

HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM THE FREE CHURCH OF SCOTLAND

Introduction

We are grateful for the opportunity to respond to this consultation. The Free Church of Scotland is a small but growing Presbyterian denomination which has a long history of social involvement and of contributing to discussion on public issues.

We support organ donation and transplantation and efforts to increase the number of donated organs available, but we do not believe that introducing the opt-out system is the right way of achieving this. Our objections are detailed below.

We would point out that the system in Scotland, since the Human Tissue (Scotland) Act 2006, is not entirely opt-in. This is because a nearest relative may (1) add to the list of body parts that can be removed and transplanted without knowing the donor's wishes with regard to these body parts and (2) give permission for removal of body parts even if they do not know if the person was in favour of this (section 7 of the Act). In any revision of the Act, we would prefer that these be altered, to remove any element of presumed consent.

We are pleased to note that attention has been paid to improving the procedures associated with organ donation and transplantation, particularly with regard to educating and informing the public, the appointment of Specialist Nurses for Organ Donation and better cooperation between medical and surgical specialties. There is convincing evidence that these are much more important in increasing the number of organs available for transplantation than the introduction of an opt-out system.

However, seen against the background of a grossly under-resourced and understaffed NHS in Scotland, these changes will have a limited effect. The whole service needs to be better resourced, better staffed and better managed.

The *Guardian* of 15 July 2018 reported that NHS Blood and Transplant's (NHSBT) impact analysis showed that the UK transplantation system is already under severe strain due to shortage of essential staff and resources leading to increased stress levels among staff. It points out that if the introduction of an opt-out system were to result in an increased number of available organs (which is by no means certain) there would not be sufficient capacity in the system to use them. This highlights the priority of improving the service by increasing staff levels and strengthening infrastructure, as well as education, training and publicity.

Question 1

What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?

Answer

Weaknesses

Opt-out system: ethical concerns

The main weakness is the introduction of 'deemed authorisation' (**Section 7, Section 6D of the Bill**). We have grave ethical concerns about this concept. We believe that organ and tissue donation should always be on the basis of a deliberate, well-informed, voluntary decision on the part of the individual. Valid consent in medical practice is always informed and voluntary. 'Presumed consent', or 'deemed authorisation' as it is called in the Bill, in an opt-out system is based on the unwarranted assumption that every single person who is not on the opt-out register was aware of the opt-out provision and has consciously taken a decision not to opt out. This is no consent or authorisation at all and a 'donation' on this basis is not a donation willingly given but more like a tax imposed.

There is an attempt to mitigate the draconian nature of this provision in 6D (2) (d) which provides that a 'person' may produce convincing evidence that the adult 'was unwilling for the part to be used for transplantation'. It is difficult to see what would count as convincing evidence other than a written, signed and dated statement by the person.

The same problem arises with regard to the role of the 'nearest relative' of a non-resident adult in **Sections 6E and 6F**. The nearest relative may authorise the removal and use of any part of the body without knowing what the wishes of the person were in this regard. Quite apart from the difficulties that may arise in identifying the 'nearest relative', to impose upon them at this difficult time the duty of declaring that the person 'was not unwilling for the part to be removed and used for transplantation' is too grave a responsibility to expect them to bear.

Opt-out system: lack of evidence for its effectiveness

There is very little evidence that an opt-out system increases the number of organs available for transplant. In Spain, an opt-out system was in place for 10 years before the transplant rate increased and this was due to the setting up of a well resourced and managed coordinated national system for collecting organs and for transplantation. Repeated studies have shown that these other measures are more important than the introduction of an opt-out system, as pointed out in the Scottish Government's Rapid Evidence Review.

Since that Review was published a study carried out by Queen Mary University of London published in the *Journal of Experimental Psychology: Applied* on 16 August 2018 has concluded that under an opt-out system relatives would be more likely to veto the removal of an organ for transplantation than when the deceased was on the donor register.

Thus the introduction of an opt-out system may well prove to be counter-productive, as public trust may be eroded.

Question 2

What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

Weaknesses

These are mostly related to the introduction of 'deemed authorisation'. If this element were removed, the procedures proposed appear to be well designed and should be effective, provided they are clearly explained to the relatives and then applied conscientiously.

Question 3

Do you have any other comments to make on the Bill?

Excepted organs and tissues

We would like to see an absolute ban on the removal for transplantation of (1) gonads and gonadal tissue as well as gametes (sperm and eggs) and (2) embryonic and foetal organs, tissue and cells.

Importance of education and publicity

It is important to maintain the altruistic motive of organ donation. Better education and publicity is required to encourage this. Already Scotland has the highest percentage of the population on the Donor Register (over 50%) compared to other parts of the UK and this shows that recent efforts at promoting donation have had an effect. Encouraging a community ethos of altruistic donation will be much more fruitful in the long run than introducing an opt-out system.

Rev Dr Donald M. MacDonald

23 August 2018

On behalf of

The Free Church of Scotland
15 North Bank Street
The Mound
Edinburgh
EH1 2LS

Tel: 0131 226 5286

The Free Church of Scotland SC012925