

Witness Name: Maree Todd MSP

Statement No.: WITN5764001

Exhibits WITN5764002-WITN5764003

Dated: 21 July 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MAREE TODD

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 June 2021.

I, Maree Todd, will say as follows:

1. Please set out your name, address, date of birth and the positions you hold and have held in the Scottish Government, relevant to the Inquiry's terms of reference.

1.1 My name is Maree Todd. My work address is St Andrew's House, Regent Road, Edinburgh, EH1 3DG. My date of birth is GRO-C 1973.

1.2 I have been Minister for Public Health, Women's Health and Sport since May 2021. Prior to that, I was Minister for Children and Young People from 2017 to 2021.

2. Can the increased annual payments for beneficiaries be claimed by the estate of the beneficiary or the surviving partner of a beneficiary if that beneficiary was alive on 1 April 2019 but has subsequently died?

2.1 Yes, it has been agreed with officials in the Department for Health and Social Care (DHSC) that estates can claim any backdated payments for the period between

1 April 2019 and the date of the beneficiary's death. Scottish Government officials have worked with the Scottish Infected Blood Support Scheme (SIBSS) staff to finalise a short form for estates to apply for these backdated payments.

3. With respect to the new £10,000 lump sum payment made on the death of a beneficiary to the bereaved partner of a beneficiary who has died or, if they did not have a partner, the deceased person's estate:

a. Is this payment available only where the beneficiary has died since 1 April 2017? If so, why?

3.1 Yes. This decision was made by the UK Government on the basis that it includes all those whose relatives have died since SIBSS began operating on 1 April 2017.

b. Will it be necessary to show a link between the deceased beneficiary's death and their infection with either HIV or HCV, to qualify for the payment?

c. If so, please set out the criteria, how it can be met, and the reasons for this policy.

3.2 No. There will be no need to show a link between the deceased beneficiary's infection and their death to qualify for this new payment.

4. With respect to the announcement that HIV lump sum payments are to be increased for existing infected beneficiaries who have received less than £80,500, is it correct that this payment will not be available to the partner or estate of any beneficiary who has died prior to 25 March 2021? If so, what is the reason for this?

4.1 Yes this is correct. This was a decision made by the UK Government so they may be able to confirm the reason for this.

5. Please set out your understanding of any remaining differences between the four schemes. How will the remaining differences between the four schemes be dealt with?

5.1 The schemes will become very similar in terms of eligibility and payment levels. The main ongoing differences relate to the following:

- HCV Stage 1 categories - for those SIBSS beneficiaries with chronic hepatitis c (HCV) (often referred to as 'Stage 1') or their widows, widowers, civil partners or long-term cohabiting partners, in line with the recommendations of the 2018 Clinical Review of the impacts of chronic HCV, SIBSS has three separate categories of beneficiary: (i) those who are severely affected, (ii) those who are moderately affected and (iii) those whose infection has no noticeable impact on their day to day life. The English and Welsh schemes have two Stage 1 categories and the Northern Irish scheme currently only has one category, but this is being reviewed.
- HCV Stage 1 assessment - SIBSS beneficiaries or their widow, widower, civil partner or long-term partner self-assess to determine the category within which they should fall. The Welsh scheme has a similar self-assessment approach to SIBSS; however the English scheme requires clinician assessment for those wishing to apply for the higher level of payment (the Special Category Mechanism).
- Status of coinfecting beneficiaries - SIBSS beneficiaries who are coinfecting with HIV and HCV who were previously categorised as at Skipton Fund Stage 1 were all moved to Stage 2 in line with the recommendations of the Financial Review Group in 2015 and so received an additional £50,000 lump sum payment in 2016-17 and now receive the same payments as those previously categorised as Stage 2. This differs from the approach in the other nations, where the coinfecting beneficiaries remain identified as either Stage 1 or Stage 2.
- Discretionary payments - while all four schemes offer one-off grants and have so far offered income top-up support, there are some differences in eligibility, the approach to means testing and what grants can be claimed for.

