

**Witness Name:** Robin Swann

**Statement No.:** WITN5570028

**Exhibits:** [WITN5570029]

**Dated:** 25 August 2021

## **INFECTED BLOOD INQUIRY**

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### **FIFTH WRITTEN STATEMENT OF ROBIN SWANN MLA**

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I, Robin Swann, in response to the Rule 9 request from Jillian Roe, Infected Blood Inquiry, dated 1 June 2021, will say as follows:

1. I addressed question 1 in my fourth written statement dated 6 July 2021.
2. **With respect to the announcement that a model will be developed in consultation with stakeholders so that enhanced support payments for eligible Hepatitis C Stage 1 beneficiaries can be introduced in line with rates paid in England and backdated to 1 April 2019:**
  - a. **Please set out the steps that need to be completed before this model can be introduced.**
- 2.1 I have decided to conduct a targeted consultation with infected blood stakeholders in Northern Ireland (NI) to seek their input on developing a policy for enhanced support for those with Hepatitis C stage (HCV) 1 infection. The survey that was carried out in autumn 2020 (**WITN5570009**) showed that there were conflicting views among individuals and groups representing beneficiaries

in NI on this matter. Some were of the view that the distinction between stage 1 and 2 should remain clear and a differential in payment levels maintained, whereas others felt that all HCV beneficiaries should be considered for the higher payment currently made to stage 2 beneficiaries. I am of the view that consultation on this matter is essential in developing a model for support to ensure all those who this may affect have the opportunity to have their say.

2.2 In order to assist with this work, I wrote to all beneficiaries on the NI Scheme and to the Chairs of the main representative groups in NI (**WITN55700029**) to seek expressions of interest in being part of a working group, to meet in a virtual capacity, which will provide a platform for the sharing of valuable knowledge and insights at an early stage in the policy development process. This group will provide an opportunity for stakeholders to contribute to the development of the policy from the outset.

2.3 A consultation document will be developed and agreed in liaison with the working group, before being issued to all Scheme beneficiaries and other relevant stakeholders agreed with the working group, for response. It is important that all scheme beneficiaries, including those who will not be directly affected by the new policy, are given an opportunity to respond.

2.4 Following the consultation period, the working group will agree a number of options to be submitted to me for a decision.

**b. Please set out an indicative timetable for these steps.**

2.5 The timeframe for this work will be agreed in consultation with the working group therefore I cannot provide an exact timeframe at this stage. The letter seeking interest in participating in the working group was issued on 5 July 2021 for expressions of interest and the membership and terms of reference of the working group are being finalised. I would hope that the working group would be in a position to meet in September 2021 and once the group has agreed a consultation document, the consultation process should take no longer than eight weeks.

2.6 Regardless of when the enhanced support comes into operation, I have made a commitment that payments will be backdated to 1 April 2019 for all those who are eligible and registered with the Scheme at that time. Therefore, payments will be backdated to the date of registration with the Scheme for all who are eligible and registered with the Scheme on or after 1 April 2019.

**c. Please explain why this is only to be backdated to 1 April 2019 given that the Special Category Mechanism in England was introduced in the autumn of 2017.**

2.7 The Department of Health and Social Care (DHSC) in England agreed to fund payments to support the introduction of enhanced support for Hepatitis C stage 1 beneficiaries backdated to 1 April 2019. I agreed to these terms and whilst the date of 1 April 2019 was proposed by DHSC, I understand that date was identified as the effective date for the agreed changes to all annual payments as that was the date when DHSC introduced the increase in annual payments which led to the divergence in financial support available across the UK. As part of the 25 March 2021 UK parity agreement, I agreed to 1 April 2019 as the effective date for the introduction of enhanced payments for Hepatitis C stage 1 along with the other devolved administrations to help ensure that all four UK schemes achieved the best parity of financial support possible within the available funding and to adhere to the agreed principle that no beneficiary in any UK scheme should be left disadvantaged as a result of a change in another scheme. Further questions on why this date was chosen and whether increased payments could be backdated before 1 April 2019 should be appropriately directed to DHSC.

