

Consent for organ and tissue donation after death

MEMBER BRIEFING



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This briefing is intended to provide background information to RCN members across the UK who wish to complete **the RCN survey** on consent for organ and tissue donation after death. The survey will be open from 15 January to 11 February 2018.

Why is the RCN reviewing its UK position?

The RCN produced a position on consent for organ and tissue donation in 2009. At that time, after gathering and discussing member views, the RCN Council decided to support the opt-in arrangements which were then in operation across the entire UK. They also agreed to review this position at a later date.

Each of the four countries of the UK is able to make its own laws on consent for organ and tissue donation. In 2015, the law changed in Wales to introduce a “soft opt-out” system for organ and tissue donation from people aged 18 and over who are normally resident, and die, in Wales. There have also been moves since 2009 to change the law in Northern Ireland and Scotland to opt-out systems. Whilst these attempts did not succeed, there are new plans being debated in both England and Scotland to legislate to introduce opt-out systems for organ and tissue donation.

Given all these changes since 2009, the RCN has decided that it is now time to gather views and review its current UK position on consent for organ and tissue donation after death. This factual briefing is intended to help inform RCN members, who we are encouraging to complete **a short survey** to support that review. The RCN’s reviewed position will be available in spring 2018.

Some members will be dealing with these issues every day; many others will not. Whatever your experiences and wherever you live and work, we want to hear your views as a member.

The issues surrounding organ and tissue donation are varied and complex. Not every issue can be covered in detail in this short briefing. Suggestions for further reading are included at the end.

For clarity, this document and the accompanying **survey** are focused only on member views on the legal framework around consent for organ and tissue donations after death. It is not intended to cover issues around “live” donations where, for example, someone chooses to donate one of their kidneys to a relative whilst still alive. Nor does it cover wider aspects of practice around organ and tissue donation and transplantation.

What do “opt-in” and “opt-out” mean?

The terms “opt-in” and “opt-out” refer to the different legal systems which govern how people consent to donating their organs and tissue after death.

Opt-in

In the systems currently used in England, Scotland and Northern Ireland, people can opt-in to making organ and tissue donations after death. A person could do this by signing up to the organ donor register or by telling a family member what they would want to happen after their death. However, where someone has not made their decision on donation clear during their lifetime, a close family member would normally be approached by a specially trained professional to make a choice about donation.

There are nuances to this. For example, people can already make clear that they do not wish to make any donations after death by registering their preference on the organ donor register during their lifetime. Or they can choose only to donate certain organs or tissue when signing up as an organ donor. In practice, in those parts of the UK operating an opt-in system, organ donation is not forced in the face of opposition from a person’s family.

Opt-out

In an opt-out system (sometimes referred to as a system of “presumed consent” or “deemed consent”) people are presumed to have given their consent to organ and tissue donation after death, *unless they have actively recorded their decision to opt-out on a formal register*. Applying

this rule to anyone who has died and is eligible to donate organs or tissue at the time of their death is sometimes referred to as a “hard opt-out”.

A “soft opt-out” will permit families some level of involvement in the decision to remove organs or tissue after death; exactly how much will depend on how the framework is designed. There are often additional safeguards placed on the presumption that someone has consented to donate. So, for example, people who lack the capacity to make an informed choice during their lifetime might be excluded from an opt-out system. Such safeguards are written in to the legal framework

There are many variations of safeguards that can be attached to an opt-out system. The “soft opt-out” system in Wales, introduced in 2015, comes with a number of safeguards. For example, the Welsh system only applies to adults (aged 18 and over) and to people who meet certain criteria about being resident in Wales, and it excludes certain organs and tissues from the opt-out system. Information on where to find more detail on all the specific safeguards in place in Wales is included below.

The safeguards which will be attached to the proposed new opt-out laws in Scotland and England, if passed, are still to be determined.

Why is there a focus on consent at this time?

There are more people waiting for organ and tissue transplants across the UK than the donations currently available. As such, governments in all parts of the UK are currently focused on ways to increase the number of people who could become organ and/or tissue donors after death. Many of the approaches taken to increase donations are not about consent at all. There are current examples of publicity campaigns to increase sign-ups to the organ donor register or to encourage more people to talk to their family about their wishes during their lifetime. In Northern Ireland, for example, a consultation is taking place between December 2017 and March 2018 on how to increase donation rates without changing the law on consent¹.

However, there is ongoing debate about the impact of different systems of consent on the availability of donors. There are different views on whether an opt-out system for organ and tissue donation may or may not support an increase in the number of donations after death.

Changing how consent is given for donation after death requires a change in the law and raises particular ethical issues on which many people have strong opinions. As such, there are specific debates which are needed on the issue of consent to allow the democratic process on introducing, changing and implementing laws to take place.

