HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM THE CHRISTIAN INSTITUTE

Introduction

The Christian Institute is a non-denominational charity established for the promotion of the Christian faith in the UK and elsewhere, and the advancement of education. We are supported by around 4,000 churches and church ministers from almost all the Christian denominations. We have over 55,000 supporters throughout the UK, including around 6,000 in Scotland.

The Christian Institute’s central concern about an opt-out system is that presuming consent shifts the balance of power from individuals and families to the State. There are several other weaknesses to the proposed deemed authorisation system, including serious doubts that it will actually increase organ donation.

Throwing away consent

It is fundamental to genuine consent that it should be informed and freely given. In most areas of our society we are tightening up the rules around consent – the General Data Protection Regulation being a case in point. Yet, remarkably, the rules on consent for email addresses will be stronger than for organ donation under this legislation.

Transplantation does tremendous good for many people. We understand the desire to save the lives of those awaiting transplants, though there is doubt as to whether an opt-out system will do so (see below). However, there are crucial points of principle at stake.

Deciding what happens to one’s body is a key individual right. Just because someone dies does not mean that their body becomes the property of the State. Families are responsible for what happens to a deceased person’s body. It is wrong to assume from silence that someone’s organs are there for the taking.

We would not take this approach to property. When someone dies intestate, without a will setting out their intention for their estate, the State does not presume ownership. The estate only passes to the Crown if there are no surviving relatives. There would be an outcry if there was a proposal to change the rules so that estates passed to the Crown automatically if there is no will.

Sideling relatives

The Bill rightly puts the emphasis on giving effect to the wishes of the potential donor. Donors’ registered decisions should not be vetoed by families, unless the family has clear evidence that a person changed their mind since their last registered decision. However, the Bill wrongly treats “deemed authorisation” as a decision that cannot be overridden by relatives.
When someone has not opted out, all that is known is that they have not formally expressed a view. Did they want to be a donor? Were they indifferent? Were they intending to opt-out but had delayed doing so because they were not expecting to die? Did they know that they had to opt out to stop the State presuming they wanted to be a donor? Did they even know opting out was possible? Family members are best placed to be able to answer these questions. But to overturn the presumption of consent the Bill says families would have to provide convincing evidence that the deceased would not have wanted to donate. What sort of evidence will be required? Families should not have to present evidence to overturn a presumption that has no evidential basis.

The current opt-in system allows consent to be given by the individual or their family after their death. An opt-out system should allow opting out by the individual or their family – unless the individual has made a clear decision to opt in. Where someone has neither opted in nor opted out they should not be treated as making a decision. In this case, the final decision should always rest with the family.

**Appropriation is not donation**

Organ donation should be a gift, as it is under the opt-in system. Either the person themselves, or their family after their death, choose to benefit others. When consent is presumed, the whole ethos of donation is lost. Instead of being a gift, it almost becomes an obligation.

**Requirement to raise and maintain public awareness**

Although the Government’s aim to save lives is laudable, it must not take advantage of people’s inaction. That is unethical. The opt-out system turns the principle of informed consent on its head. Extensive awareness-raising will therefore be essential.

If consent is to be presumed for organ donation, it can only be remotely defensible if each individual a) knew they could opt out, b) understood the consequences of not doing so, and c) chose not to take readily-available opportunities to do so. It is incumbent upon the Government to make every effort to ensure that these elements are true of every person in Scotland.

The Scottish Government will therefore need to run major, cross-platform advertising drives about the new rules both before and after the change. More than that, the Government will have to maintain a high level of awareness through ongoing information campaigns. These will have to have much greater visibility and saturation than anything to date under the opt-in system. The fact that the State presumes to take citizens’ organs after death will have to be taught repeatedly in schools.

The latest figures from Wales show that only 70 per cent of people said they were aware of any changes to the organ donation system when asked unprompted.\(^1\) Young people were less likely to know about the change. This is despite the Welsh Government’s information campaigns. Consent cannot be presumed for people who are unaware.