**d. Will the payment be claimable by the estate of a beneficiary who (i) was alive on 1 April 2019 and (ii) can meet the criteria for the payment on 1 April 2019, but has since died? If not, why not?**

2.8 Backdated payments cannot be made to the spouse/partner or estate of any Hepatitis C stage 1 beneficiary who has passed away prior to the introduction of enhanced support payments. This is because, while I have not yet decided on a model for assessment of eligibility, any process that is put in place will require some form of eligibility assessment which would not be possible once a beneficiary has passed away.

**e. Will the payment be claimable by the estate of a beneficiary who died prior to 1 April 2019? If not, why not?**

2.9 No, as set out in my answer at paragraph 2.6, payments will not be backdated beyond 1 April 2019 as this is the UK-wide agreed effective date for all changes to annual payments.

**3. With respect to the announcement that the £10,000 bereavement lump sum, which has been provided since the NI Scheme was established in 2017, will also now be payable to the estate of the deceased in cases where there is no living spouse or partner, in line with the position in England and Wales (and it will be backdated to 1 April 2017, 'meaning all eligible beneficiaries currently registered on the Scheme will receive the appropriate payment in arrears'):**

**a. Is this payment available to the estate of a beneficiary who has died between 1 April 2017 and today?**

3.1 Yes, where there is no qualifying spouse or partner and if the amount was not been previously paid by an AHO scheme, this payment will be payable to the estate of any beneficiary who has died between 1 April 2017 and the present day.

**b. If so, does the estate need to be 'currently registered on the Scheme' to qualify for the payment?**

3.2 No, the payment will be made to newly registered estates where there is no qualifying spouse or partner and where the necessary evidence is provided for proof of entitlement to administer estate.

**c. 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?**

3.3 No, there is no requirement for a link between the cause of death and the deceased's infection.

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

3.4 Not applicable.

**4. With respect to the announcement that the lump sum payment to a Hepatitis C Stage 1 beneficiary will increase from £20,000 to £50,000, with the additional £20,000 which will bring the policy in line with the position in Scotland and will be backdated to 1 April 2017, 'meaning that all eligible beneficiaries currently registered with the Scheme will receive this additional payment in arrears':**

**a. Please set out who will receive this payment. In particular:**

**i. Is this increase in the lump sum payment available to the bereaved partners or estates of those beneficiaries who died before 1 April 2017? If not, why not?**

- 4.1 No, bereaved partners or estates of those beneficiaries who died before 1 April 2017 will receive the lump sum amount that was payable at the time of death if the amount has not been paid previously. I agreed to these terms and whilst the date of 1 April 2017 was proposed by DHSC, I understand that date was identified as the effective date for backdating because this was the earliest date that any payments were made by the individual UK schemes. As part of the 25 March 2021 UK parity agreement, I agreed to 1 April 2017 as the effective date for the backdating of lump sums along with the other devolved administrations to help ensure that all four UK schemes achieved the best parity of financial support possible within the available funding and to adhere to the agreed principle that no beneficiary in any UK scheme should be left disadvantaged as a result of a change in another scheme. Further questions on why this date was chosen and whether increased payments could be made to the bereaved partners or estates of beneficiaries who died before 1 April 2017 should be appropriately directed to DHSC.

**ii. Is this increase in the lump sum payment available to the bereaved partners or estates of those beneficiaries who were members of the scheme at 1 April 2017 but have since died? If not why not, given that Scotland has been making this payment at this level since the inception of SIBSS?**

- 4.2 No, bereaved partners or estates of those beneficiaries who were members of the scheme at 1 April 2017 will not receive the increased lump sum amount. The increased lump sum amount will be payable to the bereaved partners or estates of those beneficiaries who have died on or after 25 March 2021 if the amount has not been paid previously. This approach was proposed by DHSC who are funding the payments and I agreed along with the other devolved administrations to help ensure that all four UK schemes achieved the best parity of financial support possible within the available funding and to adhere to the agreed principle that no beneficiary in any UK scheme should be left disadvantaged as a result of a change in another scheme.

