Witness Name: Mairi Gougeon MSP
Statement No.: WITN5672001
Exhibits: WITN5672002-WITN5672005
Dated: 26 April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MAIRI GOUGEON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 November 2020.

I, Mairi Gougeon, 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 in the Scottish Government, relevant to the Inquiry's terms of reference.

1.1 My name is Mairi Gougeon. My address is St Andrew's House, Regent Road, Edinburgh, EH1 3DG. My date of birth is GRO-C 1985.

1.2 I have been Minister for Public Health and Sport since December 2020. Prior to that I was Minister for Rural Affairs and the Natural Environment from 2018 to 2020.

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

2.1 Sam Baker is the team leader responsible for advising me on most of the matters covered by the questions in this request and Joanna Swanson is the Interim Deputy Director with responsibility for infected blood policy and blood-borne viruses. In addition, on hepatitis c treatment (question 7), Erin McCreadie is the team leader responsible for advising on general blood-borne virus policy and Laura McGlynn is the unit head covering this area.

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 Scottish Government has done to alleviate the financial hardship of those infected by NHS blood and blood products ("the infected").**

3.1 The Scottish Government recognises the significant impact infection has had on many of those infected with hepatitis c (HCV) and/or HIV via infected blood, and that in many cases this has affected people financially where they have been unable to work (or work full-time) as a result.

3.2 The Scottish Government has sought to support those infected for many years, first through financial contributions to the Skipton Fund and Caxton Foundation and then through establishing the Scottish Infected Blood Support Scheme (SIBSS).

3.3 Following the Penrose Inquiry report in 2015, it was clear that there were a number of concerns that the existing financial support available through the five UK schemes was not sufficient for many of the infected. As a result, the Scottish Government (under the leadership of the then Cabinet Secretary for Health and Sport, Shona Robison MSP) asked the Financial Review Group to consider and make recommendations for future financial support **[WITN4508014]**. In March 2016, Ms Robison confirmed that the Scottish Government accepted the Group's recommendations for future financial support payment levels and would be implementing them.

3.4 The Scottish Government then worked with the Department for Health and Social Care (DHSC) and the Alliance House organisations to seek to make initial changes to the lump sum and annual payment levels during the 2016-2017 financial year via the Skipton Fund and MFET Ltd (the Macfarlane and Eileen Trust Ltd). While it took some time to agree changes to the schemes' agreements with DHSC, the Scottish Government was able to ensure with Alliance House staff that most beneficiaries' increased annual payments and lump sums were paid in December 2016 or January 2017, with the annual payments backdated to 1 April 2016.

3.5 The following increased payments were made to beneficiaries as a result:

- Those with advanced HCV (Stage 2) or HIV had their annual payment increased from £15,000 to £27,000 per year.
- Those who were coinfected (either Stage 1 or Stage 2) had their annual payment increased to £37,000 per year.
- Those with chronic HCV (Stage 1) were paid an additional £30,000 lump sum (or a £50,000 lump sum in the case of new applicants joining the Skipton Fund).
- Those who were coinfected at Stage 1 received an additional £50,000 lump sum.

3.6 In the meantime, the Scottish Government worked with NHS National Services Scotland (NSS) and the Alliance House organisations to set up the SIBSS and ensure it could be operational by 1 April 2017. Officials also worked with HM Revenue and

Customs, the Department for Work and Pensions and Scottish Government local government finance colleagues to ensure that regular payments from SIBSS were not subject to income tax and that SIBSS payments would not be taken into account in calculating beneficiaries' entitlements to means-tested benefits or the council tax reduction scheme.

3.7 Once established, SIBSS aimed to provide support, primarily through high levels of lump sums and annual payments to reduce the need for means-tested one-off grants. However, SIBSS also provided Support and Assistance grants, including an increased, non means-tested living costs supplement of £1000 per year for those beneficiaries not receiving annual payments as a more generous grant to replace the Alliance House winter fuel allowance (which was then £500 per year).

3.8 SIBSS also provided income top-up support to those who needed it. It offers one-off grants as well for goods or services which are needed by a beneficiary as a result of their infection, such as, for example, counselling (see question 5), home adaptations or mobility aids.

3.9 In 2017, the Scottish Government asked Professor David Goldberg of Health Protection Scotland to chair a clinical review of the impacts of chronic HCV in response to a recommendation of the Financial Review Group on considering financial support for those with chronic HCV (Stage 1) further. The Clinical Review Group involved a number of staff with relevant clinical expertise as well as stakeholders representing the infected and affected. The Clinical Review group reported in June 2018 **[GGCL0000168]**.

