

Irish Donor Network

1 organ donor can save up to 7 lives

‘Making Organ Donation the Norm in Ireland’

A briefing paper in support of ‘Soft Opt Out’ organ donation

Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and
Public Display)
Bill 121 of 2022

Second Stage of the Legislation
24 January 2023

IDN

January 2023

About this Submission to T.D's from the Irish Donor Network (IDN)

This short briefing paper is designed to give TD's some briefing notes in support of the proposed 'Soft Op Out' Organ donation consent in the Human Tissue Bill.

The second stage of the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and Public Display) Bill 121 of 2022 is due to commence on 24th January 2023.

The Irish Donor Network (IDN) is comprised of the following national patient/voluntary groups:

The Irish Donor Network

Alpha One Foundation
Children's Liver Disease
Cystic Fibrosis Ireland
Cystinosis Ireland
COPD Support Ireland
Irish Heart and Lung Transplant Association
Irish Lung Fibrosis Association
Irish Thoracic Society

Background

In the Programme for Government, 2020, the Irish Government pledged to:
'Enact the Human Tissue Bill, providing the legal basis for an opt-out system of organ donation and deliver a public information campaign'.²

This commitment and the recent publication of the Human Tissue Bill are warmly welcomed by the Irish Donor Network, a network of patient groups concerned with organ donation and transplant issues in Ireland.

One organ donor can potentially save 7 lives.¹ There are also benefits to recipient families and Irish society in general, including the Irish health system and the wider economy in promoting transplantation and working towards the most effective organ donor system possible.

¹ One deceased organ donor can potentially provide 2 lungs, 1 heart, 2 kidneys, 1 pancreas and 1 liver. One donated liver can be split, so it is even possible to save 8 lives.

Optimising the availability of organs for transplantation is the goal of all countries with an active transplant programme. Ireland is among the European countries that has developed the expertise to undertake transplants for the 5 major 'solid' organs - kidney, lung, heart, pancreas and liver.

The national transplant programmes in Ireland are undertaken in 3 hospitals- the Mater Hospital (heart and lung); Beaumont Hospital (kidney) and St Vincent's Hospital (liver and pancreas). These programmes further rely on the support of all major ICU hospitals around Ireland and for coordination by the Office for Organ Donation and Transplantation Ireland (ODTI).

Many remain on the waiting list for a transplant in Ireland

In 2021 there were 669 people reported to be on the overall transplant waiting list in Ireland and there were 31 deaths reported of those waiting for transplant.²

Despite much public good will and excellent clinical expertise and dedication, organ donor and transplant rates in Ireland are below average when compared with our European neighbours. Ireland was only in 18th place out of EU28 for transplants in 2020 and only in 17th place for deceased organ donation that same year.³

Action is needed to move Ireland into the top 10 EU countries for donation and transplantation. In this context The Irish Donor Network supports the introduction of Soft Opt Out in the Human Tissue Bill. We also call on Oireachtas members to press for the necessary additional resources to make this donor consent change work.

These additional resources are needed both for organ donation, transplant and post-transplant care such as: Additional beds for pre and post-transplant care; operating theatre resources; public awareness, doctors and MDT staff including nurses, psychologists and microbiologists.

² Statista (2023) <https://www.statista.com/statistics/538327/number-of-patients-active-on-organ-transplant-waiting-list-in-ireland/>. Figures relate to 2021
<https://www.statista.com/statistics/540075/patient-deaths-on-organ-transplant-waiting-list-in-ireland/>

³ Irish Donor Network. (20 September 2021 Press Release. <https://www.cfireland.ie/about-cf/latest-news/irish-donor-network-expresses-concern-at-significant-decline-in-transplantation-and-organ-donation-rates>

The Proposed Change to Soft opt out Organ Donation

The Human Tissue Bill introduces a Soft Opt Out system of consent for organ donation. Under this system, consent for organ donation will be deemed unless the person has, while alive, registered his/her wish (online) not to become an organ donor after death.

This is a change from the current system where decisions on organ donation are the responsibility of the next-of-kin and assumes that an individual has a desire to donate their organs after their death unless they make a statement of objection to donation.

The next of kin will continue to be consulted before any action is taken, and the wishes of the deceased should be central to this decision. Soft Opt Out differs from Hard Opt Out in relation to the point of consultation with next of kin. In the Hard Opt Out approach (not envisaged for Ireland) next of kin would not be consulted.

The Human Tissue Bill also provides a framework for the donation of organs and tissues and cells from living donors including the introduction of a legislative basis for non-directed altruistic living donation.⁴

It is anticipated that these measures will help increase the donor pool in the State and will encourage organ donation to save lives in circumstances where this is possible.

