

Written Statement

Witness Name: Robin Swann

Statement No.: WITN5570001

Exhibits: [WITN5570002 – WITN5570018]

Dated: 20 April 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROBIN SWANN MLA

I, Robin Swann, in response to the Rule 9 request from Andrew Black, Infected Blood Inquiry lawyer dated 18 November 2020, addressed to the Department of Health, will say as follows:

Section 1: Introduction

- 1. Please set out your name, address, date of birth and the positions you hold and have held at the Department of Health (“DH”).**

1.1 My name is Robin Swann. I am the Minister of Health in the Department of Health (Northern Ireland) (“the Department”) and am based in Castle Buildings, Stormont Estate, Belfast. I took up post on 11 January 2020.

1.2 I am a Member of the Legislative Assembly (MLA) for North Antrim and I sit on the NI Executive that is made up of the First Minister, deputy First Minister and eight departmental Ministers.

2. Please identify the senior officials within the DH involved in providing advice or information to you about the issues set out below.

2.1 The issues set out below fall within the remit of Population Health Directorate (PHD), which sits within the Chief Medical Officer's Group (CMOG) in the Department of Health NI (DoH NI). Liz Redmond is the Director of PHD and is responsible for development and oversight of policy specific to protecting and improving population health. Ms Redmond reports through the Deputy Chief Medical Officer (Public Health), Dr Naresh Chada, to the Chief Medical Officer, Dr Michael McBride. The NICE guidance set out under section three falls within the remit of Donna Ruddy, the acting Director of Regulation, Quality and Improvement (Andrew Dawson has now been appointed Director of Regulation, Quality and Improvement). Ms Ruddy reports through the Deputy Chief Medical Officer, Dr Lourda Geoghegan, to the Chief Medical Officer, Dr Michael McBride.

Section 2: Alleviating the suffering of those infected and affected by infected blood and blood products

3. Please set out, in as much detail as you are able to, what the DH has done to alleviate the financial hardship of those infected by NHS blood and blood products ("the infected") during your time as Minister.

3.1 Work on developing the Northern Ireland Infected Blood Payment Scheme ("the Scheme") had been underway following its establishment in November 2017. This work was initially on hold in the absence of a Northern Ireland Health Minister to take key policy decisions which required significant long-term funding commitment. Since taking up post as Health Minister in

January 2020, I have ensured my officials have picked up where this work was previously left off.

3.2 On 9 January 2020, three years after the collapse of the NI Assembly, the Secretary of State for Northern Ireland and Irish Tánaiste published the text of a deal to restore devolved government in Northern Ireland. The deal, entitled '*New Decade, New Approach*' ("NDNA") ([WITN5570002]) was agreed by all Northern Ireland Parties during political talks at Stormont House and is intended to transform public services and restore public confidence in devolved government. The agreement of NDNA led to the full restoration of the institutions of the Belfast/Good Friday Agreement including the NI Executive, the NI Assembly and the North/South Ministerial Council, with the Assembly and Executive forming on 10 January 2020. NDNA includes a section on '*Delivering a fair and compassionate society that supports working families and the most vulnerable*' and within this section at page nine there is a commitment by the Executive "*to bring about parity in financial support to victims of contaminated blood in Northern Ireland with those in England*".

3.3 Therefore from the date of my appointment as Minister of Health in Northern Ireland on 11 January 2020, addressing the financial hardship of those infected by NHS blood and blood products was an immediate priority for the NI Executive. I was aware of the terrible suffering and financial hardship that people have endured as a result of receiving NHS contaminated blood and, in particular, the hurt that was caused to victims in Northern Ireland by the divergence that resulted from a significant increase in payments announced by the Department of Health and Social Care in England for English beneficiaries in April 2019.

3.4 I was determined to address that hurt and alleviate financial hardship and on 27 January 2020, just over two weeks after taking up post, I announced interim payments ranging between £4,000 and £8,000 per person (depending on individual diagnosis) to people on the Scheme who were diagnosed with Hepatitis C or HIV after receiving NHS-supplied infected blood. The interim payments were made possible by a £1 million allocation to my Department through the Department of Finance's January monitoring round. [WITN5570003]

3.5 In January 2020, I also stated my commitment to taking forward a three-phase review of the Scheme. Phase 1 has addressed the immediate disparity with England on annual payments to the infected beneficiaries; phase 2 (which is ongoing) will address other aspects of the scheme, with a view to working towards greater parity of support across the UK schemes, while phase 3 will address recommendations from this Inquiry.

