

Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill – Parts 2 and 3

The Scottish Parliament

Thursday 17 September – Note by the Clerk

Attendees:

Bob Doris MSP

Rhoda Grant MSP

Dennis Robertson MSP

Richard Lyle MSP

Bill Wright – Chair, Haemophilia Scotland

Dan Farthing-Sykes – CEO, Haemophilia Scotland

Philip Dolan - Convener Scottish Infected Blood Forum (SIBF) and (Trustee- Action against Medical Accidents)

Tommy Leggate – Advisor to the Scottish Infected Blood Forum

Mary McCluskey - Scottish Infected Blood Forum (SIBF)

Sandra Martin - Scottish Infected Blood Forum (SIBF)

Summary of areas discussed:

At the meeting the members and participants discussed the proposed duty of candour (part 2) and the new criminal offences of ill-treatment or willful neglect in health and social care settings proposed in part 3 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill.

Participants discussed their personal experiences and the importance of any apology under part 2 coming from those whose error had either caused or could have caused the harm. This was important because:

- it ensured that those responsible under the duty would understand the consequences of their mistake;
- the personal nature of this apology would give greater impetus to ensuring that the mistake didn't arise again and would drive improvement;
- it was more likely to be from someone with whom the service recipient already had a relationship so would be more meaningful (this is especially the case with rare conditions).

As an example of this, participants confirmed that the apologies given by the First Minister, Scottish Government and NHS Health Boards were welcome in relation to the Hepatitis C/HIV acquired infection from NHS treatment in Scotland with blood and blood products. Participants however felt that the apology from the Scottish National Blood Transfusion Service (SNBTS) was more important given SNBTS was more involved in the lives of those who were harmed.

Also discussed was the impact on people of not being told that harm had occurred – participants spoke of the missed opportunities over a number of years to try and improve their health through changing their lifestyles and the lost opportunity to seek medical support to address the symptoms of the harm caused. Participants spoke of the life changing and detrimental impact of feeling unwell without being told why. This impacted detrimentally on their personal lives, on their careers and participants spoke of the consequences for their families and friends especially in when harm could be inadvertently passed on to loved ones (such as through bodily fluids).

There was support for the duty of candour. One participant highlighted that this duty would make it more difficult for organisations to hide information from service users or prevent disclosure of medical records. Members heard that this was especially important given participants' experiences of having their medical records hidden or lost. This, they explained, had caused them long term harm, prevented treatment and impact on all aspects of their lives.

It was highlighted that having a requirement to disclose harm or potential harm and apologise would also enable easier identification of cases of willful neglect or ill treatment. It was also considered that this duty might address the 'paternalistic' attitude of some doctors, which had been identified in the Penrose report, by requiring them to identify to service users when unintended harm had been caused as they would have a right to know. Participants agreed it was important that mistakes were learned from. In that context the Duty of Candour could have an important role in providing a framework for sharing learning. The process of admitting to a mistake through an apology and learning lessons could provide an opportunity for clinicians to learn from each other's experiences and help improve the practice of all.

There was discussion of the measures and professional standards which already exist in relation to a 'duty of candour' and whether these were adequate. Members heard that whilst measures such as the yellow card and professional codes were in place, these were generally not used as much as they should be as the assumption was that someone else would report it. In that regard the duty of candour in the Bill would provide a consistent approach across the health and social care sector.

Members heard that the failure to inform patients that could have or had experienced harm also impacts on the confidence people have in their doctors. The participants experiences of finding out, years later, that they had experienced harm but had deliberately not been told meant that they and their families had little confidence in doctors and as one participant put it "what else haven't they told us".

Members heard from the participants that health professionals not being candid with patients is in itself willful neglect and that that duty of candour will support the willful neglect provisions of the Bill by preventing the types of harm experienced.

Participants discussed the kinds of unintended harm that should trigger the duty of candour procedure. The members heard that the range of harms identified within the Bill documents were broadly accurate but that the important point was that where unintended harm had or could have arisen service users were told and apologised to. It shouldn't be left to service users to pursue their concerns about unintended harm as many may not feel confident to challenge doctors. In that regard participants agreed that notifying service users of unintended harm or potential harm outweighed the potential impact apologising might have on doctors' reputation or career (in the case of junior doctors).