**b. Does the phrase 'all eligible beneficiaries currently registered with the Scheme' include:**

**i. Any beneficiary, including bereaved widows or partners or estates who have registered with the scheme at any time to receive any payment or grant? If not, why not?**

4.3 No, see paragraph 4.2 for explanation.

**ii. A beneficiary who was registered with an Alliance House Organisation but is not registered with the current scheme? If not, why not?**

4.4 Any infected individual who was registered with an Alliance House Organisation (AHO) scheme but not registered with the NI Scheme would be entitled to receive this uplifted payment as a new beneficiary of the NI Scheme, excluding any amount they had previously received from the AHOs. I would expect that most NI beneficiaries who were registered with the AHOs will have already transferred to the NI Scheme before it became operational in November 2017; however, I am aware that there may be a small number who did not automatically transfer at the time the NI Scheme was established because consent was not received by the AHOs and the NI Scheme manager was unaware of these individuals until they contacted the NI Scheme. For bereaved partners or estates, see paragraph 4.2 for explanation.

**5. With respect to the announcement that the lump sum payment to a HIV beneficiary will increase from the current range of payments up to maximum of £80.5k (depending on circumstances) to an automatic £80.5k, backdated to 1 April 2017, meaning all eligible beneficiaries currently registered with the Scheme will receive any appropriate additional payment in arrears subject to the lump sum amount previously received:**

**a. Is this increase in the lump sum payment available to the bereaved partners or estates of those beneficiaries who died before 1 April 2017, where they have received less than £80.5K?**

5.1 No, see paragraph 4.1 for explanation.

**b. Is this increase in the lump sum payment available to the bereaved partners or estates of those beneficiaries who were members of the scheme at 1 April 2017 but died before 31 March 2021, where they received less than £80.5K?**

**i. If not why not, given that Scotland has been making this payment at this level since 1 April 2017?**

5.2 No see paragraph 4.2 for explanation. It is my understanding that the payment in Scotland was £70,000.

**c. Does the phrase 'all eligible beneficiaries currently registered with the Scheme' include:**

**i. Any beneficiary, including bereaved widows or partners or estates who have registered with the scheme at any time to receive any payment or grant? If not, why not?**

5.3 No, see paragraph 4.2 for explanation.

**ii. A beneficiary who was registered with an Alliance House Organisation but is not registered with the current scheme? If not, why not?**

5.4 See paragraph 4.4 for explanation.

**6. Please set out your understanding of the remaining differences between the schemes once the changes have been implemented. How will the remaining differences between the four schemes be dealt with?**

6.1 Whilst it has been agreed that the payment rates for enhanced HCV stage 1 will be the same across the four UK schemes, there are differences in the systems for assessing eligibility for this support. My understanding is that there are also a number of differences remaining between the schemes on areas such as discretionary support, psychological support and signposting to help with welfare and benefits advice, for example. I am aware that engagement across the four nations at official level is continuing and I would expect my officials to keep me up to date on any matters emerging from those discussions and present me with any recommendations where further steps towards parity may be possible.

**7. 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?**

7.1 I am not aware of any plans to consult directly in relation to any further work on parity. I am happy to work alongside the other UK administrations on any proposals for consultation.

7.2 The Review of the NI Scheme that I announced in January 2020 is continuing and paragraphs 2.1-2.3 set out the steps being taken to consult with the infected

and affected community in NI on the introduction of enhanced support for HCV stage 1. My officials are making plans to ensure there are opportunities for ongoing consultation with our beneficiaries in the future.