3.6 On 13 February 2020, I met with groups of those infected, along with their political representatives. I listened to each of their individual accounts of how they had been affected by contaminated blood and how this impact was not only on their physical and mental health, but also on finances, family life, career, education and relationships. I heard at first hand of the fear people have experienced and the significant mental health impact and the negative effect of the stigma of infection, a particular problem in small communities such as in Northern Ireland. At the meeting, I provided an update on the payments I had announced in January and how I intended to make further payments before the end of the financial year. I advised of my commitment to the ongoing review of the Scheme and explained that I wanted to build a robust business case to secure recurrent funding. I provided assurance that those infected and/or affected by contaminated blood had my full support. [WITN5570004]

3.7 I met again with groups representing those infected and/ or affected on 23 March 2020, this time by teleconference due to the COVID-19 pandemic. I asked for this meeting to be arranged so that I could tell them personally of additional payments I intended to announce and to advise of the financial implications going forward. I provided a commitment to the continuing review to consider all aspects of the Scheme. [WITN5570005]

3.8 On 23 March 2020, I announced additional payments for infected beneficiaries on the Scheme, ranging from around £3,000 to £6,700. These payments, added to those already paid in January, brought Northern Ireland's regular annual payments to infected beneficiaries into line with those in England

for the 2019/20 financial year and meant that no infected beneficiary on the Scheme was worse off than their counterparts in England. [WITN5570006]

3.9 On 9 April 2020, I wrote to the Chairs of Haemophilia NI, Families and Friends of Haemophilia NI and the Haemophilia Society, to confirm that the disparity with England in payments for 2019/20 had been addressed and that I intended to now move forward with Phase 2 of the Review. [WITN5570007] I provided an assurance that the £1m announced in the NI Budget for 2020/21 would be used in full, as intended, to provide support to those impacted by infected blood and that I would make a further announcement of payments for 2020/21 once I had given full and proper consideration as to the most appropriate way to use the funding available.

3.10 I was conscious that the COVID-19 pandemic added greatly to the concern already felt by many in the infected blood community and I wanted to be able to provide them with more permanent financial certainty. On 31 July 2020, I asked officials to take forward as a matter of urgency the necessary steps to implement an uplift in payments that would bring Northern Ireland into line with England on annual financial provision to infected beneficiaries on a permanent basis. On 30 August 2020, I was delighted to announce a permanent uplift of payments to infected beneficiaries in Northern Ireland at the same level as the rates paid in England, ranging from £18,745 to just under £45,000 (depending on diagnosis). [WITN5570008]

3.11 The uplift represented an additional annual commitment of £1.1 million for my Department and the payments were made to beneficiaries during week commencing 7 September, backdated to 1 April 2020. As in England, the payments will increase annually in line with inflation (using the Consumer Price Index). This funding commitment was made possible by an additional £1m of ring-fenced recurrent funding announced in the 2020/21 Northern Ireland Budget, with the remaining balance being made up from within my Department's overall budget baseline.

3.12 I consider my announcement on 30 August 2020 to be the first step in phase 2 of the review and it addressed the most pressing and immediate priority

for those impacted by contaminated blood in Northern Ireland. However I am keen to build on the progress already made and, despite significant pressure on my Department responding to the unprecedented challenge of the COVID-19 pandemic, phase 2 of the review of the Scheme has continued and my officials are considering what further reform could be introduced within budget constraints. It was important to me that all Scheme beneficiaries had an opportunity to share their views on the current support provided via the scheme. Therefore, I asked for a survey of scheme members to be carried out during September and October 2020 to provide me with valuable feedback on all aspects of the scheme from those directly affected and to provide an important evidence base for any decisions I make on further reform. [WITN5570009]

4. Please set out, in as much detail as you are able to, what the DH has done to alleviate the financial hardship of those whose relatives and loved ones have been infected by NHS blood and blood products (“the affected”) during your time as Minister.

4.1 I was aware of the devastating consequences for those infected and / or affected by NHS blood and blood products and addressing this issue was an immediate priority for me on becoming Health Minister. When I met with groups from this community in February 2020, I was particularly struck by the significant impact contaminated blood had had not only on those directly infected with HIV or Hepatitis C, but also on their families and in particular widows and widowers who often had to give up their careers or put their own lives on hold to care for their spouse and the financial difficulties encountered after their loved one passed away.