3.10 As a result, the Scottish Government adopted the group's recommended approach of asking beneficiaries with chronic HCV to self-assess whether they are severely affected by HCV, moderately affected or whether HCV has no impact on their day to day life. SIBSS paid the new annual payments to all those chronic HCV beneficiaries who applied in December 2018, backdated to September 2018 for those who submitted their application by early November 2018. Following this change, the great majority of SIBSS beneficiaries now receive regular annual payments and the need for income top-up support and one-off grant payments is now significantly reduced.

4. **Please set out, in as much detail as you are able to, what the Scottish Government 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").**

4.1 The Scottish Government brought forward the Patient Rights (Scotland) Act 2011, section 22 of which amended section 28 of the Smoking, Health and Social Care (Scotland) Act 2005 to ensure that payments could be made to the widows, widowers, civil partners or long-term cohabiting partners of those who were infected and had died. These payments were initially made via the Caxton Foundation and subsequently via SIBSS. The amendments also ensured that the Skipton Fund could make estate payments to relatives of those who had died prior to 29 August 2003 as it was recognised that the original bar to applications to the Skipton Fund from estates was unfair to the relatives of those who had died earlier.

4.2 When SIBSS was established, as a result of the Financial Review Group's recommendations, it made available new annual payments to the widows, widowers and civil partners of those who had died. On 7 September 2017 an amending scheme document was published to make adjustments to the original Scottish Infected Blood Support Scheme 2017 by including long-term cohabiting partners as also eligible for these payments.

4.3 The payments provide for most widows, widowers, civil partners and long-term cohabiting partners to receive 100% of the annual payment their spouse or partner would have been entitled to if they were alive for the first twelve months after their death. At that point, they are from then on entitled to payments at 75% of the level their spouse or partner would have been receiving if they were alive[1].

4.4 Initially these payments were for those whose spouse or partner had advanced HCV, HIV or was coinfected. In addition, where there was evidence that a person's spouse or partner had had chronic HCV, but had died as a result of their HCV or HCV treatment, they are also entitled to receive annual payments as if their spouse or partner had advanced HCV. Following the recommendations of the Clinical Review group, annual payments were also made available to those widows, widowers, civil partners or long-term cohabiting partners of those with chronic HCV who had died where they assessed that their spouse or partner was either severely or moderately affected by their HCV in the last few years before they died.

4.5 In addition, the Scottish Government also agreed that spouses and partners of those with chronic HCV who had not received the £30,000 additional lump sum prior to their death (which was those who had died prior to April 2016) should receive this £30,000 lump sum as well, as a grant.

4.6 Widows, widowers, civil partners and long-term cohabiting partners of the deceased, along with dependent children under 21 years old who are in full-time education, are also able to apply for one-off grants from SIBSS if they wish, for example for support with funeral costs or to help pay for education or training in order to help them move into a new career or different role following their parent, spouse or partner's death.

5. **Please set out, in as much detail as you are able to, what the Scottish Government 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. 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?**

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[1] Note – this applies to all categories except those whose spouse or partner had chronic HCV, but died as a result of either their HCV or HCV treatment, as they receive payments at the same level as those whose spouse or partner had either HIV or advanced HCV in each year following the year of their spouse's death. See Schedule 1, paragraph 4, in the Scottish Infected Blood Support Scheme 2017 (as amended).

5.1 In addition to psychological and other mental health services available via NHS Scotland, the Scottish Government and NHS National Services Scotland's National Services Division (NSD) jointly fund the Psychological Support Service for Inherited Bleeding Disorders, which has been managed by NHS Lothian since 2015-16. This provides psychological and psychiatric support to patients with bleeding disorders and/or their family members. Initially the support focussed on patients living in the NHS Lothian area as a pilot service, but it subsequently became available to patients across Scotland, both via in person appointments in all five Scottish haemophilia centres or via online or telephone consultations. The Scottish Government has provided annual funding for the service since 2015-16 and provided £53,001 to NHS Lothian for this service in 2020-21.