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

- 8.1 Yes, beneficiaries in Northern Ireland will continue to be able to make applications for discretionary one-off grants. At present the NI scheme continues to use the England Infected Blood Support Scheme (EIBSS) criteria to assess applications, however a NI specific policy will be developed in due course as part of the ongoing Review. I am unable to say what the criteria will be at present, however I would be happy to provide a copy of the NI discretionary support policy to the Inquiry once it has been developed and agreed.

**9. 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?**

- 9.1 Applications for child care payments are not currently provided on the NI Scheme.

**10. To what extent will there be means testing in relation to any element of the scheme once the changes announced on 25 March have been implemented?**

- 10.1 There is currently no means testing in place on the NI Scheme since I decided to stop income top-ups in September 2020 for the infected and March 2021 for non-infected. This will continue to be the case following the implementation of the 25 March 2021 parity agreement.

**11. What steps will the Government in Northern Ireland take (themselves or by instructing the Infected Blood Payment Scheme for Northern Ireland), to ensure those who are not currently registered, but eligible for these payments are aware of them?**

- 11.1 As part of the ongoing Review of the NI Scheme, my Department is considering how to improve communication and promotion of the Scheme. A range of options is being considered, with the target audience in mind, including leaflets and posters to be displayed in relevant settings such as GP surgeries and pharmacies, as well as use of digital communications methods such as online and social media.



**12. When will the Infected Blood Payment Scheme for Northern Ireland be able to update beneficiaries on what their payments will be and when they will be made?**

- 12.1 The NI Scheme manager wrote to eligible beneficiaries in July 2021 to inform them of what payments are to be made to them as a result of the four nations parity agreement. I do not have a copy of this letter but I am informed that these payments were made on 23 July 2021, with the exception of enhanced support for Hepatitis C stage 1 beneficiaries for which a model for assessment will need to be considered following a consultation process (see paragraphs 2.1-2.5) It is anticipated that these payments will be implemented in late 2021 or early 2022.

**Additional matters**

**13. Further to paragraph 9.1, what is the justification for the Northern Ireland scheme not making such payments available, when they are available to beneficiaries of EIBSS?**

- 13.1 In Northern Ireland, a small number of beneficiaries who were in receipt of support for children as part of their AHO income top-up payment continued to receive these payments upon transfer to the NI Scheme up until income top-ups ceased and were replaced by significantly higher annual payments.
- 13.2 As stated in my first statement to the Inquiry (WITN5570001), when I became NI Health Minister in January 2020, I was aware the NI Scheme had maintained parity with the England Infected Blood Payment Scheme (EIBSS) in most respects (including annual support) until England announced significant increases to its regular payments on 30 April 2019 which led to a disparity with Northern Ireland. However, I also knew that there were a number of differences remaining across the four UK infected blood support schemes which needed to be addressed, including enhanced support for Hepatitis C stage 1 (known as the Special Category Mechanism or SCM in England) and discretionary support.
- 13.3 Between January 2017 and my taking up post in January 2020, there was neither a Northern Ireland Executive nor Direct Rule from Westminster, therefore the Department did not have a Minister to make significant decisions in relation to Scheme policy, particularly decisions that would necessitate recurrent long-term financial commitment. During this period, changes were

made to the EIBSS such as the introduction of the SCM and means-tested discretionary payments to help with the costs of bringing up children of an infected beneficiary. This new provision could not be replicated in Northern Ireland without a functioning Executive in place. That is why on taking up post as Health Minister in Northern Ireland I announced a review of the NI Scheme in order to address those divergences.

- 13.4 In addition to the ongoing Review of the NI Infected Blood Payment Scheme, work has continued across the four UK nations in order to achieve '*greater parity*'. Further to the announcement made on 25 March, a consultation process will shortly commence on the introduction of enhanced support for Hepatitis C stage 1, while provision of financial support for children is another area that has been identified for consideration of potential reform to ensure a consistent approach across the UK. I expect my officials to keep me fully briefed on any matters emerging from those discussions and present me with any recommendations where further steps towards parity may be possible.

**Statement of Truth**

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

Signed \_\_\_\_\_  
GRO-C

Dated 25 August 2021