4.2 I have received correspondence from people bereaved due to contaminated blood who report feeling forgotten or overlooked. It is for that reason that in March 2020 [WITN5570003] I secured funding from within my Department's budget to make £5,000 payments to non-infected widows and widowers on the Scheme, who are only entitled to winter fuel payment and (in some cases) income top-ups, but who have suffered substantial financial

hardship due to contaminated blood and did not benefit from the payments I had announced in January 2020. These widows and widowers endured significant emotional impacts and financial hardship as a result of their spouse or partner receiving contaminated blood and that suffering has often continued after their loved ones passed away because often those infected with HIV or Hepatitis C were unable to secure a pension or life insurance to provide financial security for their spouse.

4.3 Despite the fact that these groups of people received NHS contaminated blood long before devolution in Northern Ireland, no additional funding was provided from UK Treasury to support the payments I made to the bereaved or for the uplift I announced for the infected beneficiaries and this has all been financed from within the Northern Ireland budget at a time when the Department is facing a funding shortfall to maintain its existing services in addition to the need to respond to the COVID-19 pandemic.

4.4 On 1 March 2021, having considered the findings of the survey conducted in Autumn 2020, I announced annual financial support for non-infected bereaved spouses and partners on the Scheme in Northern Ireland [WITN5570017]. The payments are 75% of the rate the beneficiary's infected spouse or partner was in receipt of at the time of death, or would have been in receipt of had they applied to the Scheme. These payments, ranging from £14,079 to £33,561 per year, represent a Departmental funding commitment of around £400,000 annually and will be backdated to April 2020 and rise annually with inflation.

- 5. Please set out, in as much detail as you are able to, what the DH has done to alleviate the suffering of the infected and affected and in particular what psychological support it has made available for the infected and affected community during your time as Minister. In particular has any consideration been given and, if so, what to the need for specialist**

psychological support? If so, have any ring-fenced funds been allocated for such services, when, how much and to whom? If not, why not?

5.1 Having met with those infected and affected, the consistent message has been the need for continued access to specialist counselling and psychological support. The people I have met said they felt that they have had to battle their whole lives, both with their physical and mental health as well as for financial support. The recent survey of Scheme beneficiaries, conducted by my Department, has reinforced the message that the psychological service is a vital lifeline for many.

5.2 In March 2020, my officials provided me with a comprehensive briefing setting out the most common impacts of contaminated blood and blood products experienced by the victims. The briefing included an update on the report of the Infected Blood Inquiry Psychosocial Expert Group, led by Professor Weinman, which considered the psychosocial impacts of infection on people infected and affected and in particular the financial hardship experienced, with many dependent on financial assistance from Government schemes. The report confirmed what I had already heard directly from victims whom I had met and those who had written to me – that contaminated blood had significant negative consequences, both financially and in terms of mental health.

5.3 The briefing I received in March also included detailed testimonies from professionals who work with those infected and/or affected with contaminated blood in Northern Ireland, including a Consultant Hepatologist, Social Worker and Specialist Clinical Psychologist, who described in detail the emotional impact of contaminated blood, including the negative stigma, the fear of developing cirrhosis, the risk of cancer, the impact on relationships – not just with a spouse, but also children and parents of those infected - and even feelings of guilt due to Haemophilia being an inherited condition. I learned that the significant impact on the mental health and overall wellbeing of those infected and/or affected led to many people being prescribed anti-depressant and anxiety medication. In trying to manage their emotional pain, some individuals have used alcohol and other drugs to help them cope, which brought

with its own problems. Sadly, some have even reported feeling that life is not worth living.

5.4 I know that the high profile of this Inquiry and the huge media and political interest surrounding it has for many people meant having to relive painful memories which has been re-traumatising for many. Children, who are now adults and have a better understanding, have had to re-consider their experiences in a new light. Families have heard previously unknown details of their loved ones' medical history. Grief has resurfaced for families who have lost loved ones in the past.

5.5 In Northern Ireland, I can report that patients and families infected and/or affected by contaminated blood are able to access the services of a specialist psychologist at the NI Haemophilia Comprehensive Care Centre at Belfast City Hospital which is part of the Belfast Health and Social Care Trust ("the Trust"). My Department has committed to funding this service for three days per week for the duration of the Inquiry. The ring-fenced funding provided to the Trust to deliver the psychological service was £18,375 in 2018/19, £73,500 in 2019/20 and £55,125 in 2020/21.