Under a soft opt-out system, individuals have the same choice as with an opt-in system—to donate or not to donate—so individual autonomy and choice are protected and respected.

It is simply the way people's views are expressed that would change. All organ donation is and will remain a gift after the introduction of soft opt out. Further, Families are often comforted by knowing something good has come from their loss.

The expectation under an opt-out system, organ donation would become the default position which, over time, changes expectations in society and becomes the societal norm. Thus, there would be a shift where donation is the

⁴ A living person who donates one of their kidneys to someone they do not already know is called a non-directed altruistic kidney donor.

natural and expected thing to do. There is evident to support this change in other countries.

What evidence is there to support Soft Opt Out Organ Donation?

A study published in the Journal Anaesthesia (September 2020) compared deceased organ donor rates in Wales (with a soft out system since 2015) and England (which only introduced soft opt out in 2020)

After 3 years (2015–2018) *the chance of consent in Wales was double that seen in England and donor numbers had risen more rapidly* (Wales: 18.0 to 28.9 donors Per million population (pmp); England: 20.0 to 24.3 donors pmp).⁵ It should be noted that the improved rate of transplantation took time and resources after the change was introduced in 2015. The study concluded by stating:

*‘Our study and the experience from Wales provides evidence to inform and support opt-out initiatives world-wide which, if replicated, could increase consent rates and consequently improve the number of organs available for transplant’.*⁶

The change to Soft Opt Out was strongly supported by patient groups in Wales who had campaigned for its introduction:

‘Kidney Wales Trustee and Transplant Surgeon Dr Mike Stephens says: *“The opt out legislation has been a huge positive in so many ways. We shouldn’t forget that there really wasn’t unanimous opinion that this was the right way to advance organ donation, and it was only with strong pressure from groups especially Kidney Wales that this change came about. Since deemed consent has been introduced we have seen Wales move from a consent rate for organ donation that was the lowest in the UK, to the highest, with figures now very close to what we know is representative of the populations actual opinion. The success has persuaded both England and*

⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7496553/> Madden S, Collett D, Walton P, Empson K, Forsythe J, Ingham A, Morgan K, Murphy P, Neuberger J, Gardiner D. The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system. Anaesthesia. 2020 Sep;75(9):1146-1152. doi: 10.1111/anae.15055. Epub 2020 May 5. PMID: 32372409; PMCID: PMC7496553.

⁶ Ibid

Scotland to follow us, and we have recently heard that Northern Ireland are also now looking to follow.⁷

Spain has traditionally the most impressive record on transplantation and organ donation in the European Union and has had a soft opt out system since 1979. According to the Citizens Advice Bureau in Spain you are automatically an organ donor unless you opt out in writing.⁸ In Ireland it is proposed you can opt out by going to a secure online register, which is a more modern approach.

Public Consultation in Ireland

A Report on the Public Consultation Process on Proposals for a Human Tissue Bill was published by the Department of Health in December 2017 and the results summarised below:

This Six week public consultation process in 2017 had the following results:

- 257 responses – 80% from general public
- 65% in favour of the proposals for soft opt out
- 12.2% opposed the proposal⁹

There was also a previous public consultation in respect of an opt out system of organ donation in 2013. The Department of Health invited written submissions in 2013 from the general public and all interested parties. The majority of these submissions were in favour of an opt out form of organ donation but issues were raised including the need for adequate resources and infrastructure to help ensure the change will optimise the number of organs for transplantation.

Conclusion

We would urge all TD's to support Soft Opt Out Organ Donor Consent in the Second Stage of the Human Tissue Bill and the further stages of this Bill. We

⁷ <https://www.kidneywales.cymru/news/2020/11/30/organ-donation-opt-law-marks-5-year-anniversary/>
Kidney Wales Website (2023). Kidney Wales is a registered charity that was formed in 1967 and was previously known as the Kidney Wales Foundation.

⁸ <https://www.citizensadvice.org.es/in-spain-you-are-automatically-an-organ-donor-or-opt-out-in-writing/>
Citizens Advice Bureau, Spain (2023)

⁹ <https://assets.gov.ie/13155/c3451bb4de68444abe38486fcab3b2f6.pdf> Report on the Public Consultation Process on Proposals for a Human Tissue Bill December 2017. Department of Health.

would further urge you to seek more resources to ensure this change is effective. These additional resources are needed both for organ donation, transplantation and post-transplantation care such as

- Additional beds for pre and post-transplant care
- Assessment and organ retrieval
- Post-transplant doctors and Multi-Disciplinary teams
- Optimising the use of operating theatres
- Public education programmes, by state and patient groups
- Training for clinical staff

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