HEALTH AND SPORT COMMITTEE

HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

SUBMISSION FROM BRITISH HEART FOUNDATION SCOTLAND

The British Heart Foundation is the largest funder of cardiovascular research in Scotland, currently investing £70 million on ground breaking research in Scotland. It is our mission to beat heartbreak forever. Our vision is for a world in which people do not die prematurely or suffer from heart and circulatory disease.

We would like to take this opportunity to thank the Health and Sport committee of the Scottish Parliament for the opportunity to respond to this call for views. We are delighted that the Scottish Government has brought forward the Human Tissue (Authorisation) (Scotland) Bill, which has the potential to transform the lives of the 559 patients awaiting transplants in Scotland.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?

Strengths

BHF Scotland believes that there are a number of strengths to the deemed authorisation proposal.

Firstly, it allows individuals to be explicit about their views on organ donation, by providing the opportunity to either opt in or out of donation on the organ donor register (ODR). Those who do neither will be giving ‘deemed authorisation’. This is important, as there is a disparity between those who say that they wish to donate their organs after they die and those who are currently registered on the ODR. Around 80% of people support organ donation², however only 50% of Scots are registered on the ODR.³ The system proposed by the bill will help to close this gap.

Additionally, we believe that deemed authorisation could help the families of potential donors have more confidence in their knowledge of their loved one’s wishes regarding organ donation. As a result of the deemed authorisation legislation in Wales, Specialist

² NHSBT carries out biannual attitudinal surveys. The fourth wave in 2017, involved 1499 interviews carried out via online self-completion between the 10th and 21st of April 2017. In this wave, 81% of people supported organ donation in principle
Nurses-Organs Donation (SN-ODs) report encountering more instances in which family members were aware of their deceased loved one’s wishes.4

We believe that a key strength of the legislation proposed is its potential positive influence on consent rates for organ donation. Results from Wales suggest that the introduction of opt-out legislation has positively influenced organ donation consent rates: general Welsh consent rates are the highest in the United Kingdom at 72%.5

Furthermore, as the bill allows those close to the potential donor to inform health care professionals of their relative’s most recent views on organ donation, deemed authorisation ensures that the wishes of individuals in Scotland will be respected upon their deaths.

BHF Scotland believes that the inclusion of a duty for Ministers to inform the public about deemed authorisation is also an important strength of the bill. Ensuring awareness of the legislation is important: firstly to ensure that members of the public understand the deemed authorisation system, and secondly to encourage them to register their decision to opt in or out on the ODR, and to discuss organ donation with their family. This is integral to the success of the proposed system change and we fully support this aspect of the proposed legislation.

Overall, we strongly believe that the Human Tissue (Authorisation) (Scotland) Bill has a number of strengths and will be a positive step forward for Scotland.

Weaknesses

BHF Scotland did not feel that there were any specific weaknesses of the proposed bill but recognises that a deemed authorisation system, while important, is not a panacea.

We believe that, alongside deemed authorisation, continued investment in infrastructure and staff training is necessary. We also believe that campaigns to raise public awareness of organ donation are hugely important.

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

BHF Scotland has no comments to make on the key strengths and weaknesses of the plans for authorisation of pre-death procedures.

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

Please find below an extensive briefing on BHF Scotland’s position on the bill and the proposals for a deemed authorisation system of organ donation.

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ORGAN DONATION BRIEFING

British Heart Foundation's vision is a world without heart and circulatory disease.

We fund research to keep hearts beating and blood flowing. We are the biggest independent funder of cardiovascular research in Scotland, currently investing £70million on ground breaking research in Scotland.

Key Messages

- The need for organs vastly outstrips the number donated.
- During 2017/18, 426 patients throughout the UK died whilst active/suspended on the transplant list or within one year of removal from the list, including 27 people who died while awaiting a heart transplant.
- There is a gap between the number of people who state that they would wish to donate organs and the number who go on to join the Organ Donation Register.
- Countries with soft opt out legislation have on average 13-18 per cent higher organ donation rates than countries with informed consent legislation.
- The Human Tissue (Authorisation) (Scotland) bill, published in June 2018, could increase Scotland’s donation rates.
- BHF Scotland believes that the soft opt out system brought forward by the bill, is an appropriate option for increasing organ donation.
- BHF Scotland also supports continued investment in infrastructure and staff training alongside a campaign to raise public awareness.

The bill will enable those who support organ donation but haven’t registered on the Organ Donor Register to have their wishes recorded.

There is disparity between those who sign up to the organ donor register (ODR) and those who support organ donation and would wish to donate their organs after death.

Around 80% of people support organ donation⁶. However, only 50% of people in Scotland have signed up to the ODR⁷.

The proposed bill will enable those who support organ donation but haven’t registered on the ODR to have their wishes respected, by implementing a system in which those who do not explicitly opt in or out of donation will be deemed to be willing to donate their organs upon their death.

The current system is failing to keep up with the need for organ transplantation. 559 people in Scotland were waiting for an organ at the end of the first quarter of 2018/19⁸. The need for transplants is likely to increase as a result of an ageing demographic.

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⁶ NHSBT carries out biannual attitudinal surveys. The fourth wave in 2017, involved 1499 interviews carried out via online self-completion between the 10th and 21st of April 2017. In this wave, 81% of people supported organ donation in principle
During 2017-2018, 426 patients died throughout the UK whilst active/suspended on the transplant list or within one year of removal from the list, including 27 people who died while awaiting a heart transplant.

Each number here represents a life cut short and a family who have lost a loved one where it might have been avoidable. More life-saving transplants could take place each year if the gap between those indicating that they would like to donate, and those taking action to do so was smaller. The proposed bill will help to achieve this.

