

Organ and Tissue Donation (Deemed Consent) Bill - Second Stage

BHF Northern Ireland welcomes the Second Stage of the Organ and Tissue Donation (Deemed Consent) Bill and calls on MLAs to support the Bill.

The Bill seeks to amend the Human Tissue Act 2004 and change the current organ donation system in Northern Ireland. Currently in Northern Ireland donation will only ever proceed if a person had given their express consent for organ donation, usually by signing on to the NHS Organ Donor Register and/or speaking to their family. In the absence of this, the family is asked to make a decision on behalf of the patient.

Under the proposed opt-out legislation, it is considered that everyone would be willing to donate their organs unless they have formally opted out, or in certain exempt circumstances. The family would continue to be consulted about donation as well as considerations around faith and beliefs. This will not change.

Why is action necessary?

Organ transplantation is the only effective treatment available for many patients with organ failure. Around 14 people die each year while on the waiting list in Northern Ireland.

- **As of 30 June 2021, there were 125 people waiting for an organ transplant in Northern Ireland, 16 of them waiting on a new heart.**¹
- Over 90% of the population in Northern Ireland supports organ donation but only 50% have recorded this decision on the NHS Organ Donor Register.²
- A recent poll commissioned by BHF showed that 74% of people here support the introduction of a soft opt-out system for organ donation.³

Evidence from other countries

Many countries have adopted a soft opt-out system. The vast majority (90%) of countries with the highest organ donation rates have an opt-

¹ <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/>

² <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/24209/nhsbt-northern-ireland-summary-report-jun-21.pdf>

³ Poll conducted by YouGov on behalf of British Heart Foundation Northern Ireland. Total sample size was 500 adults. Fieldwork was undertaken between 24th - 29th June 2021. The survey was carried out online. The figures have been weighted and are representative of all NI adults (aged 18+).

out system in place. Countries that have introduced this system as part of a wider package of measures are associated with a higher number of donations.

Spain has sustained its position as the country with the highest donations rate by introducing a package of measures alongside a change in the law. This includes increased availability of formally trained transplant co-ordinators at the point of care, increased numbers of intensive care beds, and increased training and positive communication links between the national transplant authority and public.

To **maximise the potential of a soft opt-out system**, legislation must be accompanied by:

- o a comprehensive communications strategy pre and post the introduction of a soft opt-out system;
- o investment in health structures including workforce to maximise the potential of a soft opt-out system;
- o organ donation becoming a key part of the everyday routine within hospital practice.

Wales

- Evidence from Wales, which introduced a soft opt-out system in 2015, has shown an increase in both consent rate and donation rate as well as support from health service staff for the change in organ donation system.
- Concerns about a potential backlash and mass opting out were not realised in Wales. 6% of the population in Wales have registered to opt-out.
- Wales now has the highest organ donation rates per million population (pmp), in the UK as well as the highest consent rate at 69.5%. This compares to England (68%), Scotland (65%) and Northern Ireland (62%). The consent rate is the percentage of eligible donor families approached for formal organ donation discussion where consent was ascertained.⁴
- In England, a new opt-out system came into effect from 20 May 2020. Scotland's opt-out system came into effect on 26 March 2021.

Organ donation as a gift

⁴ <https://www.odt.nhs.uk/statistics-and-reports/annual-activity-report/>

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The BHF believes a soft opt-out system of deemed consent, maintains the principle of organ donation being a gift voluntarily given by the donor, because the ability to opt-out is built in to the legislation. There is no evidence to show that an opt-out system would harm the sense of donated organs as altruistic acts, thereby potentially damaging donation rates. Reiterating the value of the gift of organ donation should be an integral part of any communications strategy.

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