5.2 As previous Public Health Ministers have explained in their correspondence or statements to the Inquiry, the Scottish Government and the governments of the other UK nations have committed to increasing parity between the four UK schemes, but have also been clear that there should continue to be flexibility to respond to their own stakeholders' or beneficiaries' priorities where appropriate. Given the different

consultation processes and reviews which have been used to form the current support schemes, it is natural that there will be some ongoing differences.

5.3 Therefore, officials will continue to discuss any areas where there is potential to increase parity, including looking at scope for changes to discretionary support to increase consistency between the schemes. However, the Scottish Government does not plan to change its approach in relation to the first three bullets set out above, HCV stage one categories and assessment and the status of co-infected beneficiaries.

5.4 In relation to the approach to support for those with chronic HCV, officials consulted the Clinical Review Group in May 2021 in light of the parity agreement, and I understand that the group felt that the current approach of having three separate categories and allowing beneficiaries to self-assess remained valid. Therefore I have decided that this approach should continue. I understand that views within the group differed on the level of annual payment that should be received by those who have self-assessed that HCV has no noticeable impact on their day to day life. The Scottish Government has therefore decided that those in the 'no noticeable impact' group should receive an annual payment from now on (including backdating to 2019-20), but that this should be at a lower level than for those in the moderately affected group. This is to ensure that there is a recognition that those in the moderately affected category are more affected. However, we will keep the position on these payment levels under review, particularly in light of any recommendations this Inquiry makes.

5.5 Finally, it is worth noting that, in light of further discussions between officials from the four nations' governments, I have agreed that those SIBSS beneficiaries who are both infected themselves, but are also the bereaved spouse or partner or someone who was an infected beneficiary, should in future receive both an annual payment in relation to their own infection and a bereaved partner's annual payment. Until now, anyone in this position would only receive one annual payment (whichever payment level was higher). This change will bring the SIBSS approach more into line with some of the other schemes.

6. To what extent will the infected and affected communities (including the wider bereaved community such as parents, adult children and carers of those infected) be involved in the future discussions about parity between the four schemes?

6.1 I anticipate having discussions with organisations who represent the infected and affected communities, such as Haemophilia Scotland and the Scottish Infected Blood

Forum, to help ensure that their views about priority areas can be taken into account in any future discussions about parity between the four schemes.

7. Will beneficiaries be able to make applications for discretionary one off grants? If so, what will the criteria be?

7.1 Yes. One-off grants will continue to be available and the criteria for these remain unchanged¹.

7.2 The only change agreed with the other UK Health Departments is that, given the new £10,000 bereavement payment is particularly designed to cover the costs of funerals and associated expenses, SIBSS will no longer offer one-off grants to cover funeral costs in future.

8. Will beneficiaries be able to make applications for child care payments? If so, what will the criteria be, and at what levels will the grants be paid?

8.1 SIBSS does not provide additional grants specifically for beneficiaries with children. While this has been raised with DHSC as an area that could be considered in future discussions about parity and discretionary payments, DHSC has informed officials that the parity funding it will make available could not be used to fund discretionary payments such as this.

9. To what extent will there be means testing in any element of the scheme?

9.1 As previously, the only payments which are currently means tested are income top-up support and most one-off grants, although grants for counselling, for prescription pre-payment certificates or for costs of hepatitis c or HIV tests or treatment (for those living abroad and required to pay for this) are not subject to means testing.

9.2 The Scottish Government aims to move away from means testing where possible. In particular, as a result of previous, and also the latest, increases in the level and eligibility for annual payments we do not expect that anyone will be claiming income top-up support in future. As noted under question 4 above, I would hope that there will be further discussions between the four nations' governments to

¹ Please see the guidance on Support and Assistance Grants on the SIBSS website at <https://www.nss.nhs.scot/publications/sibss-guidance-and-forms-for-support-and-assistance-grants/>

consider the potential for greater parity between the four nations' schemes in relation to one-off grants.

10. What steps will the Scottish Government take (themselves or by instructing SIBSS), to ensure those who are not currently registered, but eligible for these payments, are aware of them?