5.2 The Scottish Government recognised that patients infected via blood transfusions or tissue transplants or their families may also need psychological or other mental health support. Therefore, when SIBSS was established in 2017 it made available one-off grants for those who wished to access counselling or psychological support. We have since worked with NSS to make sure these grants are publicised via the SIBSS newsletter and that they are not means tested. In addition, we agreed with NSS that the suggestion in the scheme guidance that beneficiaries should only seek these grants where they could not, or were facing long waits to, access support via the NHS should be dropped in order to make it easier for beneficiaries to access the grants. There are no ring fenced funds for this within the SIBSS budget as the level of funding provided by SIBSS is demand-led and depends on the number of grant applications from beneficiaries.

5.3 Following, Sir Brian Langstaff's comments in February 2020 regarding putting in place dedicated psychological support for all those infected and affected, the Scottish Government worked with NSS to seek feedback from beneficiaries via the 2020 SIBSS member survey **[WITN4728013]**. Of those who indicated that they were not currently receiving any form of mental health support, 11% indicated that they and/or a family member(s) would want to access some form of support, while a further 21% were unsure[2]. Following these responses, officials sought more detailed feedback via the September SIBSS newsletter where we asked those who might be interested in accessing the service for views for example on whether they preferred in person appointments or telephone or online appointments and whether they were willing to use a service provided by the NHS.

5.4 As a result, NHS Lothian has worked with us to develop proposals for a new service for those infected and affected by infected blood and I have recently approved the funding for this [see **WITN5672002]**. This service is seeking to recruit at the moment and will hopefully be up and running this spring. It will be separate from, but work closely with, the service for patients with bleeding disorders. It will be based at the Astley Ainslie Hospital in Edinburgh, but also be available to patients across Scotland, offering a mixture of in person and telephone or video consultations depending on the preferences of the patient. NHS Lothian will seek support from other NHS Boards with providing appropriate venues for in person appointments; these are expected to be within general psychology service locations where possible.

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[2] See 2020-sibss-survey-report-final-for-publishing.pdf (nhsnss.org)

5.5 NHS Lothian has estimated that the cost of the service for the first year of operation will be £78,421. We will monitor progress with NHS Lothian to ensure the service is meeting the needs of those who are infected or affected and will work with SIBSS, the Scottish Infected Blood Forum and others to seek to raise awareness of the new service.

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 Each UK nation has used its own approaches in consultation with stakeholders to determine priorities in addressing the hardship and suffering experienced. This has led to differing approaches, although all four nations largely seek to build on the original support previously available from the Alliance House organisations. The Scottish Government has based its own approach on advice from the Financial Review Group and the Clinical Review of the Impacts of Chronic Hepatitis C to determine its priorities.

6.2 The Inquiry will have details of each scheme and so can examine the differences between them, but in general terms SIBSS currently offers significantly more generous long-term support to widows, widowers, civil partners and long-term cohabiting partners of those who have died than the other schemes in the UK. It also offers significantly more generous lump sums than the other three schemes to those with chronic HCV (Stage 1) and their widows, widowers, civil partners or long-term cohabiting partners if they have died, as well as to those who are coinfected who were previously categorised by the Skipton Fund as being at Stage 1.

6.3 In relation to regular payments for the infected, while SIBSS previously offered higher levels of annual payments, the English Infected Blood Support Scheme has, since April 2019, offered higher payment levels than SIBSS, particularly for those with chronic HCV where either HCV has no noticeable impact on their day to day life or where they are moderately affected by HCV, but also for those who are severely affected.

6.4 As the Inquiry is aware, the Scottish and Welsh schemes take a different approach in terms of generally permitting beneficiaries with chronic HCV to self-assess the extent of impact HCV has on them, whereas the English scheme requires assessment by a medical professional and the Northern Irish scheme does not currently have a means of differentiating support among those in the Stage 1 (chronic HCV) group. Under SIBSS, based on the Clinical Review recommendations, beneficiaries can self-assess in one of three categories (severely affected, moderately affected or where HCV has no noticeable impact on their day to day life), but the English and Welsh schemes only have two categories, with their special category mechanism being similar (but not identical) to the SIBSS severely affected category.

6.5 The Scottish Government recognises that it can be frustrating for beneficiaries in each scheme where they see that another scheme is providing more generous payment levels; that applies equally within the UK as it does when beneficiaries compare support with that provided in other countries outside the UK. While the Scottish Government believes it is beneficial to have some consistency in the support between the four nations, we believe any changes to SIBSS should be based on evidence of need and not simply to match what other UK nations are doing. Where there is good practice identified in other schemes we would seek to adopt that where possible.