What do we know about donation rates in the UK?

Before looking at the figures on donation after death, it is important to remember that less than 1% of people who die each year in the UK do so in circumstances, or from conditions, which would allow them to become donors³.

Figures from NHS Blood and Transplant show that there were a total of 1,413 deceased donors⁴ across the UK in 2016/17 who donated 4,741 organs – a 4% increase in deceased donors and a 2% increase in donated organs over the previous year.

The percentage of the entire UK population which has actively opted in to the organ donor register was 36% at the end of March 2017. There has been a steady increase, year-on-year, in the numbers opted-in to the organ donor register from 15.1 million at 31 March 2008 to 23.6 million at 31 March 2017.

Overall consent/authorisation rates for donations, given by families or appointed/nominated representatives, rose slightly to 63% in 2016-17. This increased to 91% where a person’s decision was known. One hundred families refused donation even though the deceased was known to have made a decision to donate.

However, despite increases in the number of potential donors, there were still 6,388 patients on the active transplant waiting list at March 2017. This does not include a further 3,357 patients who were temporarily suspended from the active list because they were unfit or otherwise unavailable for transplantation.

During 2016/17, 470 patients died whilst awaiting a transplant on the active/suspended list, or within a year of being removed.

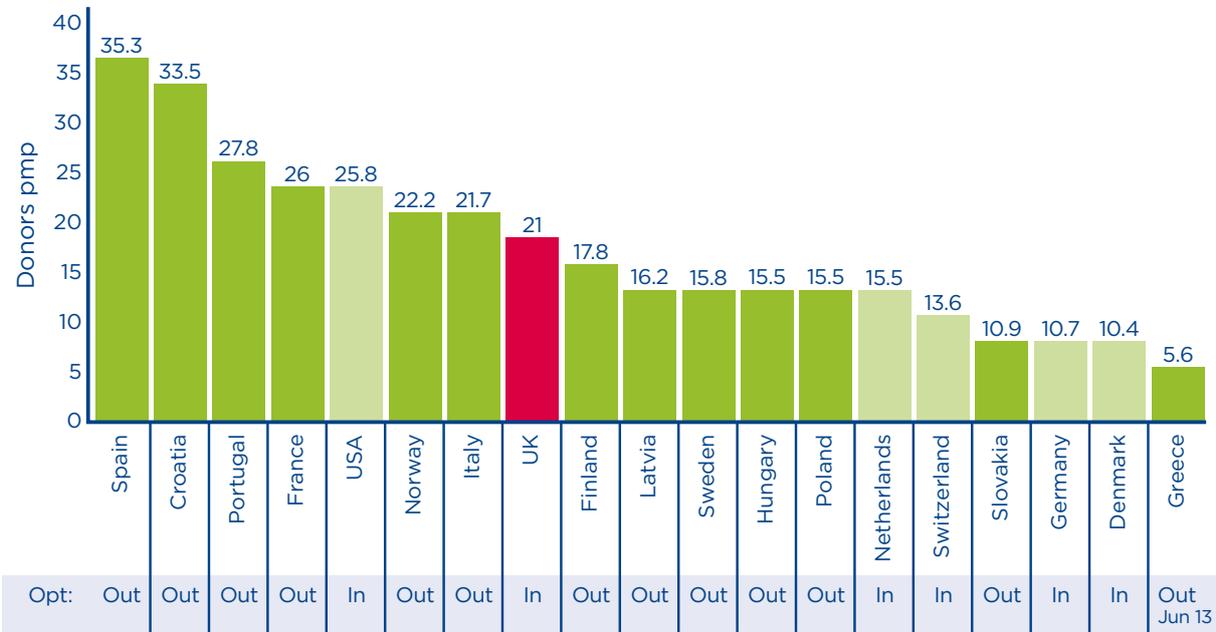
Whilst there are shortages of available donors across the population, there are particular issues in securing donations for people from black or Asian backgrounds, who are more likely to experience conditions which may require a transplant and who face a shortage of matched donors⁵.

Anyone in the UK can actively register their wish not to donate organs or tissue after death. However, the different laws on deemed consent in Wales of course means that there is a particular motivation to explicitly opt-out of the organ donor register in that part of the UK, if a person does not wish to donate. Across the UK at 31 March 2017, 204,518 people had registered to opt out of donating their organs after death; 86% of these opt outs were from people living in Wales.

What is the evidence of the impact of opt-out systems on donation rates?