It was highlighted that having a duty of candour should require some type of monitoring regime in order to determine whether it was being applied.

The members heard that it was good that the Bill enabled health professionals to apologise without admitting liability. This was important as it had been one of the barriers to health professionals admitting to mistakes. In that regard it was highlighted that had there been more candour in relation to the Hepatitis C/HIV acquired infection from NHS treatment in Scotland with blood and blood products,

perhaps issues could have been resolved more quickly and there maybe wouldn't have been a need for the Penrose inquiry with its associated costs.

Members heard that there might be opportunities to learn from the issues arising from the English and Welsh experiences of a duty of candour e.g. it was important that health and social care settings were treated equally – it also shouldn't be the case that patients moving between public and private healthcare affects whether they are subject to the duty of candour or not.

Participants considered it important that, in order for there to be public confidence in the duty of candour and for it to be meaningful, there should be some form of independence to the procedure. In that regard the Bill provision for the involvement of an independent healthcare professional in the duty of candour procedure was welcomed.

There was also discussion of part 3 of the Bill. In particular, the importance of where the burden of proof lay in proving willful neglect and ill treatment. If this burden was too high then it could lead to disillusionment as the offence becomes meaningless. There was discussion of a recent case whereby the burden of proof was felt to have been set too high, the case dropped and which had then led to service users feeling let down by the NHS and the police. Following the meeting further information was provided on this case and is attached in Annexe C.

Following the informal meeting, additional information was provided by Bill Wright, Chair, Haemophilia Scotland (which is attached as an Annexe A to this note).

Also attached in Annexe B is a copy of correspondence sent from Haemophilia Scotland to the Cabinet Secretary for Health, Wellbeing and Sport.

Annexe A

Additional Submission from Bill Wright, 20 September 2015

I very much welcomed the opportunity to meet with you on Thursday 17 September 2015 to discuss what for us is a central issue of the contaminated blood disaster. I have attached some rather more radical proposals which go well beyond the clauses of the present Bill as under consideration.

I apologise for what might seem like springing this without reference to them at Thursday's meeting but in the short time we had, with other pressures we are under to complete the Infected Blood Financial Support Review, it was only on reflection I felt that you might wish to consider some further ideas which add context to the Bill as drafted. While only just raising them now, these have been long-standing issues for us over the years following considerable thought and deliberation. With the examination of the Bill, now would appear to be an appropriate time to launch them within the Parliament.

We would be particularly grateful if you might at least consider how we might take them forward, rather than us having to go through the channels of the Petitions Committee. After all as an already exhausted, ill and sometimes dying patient group it took over 15 years from submission of P45 in 1999 to finally commencing the publication of the Penrose Inquiry this year.

Again my apologies for raising these considerations so late.

Bill Wright
Chair
Haemophilia Scotland

Potential Ways Forward that strengthen the intent of Duty of Candour – BEYOND THE CURRENT BILL.

- All patients, as a matter of best practice to always **receive full copies of any written reports and letters** between medical professionals about them personally. This form of candour acts as a receipt to the recipient of their consultation, diagnosis and/or treatment. It potentially involves patients in more responsibility but also should result in medical professionals being more aware of patients knowledge and experience of their own personal health. It means that as a matter of routine, shortcomings in patient treatment and care are already indicated.
- This admittedly radical approach which goes beyond the present clauses in the Bill, would potentially **overcome the question of at what level should thresholds be set** as the same information would already be available to patients as that to medical staff. For example, in the case of those infected via blood transfusions, it would have been much easier for them at the time of infection to have been made aware of current levels of medical understanding and the risks they were being subjected to.
- We touched briefly upon the question of **burden of proof. This has to lie with the service provider** that they had informed patients of their situation and where any departure from best practice was involved as patients cannot be expected to understand in detailed terms what best practice is. It potentially requires significant changes to the ways in which trainees and students are taught in medical and nursing schools.