6.6 The natural consequence of devolution is that there will often be differences in relation to support offered in different nations in many areas, based on stakeholders' priorities in that nation. We feel that the current support provided by SIBSS is appropriate in seeking to avoid financial hardship for beneficiaries and meets the spirit of the recommendations of both the Financial Review Group and the Clinical Review of the impacts of chronic hepatitis c.

6.7 The Scottish Government has been engaged in discussions with the other three nations' government Health Departments and the Cabinet Office about ways to increase parity of support between the four UK schemes. As part of that, the Scottish Government has submitted costings for the Cabinet Office to send to Her Majesty's Treasury to seek additional funding to enable greater parity of financial support to be provided across the UK. We are still waiting for a response from HM Treasury on this matter and are therefore not proposing any additional funding for SIBSS at this point, other than the annual CPI increase which will be applied in April and funded by the Scottish Government.

6.8 If HM Treasury is able to provide additional funding, we are keen to discuss – at both official and Ministerial level – with the other three nations how best to allocate that funding to help increase parity. Any discussions on allocation of funding would also have to be discussed with Scottish stakeholders, such as Haemophilia Scotland and the Scottish Infected Blood Forum, to ensure correct prioritisation of any additional funding.

<u>April 2021 update:</u>

6.9 Following further discussions between the four nations' governments, the Paymaster General announced[3] on 25 March 2021 that the UK Government would provide funding to enable broad parity of annual and lump sum payments between the four infected blood support schemes and that the increased annual payments would be backdated to April 2019. As this announcement was made after the start of the pre-election period in Scotland, the Scottish Government was not able to comment on the announcement in detail. However, an indicative statement was provided on the Scottish Government's infected blood webpage to give SIBSS beneficiaries some information on the changes the Scottish Government expects to be making to funding

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[3] See https://questions-statements.parliament.uk/written-statements/detail/2021-03-25/hcws895

levels[4]. This information was also included by SIBSS in a newsletter for beneficiaries **[WITN5672005]**.

6.10 In line with the guidance for the Scottish Government on the Scottish Parliament election on 6 May 2021, I am not in a position to make decisions during the pre-election period on matters of policy on which the next administration might wish to take a different view (except where there are significant reasons why a decision cannot be delayed). Therefore, while most key areas of change were agreed in advance of the pre-election period starting and are set out in the statement referred to above on the Scottish Government website, there are some issues which may require further discussion with stakeholders and those would need to be considered by whoever is the responsible Minister after the election. This includes, for example, the level of payments for those who have self-assessed that their life is not noticeably affected on a day to day basis by hepatitis c.

6.11 In addition, the Scottish Government is still seeking clarity from the UK Government on the level and timing of funding being provided and whether the UK Government will continue to provide this additional financial support from 2022-23 onwards. Therefore officials are working with lawyers and SIBSS staff to prepare for the changes and allow beneficiaries to receive additional money as soon as possible, but some points will need to be considered and agreed with Ministers after the election.

Section 3: Clinical treatment of those infected

7. **Please set out what the surveillance and treatment arrangements are in Scotland 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 Scottish Intercollegiate Guidelines Network No 133 'Management of Hepatitis, A National Clinical Guideline 2013' confirms, that those infected with HCV should be referred for specialist care. What if any steps has the Scottish Government 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?

7.1 Individual Health Boards independently plan and deliver healthcare services to ensure that they are able to most effectively meet the needs of their local populations. HCV treatment is therefore developed and provided by territorial NHS Boards, and each can decide how to deliver this.

7.2 Notwithstanding this, the Scottish Health Protection Network (SHPN) Viral Hepatitis Clinical Leads and Managed Care Network (MCN) Coordinators Network, chaired by Professor John Dillon, provides oversight of NHS Boards' HCV treatment services. The Network has representation from all NHS Territorial Boards and is accountable to and advises the SHPN Strategic Leads and the Scottish

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[4] See https://www.gov.scot/publications/scottish-infected-blood-support-scheme---payment-changes-statement/

Government. I have sought reassurance from the Chair of the Viral Hepatitis Clinical Leads and MCN Coordinators Network on the provision of services. The assessment is that there is capacity to treat patients with HCV. In Scotland, all patients have access to HCV treatment irrespective of the stage of disease or route of infection. We are unaware of any patients infected with HCV through blood and blood products that are unable to access treatment, and if there were any concerns raised about patients being unable to access treatment this would be acted upon. All SMC-licensed therapies are available, depending on individual patient needs, with consideration made to previous treatment history and liver function. These treatments cure at least 95% of those treated for HCV infection, with the small number failing treatment becoming eligible for second line treatments that cure more than 90% of patients.