The Human Tissue (Authorisation) (Scotland) Bill proposes a system with appropriate checks in place to ensure ethical practices regarding organ donation.

Firstly, the bill includes requirements to take into account the potential donor’s most recent view about donation.

Secondly, the removal and use of less commonly donated types of organ and tissue, or the removal of commonly donated types for purposes other than transplantation from a potential donor who is subject to deemed authorisation, can only be carried out with authorisation by a nearest relative.

Deemed authorisation will not apply to children under the age of 16; adults who do not have the capacity to understand the implications of deemed authorisation; and those who have resided in Scotland for less than 12 months.

The option will remain available for individuals who fall into one of the two latter groups to opt in or out.

Children aged 12 or above but under 16 will be able to opt in or out, while younger children will require a person with parental rights and responsibilities or another close adult to inform Specialist Nurses-Organ Donation (SN-ODs) about the child’s wishes regarding donation.

The Human Tissue (Authorisation) (Scotland) Bill emphasises the important role of Specialist Nurses-Organ Donation (SN-ODs).

The approach made to grieving families to consider the prospect of donating their loved one’s organs needs to be made at an appropriate time by someone with the correct skills and knowledge to support them adequately. SN-ODs are well placed to do this.

In Wales, efforts to ensure a SN-OD is present in all instances of potential donations, have seen consent rates in these situations rise from 94% in 2015/16 to 96% in 2016/17. The language of the new Scottish bill emphasises the role of SN-ODs in approaching families to discuss the wishes of their loved one.

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8 NHS Blood and Transplant, 2018, Organ Donation and Transplantation Activity Data: SCOTLAND, Annual data for financial years 2013/14 to 2017/18 and data for 2018/19 – first quarter


SN-ODs in Wales report feeling that implementation of the new legislation has gone smoothly. They believed that they had been given sufficient training regarding the new system, and were encountering more instances in which the family knew whether or not their loved one wished to donate their organs\textsuperscript{11}.

The Human Tissue (Authorisation) (Scotland) Bill follows the example of numerous other countries with successful opt-out systems in place.

The results from Wales following the move to an opt-out system on 1st December 2015 have been positive.

General consent rates for organ donation in Wales are currently the highest in the UK, at 72%. Prior to the introduction of the new system in Wales, consent rates were 58% in 2015\textsuperscript{12}. This suggests that opt out legislation has positively influenced consent rates.

Support for the opt-out system in Wales remains high amongst the general public and NHS Staff, and only 6% of the population have opted out\textsuperscript{13}.

In 2017/18, there were a total of 74 deceased donors in Wales, compared to 61 in the previous financial year. 2016/17 saw a decrease of 5% in the number of donors in Wales, down from 64 in 2015/16\textsuperscript{14}, however this can be attributed to changes in the screening procedures used to identify potential donors, rather than an issue with the legislation itself.

Monitoring the implementation of the Welsh bill over time will shed more light on its impact on actual donor numbers; however evidence suggests that it is likely to have a positive impact. International evidence estimates that countries with soft opt out legislation have on average 13-18 per cent higher organ donation rates than countries without\textsuperscript{15}.

Countries such as Israel, Belgium, Norway, Spain & Sweden all operate opt out organ donation systems. Spain introduced their opt-out system in 1979 and has the highest levels of donations per million population in the world\textsuperscript{16}.


\textsuperscript{14} NHS Blood and Transplant, 2018, Organ Donation and Transplant Activity Data: WALES, Annual data for financial years 2013/14 to 2017/18.


The Human Tissue (Authorisation) (Scotland) Bill could increase consent rates from families, meaning more lifesaving transplants could be performed every year.

BHF Scotland is concerned with the low levels of family authorisation for organ donation in Scotland, which at 58.9% in 2017/18 is the lowest across the UK\(^\text{17}\).

Research has shown that people living in countries with soft opt-out legislation were more likely to report a willingness to authorise the donation of their relatives’ organs compared to respondents living in countries without such legislation\(^\text{18}\).

The system created by the proposed bill ensures that those close to a potential donor retain the right to make health care professionals aware of the most recent views that person held on organ donation.

The opt-out system allows people to be explicit about their wishes, and this can help families be clearer about what their loved one would want.

Consent rates are highest when the potential donor’s decision to donate is known to their family (almost 90%) so it is important that organ donation is normalised and people are comfortable talking about and making decisions on the issue.

An opt-out system along with increased campaigning will help. This has been done successfully in Wales, where The Human Transplantation (Wales) Act 2013 includes an obligation for the Ministers to promote a campaign for the purpose of informing the public about deemed consent at least once every 12 months. 55% of people in Wales reported discussing their wishes around organ donation with family in September 2017, compared with 38% who reported having done so in June 2012\(^\text{19}\).

In recognition of the importance of public awareness relating to consent rates, it will be the duty of the Scottish Ministers to raise public awareness of the terms of the new proposed bill, and specifically what is meant by deemed authorisation for transplant. This is established in section 2 of the proposed bill\(^\text{20}\).

The explanatory notes associated with the proposed bill specify that accessible public information will be produced with targeted information developed for different groups in society\(^\text{21}\). This is in addition to media campaigns and other awareness raising initiatives already required by the 2006 act. This has the potential to create a cultural change.

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\(^\text{17}\) NHS Blood and Transplant, 2018, Organ Donation and Transplantation Activity Report 2017/18, p135


regarding organ donation, making it easier for people to discuss their views with family members, driving positive change in consent rates.