- The question was raised about how the duty of candour might be monitored. This raises the wider issue of not only monitoring, but also **inspection and regulation of health services as a whole**. There is a stark contrast at present between the care sector and that of the health service. The Care Inspectorate publishes the results of its inspections of each care service and are readily available on the web.
- Clearly, for health services, this becomes more complicated where there are highly specialised treatment centres such as Haemophilia Units. The present system that tends to exist is where a small number of specialised medical professionals monitor each other against a dated set of UKHCD standards. Inspection reports are far from candid as they are not made publicly available unless pursued via the FoI route. The forthcoming launch of the Managed Clinical Network for Haemophilia should help to make progress on this. However as a general rule if monitoring of the operation of medical services is to be stepped up, then **the results of that monitoring of health services need to be made more readily publicly available**.
- Reference was made to past events with respect to evidence from the Penrose Inquiry where an official decision in the year 2000 to delay a targeted approach to potential recipients of blood products was held back until CLO lawyers had advised upon the implications of drawing patient's attention to their potential exposure and delays in treatment. From papers provided to the Penrose Inquiry, the outcome of the lawyers deliberations appear to have been destroyed. This illustrates how **less than candid reporting of strategic decisions can have a direct effect on patients to the potential detriment of their long-term health**.
- Finally with respect to the question of criminal proceedings I was reminded afterwards by our colleague Philip Dolan that **there was an additional criminal investigation into the question of contaminated blood** beyond the instance in which the former MSP was involved. We will get in touch with the patients who were involved in launching the police investigation which inexplicably drew to such an abrupt halt. Either police investigation and their outcomes might assist as case studies for the Committees deliberations.

Annexe B

Correspondence from Haemophilia Scotland to the Scottish Government, dated 15 September 2015

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

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.

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

Annexe C**Criminal Investigations into the Contaminated Blood Disaster**

An investigation by Strathclyde Police was instigated in 2003 by Infected Blood Forum which was sent to Crown Office. The result of this investigation was that there was insufficient evidence of any criminal investigation.

Complainants approached Solicitor General in 2005 to ask for an investigation into a named consultant in Edinburgh, but were informed via Scottish Government department that an investigation carried out by Strathclyde Police in 2003 for the Scottish Haemophilia Local Groups Forum which found no fault and therefore dealt with our complaint. The Scottish Haemophilia Local Groups Forum was led at the time by Philip Dolan, now of the Scottish Infected Blood Forum.

Then in 2007 the constituency MSP of one of the complainants took up the case and wrote a letter to Mr David Strang, Chief Constable, Lothian and Borders Police a copy of which was forwarded to a Detective Superintendent in the Criminal Investigation Department. Another DS was eventually given the case to investigate. To reach this point where we could actually get someone to even look into our case was very difficult; if it were not for the intervention of the MSP concerned the complainants believe they would never have achieved this.

After the DS listened to accusation from the complainants, his superior DCI Little eventually contacted the consultant concerned and asked for a copy of both Medical Records and the separate research records kept in a separate filing cabinet. The existence of these second records had previously been denied. When the police received the medical records they were all mixed together so the police were unable to tell which was which. DCI Little made an appointment with the consultant, and had a chat to him, and in 2010 the complainants received a letter from Catriona Bryden, Acting District Procurator Fiscal stating:

“.....Following careful consideration of this report, Crown Counsel have instructed that no proceedings should be taken against [the consultant].”

However, the letter also goes on to explain:

“It is a well-established principle of Scots Law that an accused can only be prosecuted if there are 2 sources of evidence that an offence has been committed and 2 sources identifying him as the perpetrator. In this case there was insufficient evidence to prove any allegation against [the consultant] and that is why no proceedings have been instructed.”

The letter went on to tell the complainants that the decision cannot be revisited.

They did meet with Ms Bryden and at this meeting the complainants asked if carrying out non-consensual research was legal and she answered NO. From the complainants point of view this seemed as though she was saying what the General Medical Council were saying – It is all in the past and he will not do it again!

The complainants all felt that the case might have progressed further had we managed to reach the established principle of Scots Law, but no one advised or explained this Law until after the decision was taken by Crown Office.

If Willful Neglect was to be a criminal offence the complainants now fail to see how one person can have 2 sources of evidence that an offence has been committed and 2 sources identifying the accused as the perpetrator, therefore under Scots Law I

think it would be very difficult for one person to achieve the requirements to proceed with a criminal case.

The complainants also stress that they felt that the police/crown office was just going through the motions, that the decision had been made before they even began.