7.3 The Scottish Government remains committed to supporting all those in Scotland with HCV, regardless of its origin, and to eliminating it by 2024. My officials and I will therefore continue to engage closely with relevant clinical expertise to ensure that appropriate treatment exists for all HCV patients.

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 Scottish Government 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?

7.4 As set out above, HCV treatment is provided by territorial NHS Boards in Scotland, using funding from the core grant they each receive from the Scottish Government. It is the responsibility of these Boards to deliver healthcare services in line with the needs of their population. However, the Scottish Government engages closely with clinicians, particularly the Strategic and HCV Leads, to understand existing service provision and keep under review performance against treatment targets.

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 Scottish Government taken to ensure that these

patients receive the recommended follow up after clearing the virus? If no steps have been taken, please explain why.

7.5 To answer this question as fully as possible, I have sought advice from the Chair of the Viral Hepatitis Clinical Leads Group, Professor John Dillon.

7.6 With this input, I can confirm that, once a patient has cleared the virus, the need for follow-up depends on the degree of liver damage present. The clinical advice is that, following clearance of the virus, there is unlikely to be progression of HCV-related damage.

7.7 All patients undergoing HCV therapy and assessment are staged for the degree of fibrosis they have. There are those with no evidence of fibrosis and there are those with severe fibrosis or cirrhosis, and there is another grouping where they have signs of mild or moderate fibrosis. This last grouping is associated with no significant clinical pathology or adverse outcome and are not followed up. The levels and definitions of these grades of fibrosis have previously been developed for SIGN guidelines for hepatitis C for a specific Scottish audience.

7.8 Patients who have signs of significant liver fibrosis or cirrhosis are followed up long term. In individual areas in Scotland, this follow-up may be by the Hepatitis C team, if they are also the Liver team.

7.9 In other areas of Scotland where the hepatitis C treatment is being delivered by Infectious Disease services, the care of the patient will be transferred to the Liver services, which are responsible for the follow-up of long-term cirrhosis patients. This transfer should be seamless as the care of hepatitis C patients across Scotland is integrated through the multidisciplinary teams and the managed care networks.

7.10 The follow-up for these patients is based on the cirrhosis, not on their previous hepatitis C infection, and is the same as it is for all patients with cirrhosis irrespective of the aetiology of the liver disease. The follow-up would be 6 monthly ultrasounds and alpha fetoprotein checks to look for the development of hepatocellular carcinoma, and 3 yearly endoscopy until the development of varices. This would be organised through NHS Liver clinics which are available in every health board in Scotland, although in some health boards where there are small numbers these clinics may be listed as Gastroenterology clinics. It is also possible that in localities this follow-up may be provided by Haematology services or Infectious Diseases services; as long as they follow the national and international guidelines, there is no issue with this labelling of the clinics.

7.11 The diagnosis of cirrhosis can be made by a number of modalities. Liver biopsy is considered the gold standard, but I am advised that this is erroneous in a number of cases, and many of the other less invasive ways of making a diagnosis of cirrhosis have defined areas of uncertainty. Therefore the term has arisen of severe fibrosis and cirrhosis being grouped together. Cut off values for the various tests that are used to stage liver disease normally set a value that would include almost all patients with cirrhosis and a number of patients who are not yet cirrhotic, but have severe fibrosis because they cannot be clearly differentiated from the cirrhotic patients and they are clearly at higher risk of progressing to cirrhosis over time. Currently in Scotland all of those patients grouped by these non-invasive measures of fibrosis, for instance fibroscan, ARFI, ELF, FIB-4, APRI and many more, will be followed up as if they have cirrhosis.

7.12 Cirrhosis is a common condition affecting around 3% of the Scottish population, of whom about half have been diagnosed. At its height, hepatitis C only infected 0.7% of the population with active chronic infection, and approximately 10% of these patients have progressed to cirrhosis. Of that grouping, a large number have sadly already passed away, for example as a result of their cirrhosis or natural causes due to their advancing age. The number of patients with hepatitis C-induced cirrhosis requiring follow-up is therefore a small proportion of the total number of patients that are being dealt with by the multi-disciplinary teams.

