Witness Name: Dan Farthing

Statement No.: WITN4081001

Exhibits: WITN4081002 – WITN4081032

Dated: 28th April 2021

INFECTED BLOOD INQUIRY

EXHIBIT WITN4081016

HAEMOPHILIA SCOTLAND

4th Floor, Hayweight House, 23 Lauriston Street, Edinburgh. EH3 9DQ
T. 0131 524 7286 hello@ GRO-C

Shona Robison MSP
Cabinet Secretary for Health, Wellbeing, and Sport
St. Andrew's House
Regent Road
Edinburgh
EH1 3DG

15 Sept 2015

Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill – Duty of Candour

Dear Shona,

As you know, Haemophilia Scotland are anxious that, despite the lack of recommendations in the Penrose Report, all practical steps are taken to learn the lessons from the contaminated blood disaster. I therefore write to you personally to draw attention to the particular significance of candour, or lack of it, to those of us, infected by Hepatitis C and or HIV.

With this in mind we have been looking the Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill currently before the Scottish Parliament. In particular, we are interested in the potential of the new Duty of Candour for ensuring that the poor communications between clinicians and patients which was revealed by the Penrose Report are never repeated.

I am therefore writing, both as Chair of Haemophilia Scotland, but also having personally having had a less than full picture from clinicians and the relevant Health Board, to put some specific concerns we have about the duty not going far enough.

While many patients welcomed the formal apologies you and the First Minister gave on March 26th, others reflected a view which was summed up by one patient in the statement "Why should Nicola and Shona be apologising for something, before their time, that Professor X was responsible for and never told us properly about?"

In relation to the "responsible individual", it isn't clear to us who that would have been in the contaminated blood products part of the disaster. The Bill's definition (25: Interpretation of Part 2) specifically excludes "individuals" (b, d, and f). However, from the perspective of people with bleeding disorders affected by the contaminated blood disaster, the relevant information and decisions would have rested with their Haemophilia Centre; often personified by the Haemophilia Centre Director. It is questionable whether any apology or explanation from any representative of NHS Scotland or a regional health board not directly involved in the provision of care would carry any weight.

In this situation it would be clear to patients that they were dealing with an intermediary. This would have an extremely damaging effect on the credibility of any undertakings to learn lessons.

HAEMOPHILIA SCOTLAND

In the Explanatory Notes, which accompany the Bill, (Part 2. Section 22 – Duty of Candour Procedure. 88) the "responsible person" is further defined.

"Individuals providing health, care, or social work services are not to be included in the "responsible persons" definition."

We are concerned that by these provisions the excellent intent of this legislation could be fatally undermined. To have the desired impact those involved in a sub-section 2 incident must be involved in the Duty of Candour process. Many of us damaged by the infection disaster believe that a culture of defensiveness, and even cover up, remains even now within the medical profession, rather than using the opportunity of contentious decisions on their part to embrace reflectiveness and learning.

In particular,

- For an apology to be meaningful it must come from someone involved in the incident.
- For patient to perceive any details about an incident to be reliable then they must come from those involved in the incident. Patients must be able to challenge these details where they are incorrect. This is particularly important in relation to 22(2) c & d of the Bill. Having a meeting without those involved in the incident present is unlikely to be perceived by patient as open, transparent, and candid. Especially in the cases of people with long-term conditions an opportunity would be lost to repair damage to the patient / healthcare professional relationship. These relationships can last for many decades are crucial for the delivery of high quality care.

If those involved in an incident are not involved in these processes then how can patients have confidence that any learning, change in procedure, or other actions will actually happen? This will be particularly true when they relate to incidents where existing procedure haven't been followed or where cultural change is required.

I am anxious to know if our understanding of the Bill is correct and, if it is, we would like to ask you to strengthen the definition of "responsible person" to include those who were involved in any section 2 incidents.

As you will fully appreciate, the lessons from the infections disaster, some of them laid out in Penrose Report, dictate that we, as a country need to take firm action. For those of us infected, the matter of not being told is one of the most distressing, humiliating and frustrating elements of what happened to us.

You may well be in discussion with medical profession representatives about these proposed legal provisions. I trust that if you wish correspondingly to hear patients' perspectives, we would be only too willing to discuss them with you.

With warmest wishes,

Yours sincerely,

Bill Wright
Chair