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\(^1\) *Survey of Public Attitudes to Organ Donation: Waves 13 and 14*, Welsh Government, November 2017, page 8
Annual mailings to homes must be used to remind people about the system and their right to opt out. These could include income tax statements, tax code notifications, the electoral roll update, car tax renewal, etc.

**An opt-out system does not necessarily increase donation rates**

There is serious doubt that an opt-out system will achieve the Scottish Government’s goal. Sweden, Luxembourg and Bulgaria are all countries with opt-out systems but lower rates of organ donation than the UK according to the latest figures. The United States has an opt-in system, but much higher rates of donation than the UK. Clearly, an opt-out system is not directly correlated with more donations.

There is no evidence that the opt-out system in Wales has increased donations. Six per cent of the population has opted out, meaning they cannot be donors unless they register a change of mind. Under the current Scottish system, the families of those who have not opted in can still be approached. The Welsh opt-out has actually narrowed the pool of potential donors.

Spain has by far the highest donation rates in the world. But this is not down to its opt-out system. For ten years after its introduction in 1979, it made little difference. The change came with the introduction of the National Transplant Organization (ONT) in 1989. There was a focus on infrastructure and training, particularly of staff to approach families about donation.

**Transplants are rising under the existing system**

NHS Blood and Transplant figures show that deceased donor transplants in Scotland are currently increasing year on year – there was a 25 per cent increase between 2014/15 and 2017/18.

The percentage of the population on the Organ Donor Register (ODR) has also been rising, and in the first quarter of the 2018/19 financial year it rose to 50 per cent. This is moving in the right direction. Under the current system, families know that the deceased has explicitly
opted in. So, UK-wide, more than 90 per cent of families agree to donation when the deceased is on the ODR.9

As already stated, the Scottish Government will have to invest hugely in advertising and education to make people aware of the new system and their right to opt out. If it gave the current approach this same level of backing, then there is every reason to believe donation rates could be substantially increased without presuming consent. It would be far better to focus on continuing this incremental progress, rather than making a change that undermines autonomy.

**Disproportionate impact on those with religious beliefs**

Some of those holding the strongest views against organ donation will be in religious and ethnic communities where they are least likely to be aware that an opt-out system is being introduced. This makes awareness-raising all the more crucial.

Some people with religious beliefs oppose organ donation entirely. Others have reservations around some of the issues involved, such as the definition of death used for ‘donation after brain stem death’ (DBD). They would prefer there to be confirmed circulatory death in all cases. If someone believes that brain stem death is an inadequate definition of death, then in their opinion taking organs from someone in this condition is tantamount to killing them.

This raises serious issues of conscience. Those with strong moral objections will nonetheless have their consent presumed under the proposed new approach. While the default position under the current system protects their conscience, in the future they will have to take action. A blanket opt-out system therefore disadvantages those with moral objections compared to those who are indifferent. The Scottish Government has not given sufficient regard to this issue.

**Unfairly requiring people to keep up to date with what can be transplanted**

The current list of what can be donated is limited to the main organs, tissue like bone marrow, and corneas. But larger ethical issues would be involved if this list was to expand with technological advancement. Face transplants have already happened, raising core questions of identity. The same is true of hand transplants, where the recipient retains the fingerprints of the donor. Other unique features would raise similar ethical questions, such as irises if eye transplantation research progresses. If transplants of gonads were to become common, this raises the prospect of someone giving birth to a deceased donor’s biological children. Being presumed to consent to fathering children after death would be unthinkable for most people. But what safeguards are there to ensure that the category of potential transplants is not extended in this way in the future? Someone who decides not to opt out because they are happy to donate their main organs should not have to monitor the list of what can be donated to make sure they stay happy with it.

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9 *Organ Donation and Transplantation Activity Report 2017/19*, NHS Blood and Transplant, table 13.1