



The Irish Kidney Association's position on consent for organ donation, April 2017:

Background:

The IKA has always been a strong advocate for the introduction of an Organ Donor Registry – a central database that records people's wishes in relation to Organ Donation which is consulted by the relevant hospital staff every time before a family is approached to discuss the possibility of organ donation. Such a Registry would ensure that people have the opportunity to have their informed consent, or otherwise, properly recorded and available at the required time.

The IKA is the organisation that has produced the organ donor cards and distributes them countrywide. Initially, in 1978, some 39 years ago, the organisation formed to initiate the first ever Irish kidney donor card. As transplantation evolved to include heart, lung, liver and pancreas transplantation, the donor card equally evolved into the organ donor card we know today.

In all this time the principle of "Informed Consent" has applied and, for the last 10 years, there has been a public debate about the possibility of changing our system of consent to one of "Soft opt-out" or "Presumed Consent".

We recognise that this debate has helped increase awareness of organ donation as there has been significant public interest in the discussion 'for and against' such a change. In recent times we have observed the changes in Wales and France. The debate is topical as it highlights the plight of those awaiting organ donation and their frustration and fear of dying before an organ becomes available to them.

The Government wants to change the law on consent for organ donation to a soft opt-out system (also commonly called presumed consent). Essentially, such a 'change' in the law would see no change in practice. During previous public and private consultations on the topic, the medical professionals directly involved with consent for organ donation were unanimous that the next of kin must be consulted in the organ donation consent process and that such a 'change' in the law would not see a change in their practices.

The IKA regularly fields media interviews, phone calls, emails and social media enquiries as well as questions at public awareness talks in relation to how organ donation works. There is a common misconception that an organ donor card must be present for organ donation to be considered. This is not the case, the donor card is there as a prompt for the family conversation and as a reminder of the commitment made. A family can consent to organ donation even if a donor card is not present.

Once this is understood, many are incredulous when they hear that there is no Organ Donor Registry – the argument being that it would be a much safer way of ensuring that an individual's wishes are properly recorded and can therefore be followed through.

So why create a consent law that has already been rejected by those working in intensive care units. An argument that changing to a "Soft opt-out" position, would help the public to realise that organ donation should be the norm, is confusing to the IKA. Having a "Law" which involves saying one thing, and the "practice" being another thing altogether, would cause confusion. Soft opt-out, in practice, will still be informed consent.

This proposed change now becomes a relabelling or rebranding of consent, but the product and process will remain the same. Be assured that if the IKA thought that creating this new consent law would increase organ donation rates, we would support the proposal. Similar laws exist throughout the EU and beyond. However, in

practice in all EU countries consent for organ donation is sought from the next-of-kin, and refusal to consent is permitted and observed. What is very different in the countries that have a 'high rate' of organ donation is the infrastructure and support services in their health service for the organ donating process. We have a long way to go to improve our infrastructure and process that will enable us to maximise our organ donation capabilities.

The consent of the public is a small aspect of this process. However, the IKA do believe that, after almost 40 years of listening to the public's views, the limitations of the organ donor card need to be understood and the introduction of an Organ Donor Registry will bring us up to-date internationally and satisfy the public's request for clarity and certainty in organ donation. It will also prove to be a valuable tool for those involved in the health services seeking consent for organ donation. They alone will be able to access the registry database and inform the next-of-kin of the 'deceased' directive in the organ donor registry.

The HSE is currently seeking the views of the public on the implementation of a national consent policy. It seems logical to include consent for organ donation in the discussion. What is clear in the discussion document is that in capturing the consent of the public it is important that it is informed consent – every individual should understand what they are consenting to and this consent should be properly recorded.

Deceased Organ and Tissue Donation Register (Proposal)

Advance Care Directive

**If I die in the circumstances that organ and tissue donation can be considered
(Tick one box only)**

I consent to, and Authorise, the retrieval of all my useful organs and tissue to help others

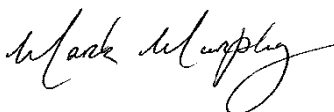
I consent to the retrieval of all my useful organs and tissue to help others, provided that authorisation is sought from my next of kin

I consent to my next of kin deciding whether the retrieval of my organs and tissue should occur

I do no consent to my organs and tissues being retrieved

This registry will give a new added direction for the public to secure their wish, for their next-of-kin to follow. The organ donor awareness campaigns will be regenerated with the modernisation of the tools available to the public and every opportunity for the family discussion to continue will be offered by the registry's design.

When the public is properly informed about organ donation there is overwhelming support for it. A properly funded education programme and a properly structured Organ Donor Registry would ensure that the public are in a position to give their informed consent and that this consent is properly recorded so that it can be acted upon.



Mark Murphy,
Chief Executive.
Irish Kidney Association



HEAD OFFICE
Donor House, Block 43a, Park West, Dublin D12 P5V6
Telephone: 01-620 5306 – **Email:** info@ika.ie – **Website:** www.ika.ie

Patron: Michael D. Higgins, President of Ireland.

CHARITY REGISTRATION NO. 20011260

