**Transplantation (Authorisation of Removal of Organs etc.) Scotland Bill**

**Scottish Intensive Care Society**

The Scottish Intensive Care Society (SICS) was founded in 1991. The membership, though mostly medical, is also drawn from nursing and other professions and as such is the foremost body representing those who work in Intensive Care Units in Scotland. The Society’s purpose is ‘to promote knowledge and practice pertaining to Intensive Care Medicine in Scotland, and to provide a forum for the dissemination of information and the representation of its members.’ The Society has been supportive of organ donation for many years and has had a representative on the Scottish Donation and Transplant Group since 2001, who also sits on SICS council.

It is important to note that nearly all deceased organ donors in Scotland arise from patients who die in Intensive Care Units, and therefore as a profession we have extensive first hand experience of the process. There are two ways patients can become donors. Donation after brain death (DBD) occurs when a patient is declared brain stem dead due to catastrophic brain damage (from causes such as trauma or bleeding), but remains on a ventilator with their heart beating until organ retrieval is carried out in the operating theatre. Donation after circulatory death (DCD) occurs when a patient on a ventilator becomes so unwell that further treatment is deemed ineffective and that a decision to withdraw treatment, including ventilation, is made. Once the heart stops beating organ retrieval is promptly carried out. In both of these situations there is always extensive consultation between Intensive Care staff and the patients’ family, usually led by the consultant in Intensive Care. This communication would initially be about the current illness, and if organ donation becomes a possibility, it is usually the ICU consultant who makes that first approach to the family about donation. We are supported in this role by a Specialist Nurse in Organ Donation (SNOD), who will sometimes be present at that first approach, and would always be involved if the family subsequently agree to organ donation.

At a recent SICS Council meeting, held on 25.09.15, we discussed the proposed Bill in some depth. While we recognised that there are a range of opinions in our community regarding opt-out measures we felt as a group representing our specialty across Scotland that the Bill, if enacted, would make significant and possibly detrimental changes to the actual processes of donation, and the interaction with the patients’ family at this very difficult time.

The Bill introduces the concept of Authorised Investigating Person (AIP). The Bill does not make clear who this person is. Currently SNODs perform most of the duties relating to gaining authorisation and liaising with families about the details of donation. Though the policy memorandum describes the AIP as a health professional, their role sounds more legal in nature. Given the timings of organ donation the AIP would need to be available on a 24/7 basis, which if they were additional to SNODS, would increase costs.
Currently in Scotland organ donation takes on average 21 hours for DCD and 32 hours for DBD, from beginning to end. (Data from NHSBT). The length of the process is already a problem for some families and often cited as a reason for not wanting to go ahead with donation, or withdrawing authorisation at a later stage. The addition of the AIP may lengthen the process further. In Section 41 of the policy memorandum there is some description of the AIPs role. Much of this is currently undertaken by the SNOD, such as checking the persons wishes and consulting with the family. In addition the AIP, as described, would have to contact the proxy.

The appointment of a proxy seems to create an additional layer in the process. At no stage does the Bill make clear who the proxy might be, if they are not the immediate family or give examples. This is further complicated by the possibility of having up to three proxies, who might give conflicting opinions. Currently discussions about potential organ donation are carried out between ICU clinical staff, SNODs and the attending family. Just which family members are involved is not defined, but it tends to be a self selected group who have chosen to be at the bedside and sometimes others more distant. The addition of the need for a proxy may complicate matters. What if the proxy, as appointed by the patient, does not agree with the family at the bedside? If the Bill were enacted, could the clinical staff remove organs against the wishes of the family, but with permission of a proxy?

The Bill does not refer to organ donation, but to the “Removal of Organs”. We appreciate that this is because the language is derived from that of the Human Tissue (Scotland) Act 2006. The families we approach about organ donation are usually in a state of great distress. therefore our discussions have to be handled in a very sensitive and professional way. The concept of donating organs that can help others, can give much comfort to families at a very difficult time. That we might be in a position of removing organs albeit with permission of a proxy, but against wishes of some family members is of great concern to us.

The flow chart on page 16 of the policy memorandum is helpful in interpreting the process but it is not clear how the bill would actually increase organ donation.

- If the person had opted in, then organs can be removed. This is little material change from present if a patient is on the Organ Donor Register, except that there is no option for the family to override this. Again, would clinical staff go ahead with organ donation if the family objected? This could create negative publicity and a public backlash.
- If there is no record of the persons wishes, it seems highly unlikely that they would have appointed a proxy. Therefore the decision would fall back to the nearest relative, so no change from the present.
- If the person has opted out, then donation will not take place, so again no change from present arrangements.
So in summary the Scottish Intensive Care Society are very supportive of organ donation, but have serious concerns that this Bill if enacted could:

1. Lead to loss of goodwill and confidence in organ donation from the public.
2. Result in increased costs
3. Lengthen the process of organ donation
4. Create additional layers of complexity, in a process that is often extremely complex already
5. Fail to increase organ donation rates

The Scottish Intensive Care Society