5.6 During the ongoing COVID-19 pandemic, all patients who had engaged with the psychological support service have continued to receive support. In fact, new referrals have been accepted during the COVID-19 pandemic. Due to COVID-19 restrictions, face-to-face psychological support was paused for a short time from 17 March 2020, when all consultations were carried out by telephone. However, since June the Trust was able to offer virtual clinic appointments via Microsoft Teams. The Trust has recently been able to resume face-to face-sessions for those who would prefer this method, whilst following stringent infection control guidance and COVID regulations. These appointments are on the basis on clinical need and, where possible, personal preference. Overall, the Trust has reported that the service continues to be well received.

5.7 The survey that was recently conducted in Northern Ireland sought beneficiaries' views on psychological support provision and this will help to

inform decisions on shaping this service for the future. It is clear that the emotional suffering and mental anguish of those infected and/or affected will not end when the Inquiry publishes its report and I have asked officials to provide options on how best we can continue to provide, and if possible improve, the mental health support available for those who need it, beyond the lifetime of the Inquiry.

5.8 An independent Quality Review Service Report into the Belfast Haemophilia Centre, carried out in 2019 [WITN5570010], reported that the multi-disciplinary team working at the Belfast Haemophilia Centre was exemplary and noted in particular the contributions made by the social worker and psychologist, who was appointed to support patients and families with issues raised by the Infected Blood Inquiry.

5.9 The report found that the psychologist, currently working three days per week, was exclusively seeing patients and families affected by the Infected Blood Inquiry issues. The review team heard that it was intended that the psychologist would continue working in the Centre once the Inquiry was over, and it will be important to consider ways in which their work can become embedded in the service, with availability to see patients attending clinics. The psychology service is one of the priority areas that I will be considering as part of phase 2 of the ongoing review of the support provided for victims of contaminated blood in NI.

- 6. The Inquiry is aware that the hardship and suffering experienced by the infected and affected has been addressed in different ways by the four United Kingdom governments. Please explain:**
- a. What you understand those differences to be;**
 - b. Whether and if so on what basis, you consider these differences to be justified for the individuals concerned;**
 - c. What, if any, steps (and when) you and any Ministerial colleagues involved are planning to address these differences;**
 - d. If no steps are being planned, please explain the reasons for this.**

6.1 Within a matter of days of becoming Health Minister in January 2020, I was provided with briefing setting out the background to the financial support scheme and this included a detailed comparison of the four schemes across the UK, so I was aware at an early stage of the differences that existed.

6.2 Prior to November 2017, there were five financial support schemes operating from Alliance House London, providing financial support across the UK for people who had been infected with HIV and/or Hepatitis C as a result of receiving NHS-supplied blood or blood products, and for their families. However, since then, each UK country has had its own financial support scheme. Health policy and by extension the Infected Blood Payment Scheme are devolved matters and the schemes across the four UK countries have evolved to best meet the needs of their own beneficiaries.

6.3 In terms of background, in 2016 the then Health Minister and now deputy First Minister Michelle O'Neill, was provided with a paper by Health Protection Branch officials setting out the key features of the schemes in England, Scotland and Wales. She made the decision in December 2016 that the new scheme in Northern Ireland should be based on the England Infected Blood Payment Scheme ("EIBSS") model. Therefore in Northern Ireland, until April 2019 when EIBSS payments were uplifted, annual payments to infected beneficiaries were the same as those paid in England, in line with my predecessor's policy decision. Between January 2017 and my taking up post, 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 long term financial commitment.

6.4 Therefore, when changes were made to the EIBSS, such as the introduction of the Special Category Mechanism ("SCM") in September 2017 and the significant uplift in rates announced in April 2019, the

Department of Health in Northern Ireland was unable to replicate these changes.

6.5 However, since taking up post as Health Minister, I have been determined where possible to address these divergences. I have already set out the swift action I took to address the disparity in financial support to infected beneficiaries, within a matter of months of taking up office.

6.6 It is important to note that NDNA did not set out specific detail of what financial parity with England should include. Therefore, although regular payments are now aligned with England, other aspects of the Scheme are still to be reviewed and I hope to make further reform where possible, prioritising the areas where this is needed most.

6.7 As I have said, another area I am keen to address sooner rather than later is financial support provided to non-infected widows and widowers. I already made payments of £5,000 to non-infected bereaved beneficiaries in March 2020. Currently Northern Ireland and England provide the same model of support to non-infected bereaved beneficiaries. However, I am aware that in Scotland, annual payments are made to non-infected widows and widowers at 75% of the amount that their spouse would have been entitled to if they were alive (with 100% of the amount being paid for the first 12 months after the infected beneficiary's death). The Welsh Government also makes regular payments to spouses / partners of scheme beneficiaries for three years following death at 75% of the annual entitlement. An update is provided at paragraphs 6.16 and 6.17.