7.13 My advice from Professor Dillon is that there is sufficient capacity to support these patients, who are likely to be non-progressive unless they have other comorbidities that are damaging their liver. The follow up protocols are relatively simple and straightforward, and referral criteria for transplantation should any complications including a Hepatoma be discovered during follow-up are equally straightforward.

Section 4: Identifying those who may be infected

8. **What if any steps has the Scottish Government 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.**

8.1 As noted in Sam Baker's statement of November 2020, 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.

8.2 380,000 leaflets and 7,500 posters were distributed to the following venues across Scotland: GP practices, pharmacies, Health Boards/hospitals, Care Homes, Citizens Advice Bureaux, dentists, leisure centres, libraries, community centres and out of hours centres. The venues were encouraged to display the posters and make the leaflets available. The materials encouraged anyone who had had or may have had a blood transfusion before September 1991 to get tested for HCV. People who felt that they may have been affected by this were encouraged to speak to their GP practice, visit the NHS inform website, where additional information about HCV and the risks from blood transfusions was provided, or contact the Hepatitis helpline, managed by Hepatitis Scotland.

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.

8.3 The then Chief Medical Officer issued a CMO letter on 20 September 2016 to remind medical practitioners to consider the possibility of HCV infection among any patients who may have received a blood transfusion or blood products in the past **[WITN0713018]**. This letter followed a previous letter on the subject issued immediately after the Penrose Inquiry Report was published **[WITN5672003]**.

8.4 In addition, prior to this, in 2009, within the context of the Scottish Government's Hepatitis C Action Plan, the then Chief Medical Officer sent a letter to GPs outlining the at-risk groups (including those who had received blood transfusions) who should be offered an HCV test **[WITN5672004]**.

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.

8.5 The Scottish National Blood Transfusion Service (SNBTS) has previously carried out a look back exercise. Details of this are provided in Chapter 35 of the Penrose Inquiry Report so I would refer you to that **[PRSE0005299]**. The Inquiry should already have a copy of all the relevant evidence supplied to the Penrose Inquiry by both the Scottish Government and SNBTS in relation to this matter, but officials would be happy to supply this if not.

8.6 In summary, where a blood donor tested positive, SNBTS would (and still would if a historic donor returned) look-back to see who had received the blood in the past if they had donated previously, trace them and offer counselling.

8.7 In the South East Scotland Blood Transfusion Service, look-back was initiated as soon as testing commenced for HCV in 1991, and the results of this pilot study were published in 1994. This established the feasibility and effectiveness of the process, and led to the adoption of systematic look-back as UK wide policy in 1995. In Scotland, when the outcome of look-back was reviewed by the Scottish Home and Health Department in 1998, the total number of patients whose HCV status was discovered through the look-back process was 133[5]. (Haemophiliacs, renal unit patients and bone marrow transplant recipients had been already screened routinely and were therefore excluded from the final results.)

8.8 In 2016, the short-life working group set up to consider the Penrose Inquiry Report recommendation considered whether any further look-back exercise was feasible or appropriate. Their findings are covered in the group's report[6], but in summary the group considered that it was not practical and would not be effective to seek to test all historic samples of blood pre-1991 for HCV given both issues with the quality of the samples after several decades of storage and the scale of the task. Therefore further testing of the samples was not recommended.

Section 5: Other

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

9.1 I have no further information to provide at this stage, although am happy to answer any further questions the Inquiry has.

Statement of Truth

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

Signed: **GRO-C**

Dated: 26.04.2021

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[5] See Table 3.8 at paragraph 3.98 in the Penrose Inquiry Report for details

[6] See paragraph 6.5.1 and Appendix 4 at The Penrose Inquiry recommendation - gov.scot (www.gov.scot)

Table of exhibits:

Date	**Notes/ Description**	**Exhibit number**
2015	Report of the Financial Review Group	WITN4508014
May 2018	Report of the Clinical Review on the Impacts of Chronic Hepatitis C	GGCL0000168
December 2020	Proposals for a Contaminated Blood Psychological Support Service	WITN5672002
2020	SIBSS Customer Survey 2020	WITN4728013
September 2016	CMO Letterhead September 2016	WITN5672003
March 2015	CMO Letterhead March 2015	WITN0713017
January 2009	Hepatitis C Testing and Diagnosis	WITN5672004
August 2016	Penrose Inquiry Recommendations	PRSE0005299
April 2021	SIBSS Newsletter Issue 7	WITN5672005