Witness Name: Professor John Dillon
Statement No.: WITN4062003
Exhibits: WITN4062004
Dated: 11th October 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PROFESSOR JOHN DILLON

I provide this statement in response to the request under Rule 9 of the Inquiry Rules 2006 dated 8 September 2022.

I, John Dillon, will say as follows: -

Section 1: HCV elimination programme

1. **Please describe the Scottish Government's Hepatitis C Elimination Programme and how it works.**

1.1 The Scottish Government's elimination strategy is to set a treatment target within Scotland that will achieve elimination. The Scottish Government has defined this as less than 5000 people within Scotland infected with hepatitis C by 2024. The strategy consists of treatment numbers and targets specified by the government for individual health boards. It is up to the individual health boards to deliver this number of patients into treatment, using pathways of diagnosis and treatment as they see fit. The government has set treatment targets for each health board from the very outset of the hepatitis C action plan and this move towards elimination simply increases these targets to achieve elimination by 2024, based on estimates of prevalence from Public Health Scotland. The setting of these targets was to be performed by Public Health Scotland but the team working on developing these targets have been diverted to COVID related activities and so these numbers have not been produced since 2019. The actual programme for delivering treatment and care is to be decided at health board level and individualised to the particular challenges and needs of the health boards. Those health boards with large urban areas will have a larger problem with hepatitis C than those more remote and rural health boards due to the changing prevalence of underlying risk factors.

2. Please outline the steps taken to identify people infected with HCV through blood and blood products via the Elimination Programme.

2.1 There are no specific steps within the elimination programme, as I have outlined above, for the identification of patients infected with HCV through blood and blood products. The possible avenues to specifically target this risk group have been covered by previous look back exercises, routine testing of risk groups and the recommendations of the Penrose Inquiry.

2.2 **In so far as you are able to, please could you outline the main lessons learnt from the experience of identifying individuals? In particular for people who received blood transfusions and people with mild bleeding disorders who may not be in regular contact with clinics?**

2.3 During elimination planning it was felt that existing pathways for diagnosis and treatment of HCV in those infected via blood and blood products should be maintained. The accumulated learning was that no additional measures were going to be helpful, in finding the very small number of remaining possibly infected people".

3. Please set out your view as to how successful the elimination programme has been in identifying those infected with hepatitis C through blood and blood products.

3.1 As stated above, the elimination programme is not focused on this group, the vast majority of the estimated numbers of patients infected having already been identified. The awareness raising that went with the elimination programme both professionally and within the communities may have an impact in improving this somewhat, but there is currently no data available from Public Health Scotland.

4. Please set out what services including testing and treatment, are offered to those identified via the elimination programme. What is the uptake of these services?

4.1 All patients identified with hepatitis C are offered therapy for it. These services remain available in all health boards in Scotland. There was some delay to initiation of therapy during the COVID pandemic as treatment teams were redeployed to Covid front line work. This was paralleled with a reduction in diagnostic activity, but these services continue to function. Prior to the pandemic there were approximately 2,500 patients entering treatment for their hepatitis C and in the past 12 months we have reached those levels of treatment again but are not reaching the levels of therapy required to move towards elimination by 2024.

5. **Please set out any barriers there are to identifying those infected with hepatitis C via blood and blood products through the elimination programme.**

5.1 As described above, there are no specific features of the elimination strategy from the Scottish Government other than an increase in capacity and the services offered by individual health boards. The barriers to identifying those infected with hepatitis C via blood and blood products remain the same as they were before. Those patients in whom there are records of blood transfusion or blood product infusions from infected donors have been approached for testing and largely tested and those that are positive have been treated. The populations who are in ongoing contact with services for the same problem have been offered testing.

5.2 The barrier remains for those patients for whom there are no records of their blood transfusions and the individual patient is unaware of having had a blood transfusion or of the risks associated with this. In the Scottish elimination strategy, there are no specific diagnosis or treatment actions for those infected via blood and blood products, those having largely been performed and completed through Haemophilia services and blood transfusion look back exercises some years ago and there is the ongoing recommendations from the Penrose Inquiry to offer BBV testing to all those who have had previous blood transfusions prior to 1991.