6.8 In terms of financial support to infected beneficiaries, I am aware that Northern Ireland is the only part of the UK that does not currently provide enhanced support for Hepatitis C stage 1 and this is one of the areas that I am keen to address. EIBSS introduced the special category mechanism (SCM) in September 2017 as a mechanism to permit those at hepatitis C stage 1 to qualify for the higher (stage 2) annual payments, if their infection is deemed to have a significantly detrimental impact on their quality of life.

Unfortunately, this new provision was introduced to EIBSS during the period when Northern Ireland was without a Health Minister and therefore no consultation in Northern Ireland was possible whilst the NI Executive was not in operation. An update is provided at paragraphs 6.16 and 6.17.

6.9 I know that Scotland and Wales have their own arrangements for enhanced support. In Scotland, Hepatitis C stage 1 beneficiaries are able to self-certify as either severely affected or moderately affected by Hep C, with different payment levels available within each category. Wales meanwhile have an 'Enhanced Hep C Stage 1+ Scheme' payment (equivalent to the Stage 2 payment) for those with Stage 1 Hepatitis C who are suffering from mental health symptoms related to their hepatitis C which have an effect on their ability to carry out day to day activities. There are also differences in the eligibility criteria for these enhanced payments.

6.10 As part of Phase 2 of the current Review of the NI Scheme, I have asked my officials to look at the pros and cons of each of the other UK models and to consider whether and how such financial provision could be included in the NI Scheme, subject to budget availability.

6.11 I know that Scotland offer one-off grants aimed at providing support to beneficiaries through contributing to the cost of essential items or services, while in Wales, beneficiaries can access numerous external grants depending on individual needs and personal circumstances. While grants are available in Northern Ireland, in the absence of a Minister, a policy was not agreed. While developing a model for discretionary support is one area for action being taken forward in Phase 2 of the review of the NI Scheme, in the meantime my officials will continue to use the EIBSS guidance to ensure consistency when assessing eligibility for grants. I am aware that there are also differences in Scotland as to how the one-off ex-gratia lump sum payments for Hepatitis C are paid to individuals when they first apply to the Scheme.

6.12 There are also differences across the UK in terms of provision of psychological / mental health support. I know that in Wales for example, a bespoke holistic service is available to individuals and their families and this includes a specialist psychological support team and advisors to support beneficiaries in other areas, such as benefits advice. As part of the NI review, I will be looking at options to ensure our much needed psychology service continues to be available beyond the lifetime of the Inquiry to support patients and their families.

6.13 I know that the Inquiry Chair has made clear he expects to see progress on achieving greater parity ahead of the conclusion of the Inquiry. Therefore, in addition to the Review being undertaken within my Department, there is ongoing engagement at an official level between the Health Departments in England, Scotland and Wales as well as the UK Cabinet Office (as the sponsor of the Infected Blood Inquiry), on how to achieve greater parity across all the schemes, while preserving the devolved status of health policy. I am aware that the Cabinet Office is planning to submit a bid to UK Treasury for funding to bring about greater parity of support across the UK Schemes and officials in my Department have contributed to a costings exercise to support this bid.

6.14 Briefing provided to me by my officials in June 2020 included a proposed timeline, provided by DHSC, for progressing work to achieve greater parity across the four nations and this included a proposed meeting of the UK Health Ministers in October 2020. This meeting has not yet taken place and my officials have asked Cabinet Office for an update on when it might be arranged, as I would welcome the opportunity to discuss this matter with my counterparts.

6.15 With regard to the question of whether I consider these differences to be justified for the individuals concerned, as Minister of Health in Northern Ireland I can only justify the actions I have taken and it would not be appropriate for me to comment on the policies of other Health Ministers in the UK.

6.16 On 25 March 2021, the Paymaster General Penny Mordaunt MP announced plans to bring the four UK schemes into broader parity and as a result I have agreed to make further changes to annual payments for bereaved spouses/partners, lump sum payments and a commitment to introduce enhanced financial support for Hepatitis C (Stage 1), at the same payment levels as in England, as soon as a system for assessment can be put into operation [WITN5570018].