Different countries across the world operate different versions of opt-in and opt-out systems for organ and tissue donation after death. The recent Scottish Government consultation on Organ and Tissue Donation and Transplantation included the table below, which compares rates of donation after death in a number of countries. However, the Scottish Government also noted that donations are affected by many factors and that those countries with some version of an opt-out system do not always show higher rates of donation. The number of donations made is, of course, also not the same as the number of successful transplants completed.

Fig 1: Deceased organ donors per million population in key countries - September 2014⁷



Published deceased donor stats Europe and USA 2014 (with opt in/opt out status included)

Within the UK, Wales is the only place to have a soft opt-out system in place. An evaluation report on the first two years' operation of this legal framework was published in November 2017, two years after the change in the law, and concluded:

- Awareness of and support for the soft opt-out system of organ donation in Wales is high among the general public and NHS staff.
- However, there has been a recent drop in awareness levels among the general public suggesting that publicity of the law needs to be maintained.
- More clarity around the role of the family in the organ donation process is required. This should encourage discussion in families, which may help them support the decision of a deceased relative.
- NHS staff working within organ donation may also benefit from further training, particularly around the organ donation conversation with the family.
- Despite the high awareness and support for the new law, analysis of routine data does not show any consistent change in deceased organ donations in Wales, or more widely from Welsh residents.
- Analysis of consent data shows an increase in the percentage of families giving approval for donation. However, this is not reflected in a rise in donors overall, implying there has been lower eligibility over the period since implementation of the law.
- A longer period of time is needed to draw firmer conclusions around the impact of the change in the law. It will be important to continue to monitor public attitudes and the routine data on organ donation in Wales (and more generally across other parts of the UK for comparison)⁶.

Where can I find further information about consent for organ and tissue donation?

Here is a short list relevant publications or websites that you may wish to explore in more detail. This is not intended to be an exhaustive list and there is a great deal of information on consent available online:

UK-wide

- NHS Blood and Transplant website (<https://www.nhsbt.nhs.uk/>)
- The Human Tissue Authority website (<https://www.hta.gov.uk/>)
- Working together to saves lives: The Organ Donation Taskforce Implementation Programme's Final Report, 2011 (<https://www.gov.uk/government/news/organ-donation-working-together-to-saves-lives>)
- The Organ Donation Transplant Activity Report 2016/17 (<https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/transplant-activity-report/>)

Wales

- Organ Donation Wales website (<http://organdonationwales.org/?lang=en>)
- An evaluation of the Human Transplantation (Wales) Act (<http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en>)

England

- Consultation on introducing 'opt-out' consent for organ and tissue donation in England (<https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england/consultation-on-introducing-opt-out-consent-for-organ-and-tissue-donation-in-england>)

Scotland

- Organ and Tissue Donation and Transplantation - a consultation on increasing numbers of successful donations (<https://consult.gov.scot/health-protection/organ-and-tissue-donation-and-transplantation/>)
- Organ Donation Scotland (<https://www.organdonationscotland.org/>)

Northern Ireland

- Promoting Organ Donation and Transplantation in Northern Ireland – a consultation (<https://www.health-ni.gov.uk/consultations/promoting-organ-donation-and-transplantation-northern-ireland>)

References

- 1 See: <https://www.health-ni.gov.uk/news/developing-holistic-approach-organ-donation-consultation-launched> (accessed 17/12/17). Please email john.knape@rcn.org.uk if you are based in Northern Ireland and are interested in contributing to the RCN response on this.
- 2 Unless referenced otherwise, all figures on donors and donations in this section are taken from: <https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/transplant-activity-report/> (accessed 05/01/18)
- 3 See: <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england/consultation-on-introducing-opt-out-consent-for-organ-and-tissue-donation-in-england> (accessed 17/12/17)
- 4 This includes both numbers of deceased donors after brain death and deceased donors after circulatory death
- 5 See: <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england/consultation-on-introducing-opt-out-consent-for-organ-and-tissue-donation-in-england> (accessed 17/12/17)
- 6 See: <http://gov.wales/statistics-and-research/evaluation-human-transplantation-wales-act/?lang=en> (accessed 17/12/17)
- 7 See: <http://www.gov.scot/Publications/2016/12/3657/downloads> (accessed 17/12/17)

General note on definitions

The Human Tissue (Scotland) Act 2006 uses terms of ‘authorisation’, rather than ‘consent’, in the current legislation with regard to donations in Scotland. Authorisation equates to the principle of “consent” on which the Human Tissue Act of 2004 is based. The equivalence of the two principles is an essential part of the continuation of the arrangements for sharing organs across the UK. For the purpose of this briefing we use the term consent.

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RCN Online
www.rcn.org.uk

RCN Direct
www.rcn.org.uk/direct
0345 772 6100

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