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Royal College of Physicians of Edinburgh

The Scottish Parliament Health and Sport Committee Human Tissue (Authorisation) (Scotland Bill) Call for views

The Royal College of Physicians of Edinburgh (“the College”) is pleased to respond to the Committee’s call for views on the Human Tissue (Authorisation) (Scotland Bill). The College is an independent clinical standard-setting body and professional membership organisation, which aims to improve and maintain the quality of patient care. Founded in 1681, we support and educate doctors in the hospital sector throughout Scotland and the world with over 12,000 Fellows and Members in 91 countries, covering 30 medical specialties.

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?

The College supports the move to ‘deemed authorisation’ in principle, provided there is a parallel process of public education about the benefits of organ donation and improved infrastructure to support families and clinical teams at the time of organ donation. The College has sought the input of Fellows in a variety of medical specialties and a wide range of views have been submitted, and it is important to note that unanimity has not been reached on several issues.

Some Fellows have expressed the view that there are a number of individuals who would be donors but have not made that view known before their death. The move to a soft opt out system would therefore likely make a small but real difference to the number of organs donated in Scotland, when implemented alongside other initiatives.

The available international evidence supports the fact that ‘opt out’ legislation is associated with increased rates of deceased organ donation. However, the legislation itself **may not** be the major determining factor for organ donation as some countries with “opt in” systems still have higher organ donation rates than countries which have adopted “opt out” legislation. There are differing opinions within the medical profession and society at large regarding an ‘opt out’ system. Some believe that “opt out” legislation effectively means acquisition by the State of organs, and removal of the altruistic aspect of donation is of real concern to some of our Fellows, who feel that bereaved families take great solace from an active act of giving. These and other ethical issues have prevented the global adoption of presumed consent legislation.

However, the higher rate of organ donation in 'opt out' jurisdictions persists even when the next of kin are still asked for their approval before retrieval (this is termed 'soft' opt out as opposed to 'hard' opt out when the relatives are not consulted).

If despite the best efforts of all involved, donation was to cause distress it should not go ahead – and this is probably the strongest argument for not changing the law, since the situation would in effect be little different from what happens now. It is therefore important to retain the ability to “opt-in” as this may give more comfort and reassurance to a distressed family that they were following the wishes of their loved one.

A higher rate of organ donation will reflect increased public awareness, societal attitudinal change to donation, and improved clinical infrastructure. In terms of infrastructure, for example, Fellows have described situations where there is a loss of potential donated organs due to surgical considerations. There are occasions where transplantation is unable to proceed because there is a lack of retrieval or a transplant surgical team, because they are already operating on other patients. Some emphasis should therefore be placed on identifying areas of improvement on the transplant side.

Considerable investment in terms of time and resource needs to be spent on continuing public education and improved infrastructure to support families and clinical teams, both in the current “opt in” authorisation system and in the circumstances of a move to “opt out”.

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

The College would generally agree that allowing more tests and treatments would seem to be positive, in general, by allowing the patients presumed wishes, i.e. to donate organs in this situation, to be followed. They are likely to have already had several similar tests and treatments and provided they cause no or minimal distress the addition of a small number of further interventions would be justified.

However, Fellows also wanted to make clear that this would depend on the discussions with the potential donor's family. While the treatments or medication provided may cause no discomfort, they may change the time line of the dying process, and in general our Fellows would be uncomfortable with altering this process without the support of the family.

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

The College notes that *“the Bill does not provide for an “override” by family members in the case of any of the decisions – opt in, opt out or deemed authorisation”ⁱ*. This may seem to be a straightforward statement, honouring only the wishes of the patient; however it does not capture the terrible reality of a death which occurs in often tragic circumstances where an individual can become an organ donor. Proceeding with organ or tissue donation against the wishes of newly

grieving relatives in this situation would be likely to lead to a very damaging breakdown in relationships and loss of trust between relatives and the medical profession/organ donation teams.

Public confidence in a soft opt out system would be quickly undermined if family did not continue to play a key role in decision making. Clinicians could be placed in the very difficult position of harvesting organs in the face of explicit opposition from immediate family members and which could undermine confidence in medical teams. The family should always be consulted about the request to harvest organs and asked about the expressed wishes of the deceased.

The role of the Specialist Nurse for Organ Donation (SNOD) is key in circumstances such as this to provide sensitive assistance and support to the potential donor's family and ensure that communication remains open and transparent. Again, this emphasises the requirement for investment in infrastructure to make progress.

There is considerable international evidence available which highlights examples of good practice in increasing rates of organ donation. The College recommends seeking expert opinion from those who have done this successfully, such as the team led by Rafael Matesanz in Spain. A successful communications programme will embed the positive aspects of organ donation in the public's consciousness. The example of higher rates of organ donation in Spain has shown that improved clinical infrastructure with enthusiasm for transplantation is vitalⁱⁱ.

Rafael Matesanz led the Spanish human transplant organisation change, and he has stated that the law change in 1979 had virtually no effect. The improved transplant coordination, however, came in 1989, and it was at that point that Spain saw the substantial increase in donation that they now experience. Conversations about donation are part of society in Spain and it is ensured that the public have awareness of organ donation through many different channels. Partnerships with schools and further and higher education will be important to embed the discussions around organ donation at an early stage.

ⁱ Paragraph 56, page 15, Human Tissue (Authorisation) (Scotland) Bill- Policy Memorandum (June 2018)
[http://www.parliament.scot/Human%20Tissue%20\(Authorisation\)%20\(Scotland\)%20Bill/SPBill32PMS052018.pdf](http://www.parliament.scot/Human%20Tissue%20(Authorisation)%20(Scotland)%20Bill/SPBill32PMS052018.pdf)

ⁱⁱ <http://blogs.bmj.com/medical-ethics/2017/09/25/organ-donation-presumed-consent-and-focusing-on-what-matters/>