6.17 The Paymaster General also announced on 25 March 2021 that an independent reviewer is to be appointed to carry out a study, looking at options for a framework for compensation, who will report back to the Paymaster General with recommendations, before the Infected Blood Inquiry reports.

Section 3: Clinical treatment of those infected

7. Please set out what the surveillance and treatment arrangements are in Northern Ireland for those infected with HCV via blood and blood products.

In particular, please address the following matters:

- a. The inquiry has received evidence, and the NICE Clinical Knowledge Summary confirms, that those infected with HCV should be under the care of a hepatologist or specialist gastroenterologist and should be offered integrated multidisciplinary care (including specialist nurse input). What if any steps has the DH taken to ensure that there are sufficient specialist multi-disciplinary teams to manage the care of people who were infected with HCV in consequence of treatment by the NHS with blood or blood products?
- b. The inquiry has received evidence from its group of experts in their report at page 35 [enclosed] that ‘ *For HCV the current treatment regimes are finite, highly effective at curing the virus and have few side effects; therefore all patients with chronic HCV*

who are well enough to receive treatment should be offered it. '

What if any steps has the DH taken to ensure that there are sufficient funds available to clinicians for such treatment to be offered to people who were infected with HCV in consequence of treatment by the NHS with blood or blood products?

- c. The Inquiry has received evidence from its group of experts that a person chronically infected with HCV who after treatment has successfully cleared the virus:**
- i. may be left with signs and symptoms of liver failure, and/or will have a long-term risk of developing hepatocellular carcinoma, oesophageal varices and, as a consequence, variceal haemorrhage; and**
 - ii. those with significant fibrosis or cirrhosis are likely to require lifelong surveillance for the risk of HCC, with ultrasound scans of the liver and +/- AFP (alpha-feto protein) blood tests every six months. What steps if any, has the DHS taken to ensure that these patients receive the recommended follow up after clearing the virus? If no steps have been taken, please explain why.**

7.1 I can advise that Northern Ireland has adopted relevant NICE guidance in relation to treatment of Hepatitis C patients. Most recently, in July 2020, my Department endorsed '*NICE Public Health Guideline PH43*', which covers raising awareness and aims to ensure that people at increased risk of hepatitis B and C infection are tested. This NICE guidance was issued to all relevant staff in Trusts and shared with all General Practitioners and Out of Hours services on 15 July 2020. Prior to this, in August 2013 the Department endorsed '*NICE Clinical Guideline CG165 - Hepatitis B (chronic): diagnosis and management for implementation within the HSC*'. In August 2016, the Department endorsed '*NICE Clinical Guideline NG50 - Cirrhosis in over 16s: assessment and management*'. It is the role of the Regional Health and Social Care Board ("HSCB") in Northern Ireland to oversee and

monitor implementation of NICE Guidelines and the HSCB is accountable to the Department of Health.

7.2 Information is available for the public on the Northern Ireland Hepatitis B & C Managed Clinical Network website at www.hepbandcni.net/content/hepatitis-c-clinical-guidelinesinformation.

7.3 In Northern Ireland, funding is not directly provided to clinicians for the treatment of patients for specific conditions. The HSCB is responsible for the commissioning of health and social care (HSC) services for the people of Northern Ireland and is accountable to the Department. HSC Trusts provide services in response to the Commissioning Plan and any significant performance issues would be brought to my attention.

7.4 I was pleased to see that an independent quality review **[WITN5570010]** into the services provided at the adult haemophilia comprehensive care centre in Belfast, carried out in 2019, showed that the highest quality provision of care was available at all times for patients and their families affected by congenital and acquired bleeding disorders. The Review reported that the service was driven by the dedicated multi-professional team, which strove to provide a safe, equitable and accessible service to all. The report found that the team provided a very good clinical service and exemplary multi-disciplinary team (MDT) who worked extremely well together in a mutually supportive way. Feedback to a patient survey demonstrated careful attention was given to families and carers and patients can access a 24/7 help line which was operated by a haematology nurse specialist.

