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

Christian Medical Fellowship

This submission is in addition to our original evidence, which was submitted in response to the call for evidence from the public, and which set out our general concerns with the draft bill.

This extra submission is in response to the meeting with faith representatives, and concentrates only on some of the detail of the proposed Bill.

**Issues related to proxies**

1. The Bill allows a person to consent to donation through a proxy (a new option). A person can only have one proxy and they can be limited to decisions about certain organs. However, there can be a second alternate proxy in case the first person cannot be contacted. Clause 4 amends section 6 of the 2006 Act so that if a person appoints a proxy their previous decisions on donation are seen as null and void. In para 14 of the Explanatory Memorandum (EM) it suggests that a person should have 3 mutually exclusive decisions – consenting to donation, registering an objection in the register or having a proxy so “there is always clarity about the person’s wishes”.

2. However, slightly confusingly, in clause 5 (which introduces new Section 6A for the 2006 Act) it suggests that the appointment of a proxy is to be considered null and void if an adult subsequently expressly consents to an organ donation or records an objection (see new 6A(14), lines 21-25 on page 3. The potential of confusion is recognized by clause 7 which introduces new Section 6C to the 2006 Act so that if the position is not clear then the adult is treated as not having made any decision. This raises the important question of whether a person’s wishes could be thoroughly undermined. For example, a person may think they had made a decision but it was not made clearly (eg it was made in a conversation) so it may be treated as it being ‘uncertain’ and therefore the persons’ wishes would not be upheld. What happens if there was a signed statement but it cannot be guaranteed to be correct? Or cannot be found? What does ‘uncertain’ mean? Or they may think they have a proxy but under 6A(14) it had been withdrawn automatically.

3. Both clauses 5 (eg. See line 35 on 2, line 1 on page 3) and 6 (see line 10 on page 4) refer to a proxy making a decision in a ‘reasonable time’ but the Bill says the authorized investigating person (AIP) can determine what a ‘reasonable time’ is. This has major implications for how the system would work in practice as if a decision is not made in that time, the fact that a person has appointed a proxy to act on their behalf becomes moot (see lines 12-15 on page 4 and new 6B(4), lines 34-37, page 4). After that the AIP is talking to relatives who may or may not know what the person wanted. A reasonable time may only be a very short period – before wishes are over-ridden.
4. The decision of the proxy trumps the decision of relatives. Clause 8 amends section 7 of the 2006 Act to that effect. See later notes on role of families.

**Issues related to authorized investigating person**

5. We have some concerns with its operation in practice. It is unclear who would take on this role and what the value of it is. If an AIP has the capacity to overrule the decision of a relative, this raises the possibility that families will feel that the organs have been taken under duress, rather than freely donated.

6. It is not set out in the primary legislation who can be an AIP. This will be determined by regulation. The Explanatory Memorandum implies it will be someone from within the NHS (see para 12) and the Policy Memorandum (see para 41) that they will be health professionals but is this the most appropriate person or would a solicitor be better?? It requires someone with responsibility to ensure a decision is made in the best interests of the deceased and family. **Will the AIP be trained?** Will every hospital have one? Who decides who is an AIP? It is a highly sensitive responsibility and important role.

**The Heart of the Ethical Concern**

7. New Section 6B of the 2006 law, proposed by clause 6 of the Bill, is the one that CMF has the major concern with. This is the process proposed.

   a. A person’s body parts can be removed if the person was an adult (defined as over 16) and was living in Scotland at the time of death; and.

   b. The AIP investigates 6 factors in this order to find out whether there is objection to donation:

      i. Is there authorization of removal by the adult in force? (If yes section 6 of the 2006 Act applies)

      ii. Is there a registered objection? (If yes this new clause would no longer apply)

      iii. Find out the view of all known proxies to be given in a reasonable time.

      iv. Only proceed to next stage if no information from proxy, or proxy not given information on views of deceased.

      v. Consult nearest relative to determine if the person had **reasonable opportunity** to register an objection – reasonable opportunity is that a person had been resident in **Scotland 6 months** and is over the age of 16 – although the presumption that the person had a reasonable opportunity to object can be rebutted under 6B(3) by the AIP judging that it was not reasonable to
expect the person to object (eg in a coma, limited capacity for some of the time).

vi. And talk to the relative to determine whether the relative had knowledge about whether the person would want to donate their organs – if the AIP can contact them within a “reasonable time”. If the relative has no knowledge, the person is presumed to have consented.

8. Reasonable opportunity is a difficult concept to quantify and ensure. What if the person had been out of the country for a period? Or did not fully understand the law? Or had language difficulties? Or was not on the internet nor seen advertising? Or been in a coma for some of the time and changed their mind? Where it is not entirely clear if a person has made a decision or not, and the family object to donation, we have strong ethical concerns about overriding the families wishes.

9. Moreover, there are no grounds for distress for the family to be taken into account, on the face of the Bill.

Notes on drafting:

- The residency should be 12 months, not 6. This is essential to ensure as many as possible will have seen the campaign. The Welsh Bill started with residency of 6 months and ended up with 12.

