both taken forward by the Clinical Review of the Impacts of Chronic Hepatitis C.

- Applicants rejected by the Skipton Fund – this recommendation has been implemented. Applicants are allowed to reapply if they were previously rejected by the Skipton Fund.

- Appeals – applicants are permitted to appear at the meeting of the appeals panel and to bring a representative with them if they wish. If their appeal is rejected they would receive an explanation from SIBSS regarding why it was rejected.

Operation of the scheme – proposals (pages 13-14) – the great majority of these recommendations have been implemented, but with the following few exceptions. In relation to the third bullet point, whilst SIBSS payments are not taken into account by the Department for Work and Pensions (DWP) or Scottish local authorities in calculating entitlement to benefits, the DWP does now require benefits claimants to declare income from SIBSS and other UK schemes. This is a matter for the DWP and not something within the Scottish Government's control. In relation to income generated from the investment of payments, this is also a matter for DWP and not within the control of the Scottish Government. The Inquiry may wish to ask DWP about this.

In relation to the fifth bullet regarding appeals, NSS has put in place a credible and transparent appeals panel with the appropriate clinical expertise. This does include a lay member who can take account of the patient voice, although they are not an infected or affected patient. The Scottish Government however decided that it was not appropriate to have an option of ultimate appeal to the Cabinet Secretary for Health and Sport; given most appeals relate to clinical matters, the Cabinet Secretary would not be well placed to reach decisions on appeals. If an applicant was dissatisfied with the outcome of an appeal, they would still have the opportunity to seek a judicial review where appropriate.

In relation to the sixth bullet point regarding accountability, given that NHS National Services Scotland is a large agency and the management of SIBSS is only one part of their work, it does not have affected patients on its Board (although they are of course able to apply to become Board members when positions become vacant). However, representatives of those affected are members of the SIBSS Advisory Group.

Finally, in relation to the final bullet point under this section, the new annual payments recommended by the Financial Review Group were backdated to 1 April 2016.

3. **Your response at 2(c) also states that the recommendations of the clinical review group were accepted by the Scottish Government. Please advise whether these recommendations have been implemented by SIBSS.**

Clinical Review recommendations implemented by SIBSS. First regular payments to applicants paid on 15/12/18 including monthly payments backdated to September 2018.

4. **In respect of your response at 3(a), please provide further details about the operation and management of SIBSS within the NHS National Services Scotland (NSS). For example, is there an operational agreement between SIBSS and the NSS relating to its day to day functioning? Or does SIBSS operate as a division of the NSS?**

The Scottish Government commissioned National Services Scotland to set up and run the Scottish Infected Blood Support Scheme on their behalf. This work was assigned to an operating division of NSS, Practitioner & Counter Fraud Services. This division was chosen to run the scheme as a number of its other business activities are to make payments to primary care practitioners. It therefore had the capability and systems expertise to run the SIBSS scheme. As with other activities operated from the business units of NSS, there are no operational agreements with NSS rather accountability for delivery is delegated to the Strategic Business Unit Director.

5. **Your response at 4(b) sets out the number of beneficiaries for each category. Please confirm whether the columns relating primary and secondary infectees capture both living and deceased persons. If the columns capture both living and deceased persons, the table seems to indicate that SIBSS currently makes payments to 3 widows/widowers/partners of deceased persons infected with HIV, but only 1 primary infectee. Please explain how these numbers are reconciled.**

The table provided for response 4(b) included only living beneficiaries. Deceased beneficiaries are shown below:-

Application Category	Estate	Primary Infectee	Secondary Infectee	Widow, widower, or civil partner	Grand Total
Payment Scheme - Advanced HCV (Stage 2)		47	1	1	49
Payment Scheme - Chronic HCV (Stage 1)	1	29	2		32
Payment Scheme - Coinfected		8			8
Payment Scheme - HIV		2			2
Grand Total	**1**	**86**	**3**	**1**	**91**

6. **In respect of your response at 4(c), please advise how decisions about discretionary payments are made. For example, are they subject to the same eligibility criteria as the other support grants? If not, please provide details about the eligibility criteria for these payments.**

   Decisions for discretionary payments are subject to the same eligibility criteria as other support grants, using the guidance shown on item D5c3 as previously supplied.

7. **The documents you have attached in your response at 5(c) do not detail eligibility criteria and guidance for applicants with HIV. Please provide details about the eligibility criteria for these applicants.**

   As it is extremely unlikely that anyone undiagnosed with HIV is still alive we do not expect to receive any applications for new HIV claims therefore we have not included this category in our guidance; however, we do have an application form prepared should we receive an application. See item **[WITN4508013]**.

8. **Attachment D5c1, which provides guidance for the assessment of chronic hepatitis C infection applications, states that "where there are difficult clinical matters to interpret, [assessors] should consult a clinical expert to ensure that the outcome of the evaluation is consistent". Is it common for assessors to seek a secondary medical opinion in assessing applications? Please give an indication of how many instances there have been where a further or second opinion has been sought. Please also provide an example of a second opinion along with the original opinion which was being tested.**

   See items **[WITN4508015]** and **[WITN4508016]**

9. **Please provide copies of 10 applications which have been granted and copies of all of those applications which have been declined since SIBSS' establishment, together with any decision making or explanatory materials in respect of each.**

   These have been provided to the Inquiry.

Statement of Truth

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

GRO-C

Signed _____

21/04/2021

Dated _____