7.5 My responses in paragraphs 8.1 and 8.6 – 8.9 below also cover surveillance and treatment arrangements in Northern Ireland for those infected with HCV via blood and blood products

Section 4: Identifying those who may be infected

- 8. What if any steps has the DH taken to identify those who may have been infected with HCV via blood or blood products, but who are unaware of their infection? In particular:**
- a. What steps have been taken to educate and inform members of the public who may have received blood or blood products before screening commenced in September 1991 that they may have been infected with HCV? If no such action has been taken please explain why, and what if any action is planned (and when) in the future.**
 - b. What steps have been taken to educate and inform clinicians whose patients received blood or blood products before screening commenced in September 1991 that they may have been infected with HCV, so that those patients can be advised to have an HCV test even if the patient has not experienced any symptoms? If no such action has been taken please explain why, and what if any action is planned (and when) in the future.**
 - c. What if any steps (including the provision of resources) have been taken to carry out a comprehensive look back exercise to identify all those who have received blood or blood products before screening commenced in September 1991 so as to invite them to have an HCV test? If no such action has been taken please explain why, and what if any plans there are to do so in the future.**

8.1 On 19 January 2021, my Department, along with the Public Health Agency (PHA), published a new action plan [WITN5570011] with the goal of eliminating hepatitis C in Northern Ireland by 2025, five years ahead of the World Health Organisation's 2030 target. The plan will provide professionals and service users with the information and support needed to drive improvements in the care of those at risk of, or with hepatitis C infection. I know that many people could be living with hepatitis C without a diagnosis, due to the infection often having no specific symptoms until

the liver has been significantly damaged. Through this Plan, we will strive to ensure people know that the condition can be cured and that anyone who has ever been at risk should get tested. A multi-agency hepatitis C elimination oversight group, chaired by the Chief Medical Officer (CMO), has been established to monitor progress and delivery on the targets set out within the plan. I am committed to making hepatitis C increasingly a disease of the past.

8.2 As I have advised, in July 2020 my Department endorsed 'NICE Public Health Guideline PH43', which covers raising awareness and aims to ensure that people at increased risk of hepatitis B and C infection are tested. This NICE guidance was issued to all relevant staff in Trusts and shared with all General Practitioners and Out of Hours services on 15 July 2020.

8.3 There is information available on Hepatitis C and the Infected Blood Payment Scheme on NI Direct. NI Direct is the official government website for people in Northern Ireland and brings together information from different government departments and agencies into one public-facing online portal. NI Direct advises of the risk of Hep C from the receipt of blood products prior to 1991 and includes a link to the Northern Ireland Hepatitis B & C Managed Clinical Network website, managed by the Belfast HSC Trust, which includes lots of information for both the public and professionals. The overall aim of the Network is to reduce the impact of hepatitis B and C on the population of Northern Ireland by improving knowledge of the diseases, increasing testing across the population and strengthening current services through improved joint working across disciplines. The Network is made up of representation from professionals across a wide range of areas including, acute services, primary care, drug and alcohol services, health promotion, and pharmacy.

8.4 I have not carried out a look back exercise to identify all those who had received blood or blood products before screening commenced in September 1991. However, I am aware that in April 1995 a lookback

exercise was announced by the Department of Health in London, the purpose of which was to trace, counsel, investigate and, if necessary, treat individuals who may have been infected with Hepatitis C through blood and blood products prior to screening. Northern Ireland participated in this exercise and a senior medical officer from the Department of Health in Northern Ireland was involved in a working group which led on that exercise. I have been advised that the outcome of this lookback exercise in NI was published in a medical journal [WITN5570012].

8.5 It is important to note that in April 1995, when the Department of Health in London announced a look back exercise to trace people who may have become infected with Hepatitis C prior to the introduction of screening, health policy was not devolved in Northern Ireland. Between 1948 and 1999, the health system of Northern Ireland was managed by the UK government via the Northern Ireland Office (NIO). In Northern Ireland, the NHS was merged with the broader social care system in 1973 and called the Health and Personal Social Service (HPSS) and later the Health and Social Care (HSC) system, rather than the NHS. This meant that, until 1999 when devolution was restored in Northern Ireland, public and social policy decisions were taken at Westminster and communicated through a secretary of state within the Northern Ireland Office, who answered directly to the UK Parliament. During the period of direct rule in Northern Ireland (1972 – 1999), the default position in terms of reform and the development of policy and strategy in health and social services was to mirror English policy decisions.

8.6 I have been advised by my officials that following devolution in Northern Ireland, in July 2004, the Department launched a consultation [WITN5570013] on an action plan for the prevention and control of hepatitis C in Northern Ireland, with the aim of reducing hepatitis C infection levels by ensuring those with hepatitis C had an opportunity to be identified and receive high quality treatment. The Department's '*Strategic Framework And Action Plan For The Prevention And Control Of Hepatitis C In Northern Ireland 2004-2007*' [WITN5570014] was

developed in the context of rising prevalence of hepatitis C, lack of public and professional information about hepatitis C and a recognition of the need for preventative action and clear clinical pathways for the management of patients. The priority areas for action were identified as raising awareness, establishing surveillance arrangements and improved testing.