- For the purpose of this Bill, an adult should be aged 18 or over, as is the case in Wales, not age 16 or over.

- The EM says it may not be possible for the AIP to contact relatives within a reasonable time and if that is case they do not get any input, see para 36. We have concerns with this.

- There is an important question about how the Bill will apply to adults who do not have capacity to make a decision, since the criteria is that the person is over 16 and the assumption is that if a person has been resident in Scotland for 6 month they will have had a reasonable opportunity to object (see 6B(3)) – introduced by clause 6 of the Bill). As stated earlier this can be rebutted on the decision of the AIP but there is no specific exemption for adults with incapacity. Furthermore, it should be noted that the law already prohibits someone who has power of attorney for such an adult to consent to donation and clause 15 of the Bill extends that to not having the power to appoint a proxy or object to donation. Hence an incapacitated person could be regarded as having no decision made and therefore may be fall under the provision of new section 6B of the Act. Policy Memorandum para 43 implies that the assumption of ability to opt out would not apply but we suggest that the lack of capacity to consent should be on the face of the Bill as a clear safeguard. The person should be automatically assumed not to have had reasonable opportunity to register objection (because of incapacity).
Role of Family

10. Relatives can still give authorisation for donation but in more limited circumstances – for instance, as stated above not if the proxy is making the decision. Family cannot override an adult’s decision to donate or not to donate and record that on the register.

11. If the AIP is in the middle of an investigation relatives cannot intervene.

12. As noted above, a situation that generates concern for us in the draft Bill is that if the deceased does not have a clear position on donation, the family do not have a right to object. And there are no grounds for distress. Their only possible objection would have to be on the grounds that the deceased did not have a ‘reasonable opportunity’ (i.e. practical justification) to object.

13. The Policy Memorandum says that if families object it is normal practice not to proceed with donation (see para 14) but it is not clear if that practice will continue. Indeed later in the Policy Memorandum it says that relatives cannot block an individual’s stated position (see para 37) and further on that “it is likely to remain the case…that family distress will be taken into account before any final decisions are made (para 55). It would be important to have this point on the face of the Bill if it is to be accepted practice.

14. It is not clear how a family would prove that their relative did not want to donate. A chat? A letter? How long ago? Who decides? There is nothing in the Bill for what is required, which undermines the role of the family further. The appointment of a proxy has to be confirmed in writing, but the request to opt out need not be. Whilst we agree with the opt out being less onerous, we are concerned that this may lead to lack of clarity and thus the application of new clause 7 (where the adult is treated as not having made any decision).

Further comments

Why should a family be able to veto donation?

1. Increased distress. The Bristol and Alder Hey controversies were fuelled by the perception that families had no real power in decision-making with respect to what happened to their loved ones body parts. They also showed how crucially important the body is to bereaved parents and friends, and illustrated the need to respect the human body, even in death. It is not simply raw material.

There are occasional situations where continuing with donation will increase distress for a family at a tremendously difficult time. The decision about whether to donate has to be made quickly, and families might well find that they cannot agree to donate. If their wishes not to donate are then overridden, even if in accordance with the wish of the deceased to donate, this might well increase the distress families are already feeling.
2. **Cultural sensitivity.** Not all cultures are as individualistic or materialistic as the mainstream Western tradition, and in some cultures, individuals wishes do not override the family’s. In such situations it may well be culturally insensitive to insist that they do.

3. **Lack of trust.** Some people fear that if they became seriously ill, they would receive less thorough treatment if they were donors than if they were non-donors because doctors want their organs. This fear – which need not be well founded to have an effect – would increase if the family’s views were known to be overridden. People look to their families to protect them when they cannot protect themselves. Publicly overriding families could make people and their families feel more vulnerable to doctors skimping on their treatment and so more reluctant to donate.

Moreover, some donors will only consent to donation of certain organs (there may be concerns about the possibility of brain and gonad transplantation, for example) and so will look to their families to ensure that their specific wishes are carried out.

An article in *Transplantation* highlights an additional concern, that the move could be counter-productive: “Some intensive care staff fear that a move to an opting-out system would make critical care more difficult and could lead to some intensive care practitioners themselves opting out of participation in donation programs. This would be disastrous for the future of organ donation, which is dependent on the active support of intensive care practitioners.”

4. **Concern about consent.** It will be almost impossible to guarantee that everyone is informed and understanding of ‘deemed consent’, knows their options and can easily opt out. Can consent be truly assumed from those who are disorganised, apathetic, disabled, less well educated or informed, isolated, lacking full capacity, of different languages and race, suffering from (temporary) mental illness, dependent, those who have less ready access to information and those who change their minds? The importance of allowing families a veto in such cases is obvious.

5. **Ownership of the body.** Underpinning the proposed change in the law is a change in the relationship between the individual and the state. The assumption about whose body it is begins to move from personal ownership to state ownership. Unless the state wishes to suggest that the deceased now belongs to it, the family must have the right to become his/her spokesperson.

Efforts should be directed to bringing about behavioural change in Society such that organ donation becomes the normal culture. If authorisation rates reached 80% that would far outweigh the impact of any change of legislation in increasing the transplant numbers.

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