10.1 As explained by other witnesses in previous submissions to the Inquiry, I understand that Scottish Government officials previously made representations to the Alliance House organisations in 2016-17, asking them to securely transfer data about those who had been accepted on to their schemes to SIBSS. We provided advice from the Information Commissioner's Office which confirmed that, under the data protection legislation in place at the time, the Information Commissioner did not believe that the organisations needed consent from beneficiaries to allow their data to be transferred to SIBSS. However, the Alliance House organisations nonetheless concluded that consent was required. In addition, they also concluded that where beneficiaries had not contacted the Skipton Fund for some time, the Alliance House organisations could not write to those individuals to seek their consent to move to SIBSS. The basis for this decision was a data protection concern arising from the possibility that those individuals had either died or moved house.

10.2 Although some people have since transferred to SIBSS, there may be a small number of infected people, or their widows, widowers or partners, if the infected person is deceased, who would be eligible for SIBSS payments, but are unaware of that possibility. However, without the information from the Alliance House organisations, SIBSS has no way of contacting these people.

10.3 While the Scottish Government agrees that SIBSS should not contact those who were asked to consent to their data being transferred, but did not provide that consent, the Scottish Government believes that attempts should have been made to contact those with whom the Skipton Fund had lost contact. While we understand the concerns of the Alliance House staff in relation to a letter inadvertently being opened by someone else if a beneficiary was no longer at the last known address, SIBSS staff could run checks via GP records to determine if, for example, a beneficiary was deceased or had changed addresses. Therefore, I should be grateful if the Inquiry would consider this point further to determine whether it is appropriate for the Inquiry to make recommendations to the legal firm now holding the beneficiary information previously held by the Alliance House organisations to make the information available to SIBSS in order that the individuals can be advised of their potential eligibility for payments.

10.4 In relation to those who may never have come forward to seek payment from any scheme, as was noted in the written statement of my predecessor, Mairi Gougeon MSP, and the third written statement of Samantha Baker, the Scottish Government issued a public information notice in October 2016, following the short-life working group which considered how to implement the Penrose Inquiry Report's recommendation [WITN0713016]. This aimed to raise awareness among the public more broadly to encourage those who may have had a blood transfusion before September 1991 to come forward for a hepatitis c test by issuing 380,000 leaflets and 7,500 posters across Scotland. These were issued to GP practices, pharmacies, Health Boards/hospitals, Care Homes, Citizens Advice Bureaux, dentists, leisure centres, libraries, community centres and out of hours centres in order to ensure the best chance that everyone would see the leaflets or posters at least once.

10.5 Given that this significant awareness raising exercise has already taken place and, in light of the short-life working group's advice that there were likely to be only a very small number of individuals in Scotland who were infected with HCV via a blood transfusion who were still alive, but were not yet aware of their diagnosis, we do not have plans for further awareness raising at this stage. However, we will continue to work with SIBSS and relevant charities to seek to ensure that those who have been diagnosed with HCV that is likely to have been acquired via a blood transfusion are aware that they can apply to SIBSS for support. In addition, for example, SIBSS has ensured it has raised awareness among GPs of the support it offers via a newsletter which goes to GP practices.

11. When will SIBSS be able to update beneficiaries on what their payments will be and when they will be made?

11.1 SIBSS has already informed those beneficiaries already receiving annual payments what their payments will be in future. I understand they have just sent out letters at the end of June confirming the amount of backdated payments to beneficiaries.

11.2 I have recently received a letter on 18 June 2021 from the Minister of State for Patient Safety, Suicide Prevention and Mental Health, Nadine Dorries MP [WITN5764002], to confirm the level and details of funding available from DHSC. Following some final discussion to seek reassurance that DHSC will underwrite the costs of the parity increases for SIBSS from 2022-23 to 2025-26, the new Scheme document has now been signed and published and SIBSS started making payments in July 2021.

Statement of Truth

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

Signed GRO-C _____

Dated 21/7/21_____

Table of exhibits:

Date	Notes/ Description	Exhibit number
18/06/2021	Letter from Minister of State for Patient Safety, Suicide Prevention and Mental Health, Nadine Dorries MP, to Maree Todd MSP	WITN5764002
18/06/2021	Annex C to letter from Nadine Dorries MP – template monitoring report	WITN5764003