8.7 The Department subsequently published, in January 2007, an *'Action Plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland'* [WITN5570015]. Through this plan, the Department aimed to achieve a reduction in the prevalence of hepatitis C in Northern Ireland through partnership working at all levels to ensure that people with hepatitis C infection were identified and received high quality, evidence-based, patient-focused treatment and care. The Plan noted that prior to 1991, when screening of blood donors was introduced, a number of those who received blood products were inadvertently infected with hepatitis C. The Action Plan stated that people with hepatitis C infection should be referred to a specialist service, led by a hepatologist or gastroenterologist with expertise in the area of hepatitis C diagnosis and management and that service would be best operated within a form of specialist Regional Hepatitis C Managed Clinical Network, which would be responsible for co-ordinating the overall management of hepatitis C patients and would ensure high quality surveillance arrangements were in place, as well as supporting the development and provision of education and training for GPs and other health care professionals about hepatitis C. I am aware that in 2004, additional funding allowed the Royal Hospitals Trust to begin to extend its clinical hepatology services, recruiting specialist nurses and later linking up with the Belfast City Hospital haematology Department

8.8 I am aware that in February 2019 the liver clinic in the Belfast HSC Trust commenced a re- engagement exercise to make contact with patients previously diagnosed with hepatitis c with whom they had lost contact, in order to offer tests and, where appropriate, treatment. Detail of

this is included in the 2020 report of the Northern Ireland Hepatitis B & C Managed Clinical Network [WITN5570016]. The Report noted that the challenge now is identifying those people not known to health services or who do not wish to engage, who may be unaware of their infection or the new treatments available.

Section 5: Other

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

In the absence of a NI Executive and Health Minister from January 2017 to January 2020, much of the work on developing our policies for supporting those infected and/or affected by contaminated blood was put on hold. Due to the substantial financial commitment that would be required to introduce any changes, along with the limited powers of the Permanent Secretary to introduce policy change, officials decided that to carry out a consultation would raise expectations when there was little scope for any significant improvement in financial provision. Since becoming NI Health Minister in January 2020, I have picked up where that work was left off. Significant progress was made in my first year as Northern Ireland Health Minister, despite responding in parallel to the very significant challenges of the COVID-19 pandemic, and I will continue to strive to improve the lives of those who have been impacted by infected blood.

Statement of Truth

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

Signed _____

GRO-C

 _____ Robin Swann MLA

Dated 20/04/21

Table of exhibits

Date	Notes/ Description	Exhibit number
8/1/20	New Decade, New Approach	WITN5570002
27/1/20	Press release: Infected Blood Payments Announced by Swann	WITN5570003
13/2/20	Note of meeting: Minister Swann and Infected Blood Groups	WITN5570004
23/3/20	Note of meeting: Minister Swann and Infected Blood Groups	WITN5570005
23/3/20	Press release: Health Minister announces additional Infected Blood Payments	WITN5570006
9/4/20	Letter from Minister to Chairs of Haemophilia NI, Families and Friends of Haemophilia NI and the Haemophilia Society	WITN5570007
30/8/20	Press release: Swann announces increased payments for infected blood	WITN5570008
30/6/20	NI Infected Blood Payment Scheme – survey questionnaire and foreword by Minister	WITN5570009
Dec '19	Quality Review Service: Care of People with Inherited and Acquired Haemophilia and other Bleeding Disorders	WITN5570010
19/1/21	Northern Ireland Hepatitis C Elimination Plan	WITN5570011
28/5/97	Article from 'Transfusion Medicine': Completed Hepatitis C Lookback in Northern Ireland – K Morris, C Bharucha	WITN5570012
1/7/04	Press release: Hepatitis C Action Plan Launched	WITN5570013
1/7/04	Strategic Framework and Action Plan for the Prevention and Control of Hepatitis C in Northern Ireland 2004-200	WITN5570014
Jan '07	'Action Plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland'	WITN5570015

2020	NI Regional Hepatitis B&C Managed Clinical Network Annual Report 2020	WITN5570016
1/3/21	Press release - Infected Blood: bereaved have not been forgotten - Swann	WITN5570017
25/3/21	Written ministerial statement – Infected Blood Financial Support	WITN5570018