6. **Please set out your view as to additional steps that could be taken to identify people infected through blood and blood products. For example, would it increase the prospect of identifying such patients, if GPs were paid to carry out a look back on their patients' records?**

6.1 There have been various attempts at reviewing patient records within General Practice for recording of blood transfusion. Current guidelines recommend the recording of blood transfusions in discharge communications with General Practices; however this recording is suboptimal currently and in the timeframe that the inquiry is interested in, it was not required and would have been worse still. So for many patients there will be no record in the GP Practice of any blood transfusion performed in hospital. Where such a record existed, it would have been paper based and in the transfer to electronic records more of that information would have been lost. Given the previous activity in finding those patients who may have been infected, the residual number to be found would appear to be very small even at the highest end of the range given for the possible size of the problem in the United Kingdom, so I believe it to be unlikely that manual searches of GP records would disclose many patients who were infected with hepatitis C but it would be hugely costly both in terms of scarce GP resource and finance. The number of patients undiagnosed with HCV across the UK may be small, with almost all of those infected with blood products diagnosed, and a substantial proportion of those with transfusion related infection having been diagnosed.

Section 2: Ongoing Liver Care

7. **In the statement you provided to the Inquiry WITN4062001 you set out a summary of the monitoring and follow up patients with cirrhosis should receive. As to this:**

    a. **Please provide the Inquiry with the relevant national and International guidelines mentioned in your statement, upon which this summary is based.**

       I attach the document EASL guidelines (WITN4062004)

    b. **Is there any update to the information that you provided to the Inquiry on this issue?**

       No.

8. **In your previous statement WITN4062001 you said there was no waiting list for treatment for HCV. Does this remain the case?**

8.1 Yes, there is no waiting list.

Section 3: Palliative Care

9. The inquiry has received evidence (both written (EXPG0000043) and oral (INQY1000190) from a group of experts in palliative care in advanced liver disease. One of the issues raised by the group was the variable access to both palliative and end-of-life care for those with advanced liver disease. What if any plans are there in place to tackle this inequality?

9.1 There are no national plans in place to tackle this inequality. Currently national professional societies are formulating the standards of care to be expected for such patients. This is a work in progress, being led by professional societies. Once such standards are developed implementation will be via local bids for funding services, unless there is a directive government policy.

10. Please outline any plans as to how the palliative care system (particularly for those with advanced liver disease) might be improved in Scotland.

10.1 Currently there are no plans but specialist interest groups within the professional societies are working on such plans, to be presented for consideration of funding by various NHS bodies.

11. Please provide any comment you consider relevant to the Inquiries Terms of Reference arising from the evidence from the expert group.

11.1 The expert group, on the whole, was talking generically about the management of end-of-life care for patients with advanced liver disease across all causes rather than confined to hepatitis viruses which is the particular remit of this inquiry. Therefore, those comments primarily focused on patients who did not have curable liver disease.

11.2 In the particular case of hepatitis C and hepatitis B, hepatitis C can be cured and hepatitis B can be controlled and once this is achieved there is stabilisation of any liver disease and often considerable improvement. So even patients who have liver failure secondary to viral hepatitis may well with cure or control of their disease regress to a state where they are no longer in liver failure and that will be the outcome for the majority. For the minority who do not achieve this, then they would be considered for liver transplantation. For the minority of those who are considered unsuitable for liver transplantation, usually because of coexistent cardiovascular or respiratory disease that make the procedure of transplantation too risky, that would be the group that would benefit from palliative care and so the viral hepatitis contribution to the group of patients needing palliative care is very small. The additional group for consideration of palliative care is those patients who develop hepatocellular carcinoma. Again, this is treatable for many patients. If it presents at a stage where it cannot be cured or comorbid conditions prevent curative treatment, this group would benefit from palliative care. In the context of chronic viral hepatitis, even with the cure of the hepatitis C or control of hepatitis B, for those patients with significant scarring or fibrosis there is an ongoing risk of development of hepatocellular carcinoma who might then benefit from palliative care provision but this provision would be generic to patients with liver failure or hepatocellular carcinoma and not different between the different aetiologies.

Section 4: Patient Advocacy

12. Under what circumstances are patient advocates available for people with complex health - conditions, such as advanced liver disease consequent to the use of infected blood and blood products?

12.1 I am not aware of the provision of such advocates by the health service. On the few occasions where I have managed a patient who had an advocate, the patient or their relatives had sourced this advocate from third sector organisations.

Statement of Truth

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

Signed **GRO-C**

Dated 11th October 2022

Table of exhibits:

Date	Notes/ Description	Exhibit number

2020	EASL guidelines	WITN4062004