

Royal College of Nursing's (RCN) consultation response: Introducing 'Opt Out' Consent for Organ and Tissue Donation in England, March 2018.

This consultation response details the RCN's UK wide position on a soft-opt out system for organ and tissue donation, and will cover the issues raised by our members, and those that are within our remit to comment on.

RCN UK position statement

The Royal College of Nursing supports an opt-out system of consent for organ and tissue donations after death, where there is evidence that certain safeguards, supports and resources are in place.

The fieldwork to seek the opinions of our members was launched in January 2018, with an all member survey closing on 11 February 2018. From across the UK and overseas, **7,746 members completed the survey; 6,189 respondents were from England and including a small number of specialist nurses** working in organ and tissue donation (SN-ODs). As Wales implemented a soft opt out system for organ and tissue donation in 2016, we tailored the questions for the members living in this country to reflect devolved differences.

Following extensive consultation, 71% of RCN members were in favour of an opt-out system of consent for organ and tissue donation (rating between 7 and 10 on a scale of 0-10 from opt-in to opt-out).

The safeguards, supports and resources we would expect to accompany any soft opt-out system are:

- Sufficient resources are made available to define and support the additional infrastructure and capacity required to increase the rate of successful donations, including increased and sustainable investment in the number of Specialist Nurses in Organ Donation, before any opt-out system is introduced.
- An evaluation is commissioned to assess the medium- to long-term impact of any opt-out system on the rate of successful donations. Any opt-out system is reviewed on the basis of this evidence.
- Governments start a public awareness campaign no less than a year before any change to an opt-out system, and then sustain that campaign. There are multiple, accessible routes for every adult to opt-out of donating at any time, if they so choose.
- Governments start an awareness and education programme for all health care professionals, tailored to the needs of specific groups, no less than a year before any change to an opt-out system, and then sustain that programme. Clear and up-to-date guidance on the operation of any opt-out scheme is available to all health care staff.
- Trained health professionals must discuss the expressed wishes of the deceased person with the person's family, where contactable, before any donation proceeds. If a family does not want a donation to go ahead it will not be forced.
- The opt-out system is limited to adults only (as defined in each UK country). Consent for donations from children and young people should continue to be addressed by existing opt-in / parental consent arrangements.

- Adults who have never had the capacity to consent would not be included in the opt-out scheme. The scheme must also make clear how adults who lost the capacity to consent for a period before death would be excluded from the opt-out.
- The opt-out scheme is limited to organs and tissue donated for transplant. Adults must still opt-in to donate organs and tissue for research and other purposes.
- Any opt-out scheme makes clear which organs and tissues are included.
- Any opt-out scheme should have clear residency criteria included to ensure that temporary residents are not presumed to have given consent.

The most important concerns raised by nurses and nursing staff working across health and care settings, and at different career stages, included: the impact an opt out system may have on an already overstretched workforce; the need for reassurance that there will be measures to raise public awareness, and; that nursing staff will have support and training to understand the impact legislative changes on organ and tissue donation will have on their work.

1. Workforce and infrastructure: safe and effective nurse staffing levels

There is a shortage of registered nurses across the UK. In the UK in 2017, for the first time in a decade, more nurses left the profession than were joining the register.¹ **The latest available data from NHS Improvement shows that at in December 2017, the NHS in England had a total of 35, 835 registered nurse vacancies. Of these vacancies, 26,276 were in acute care settings.** The majority of potential organ and tissue donors are identified in acute care settings and so, if acute care settings are understaffed, opportunities for increasing organ and tissue donations may be missed. We also know that when there are not enough nurses, patient safety is put at risk.

It is clear to us and partner trade unions that the existing organ donation services are already over stretched. Through discussions with NHS Blood and Transplant (NHSBT), we know that SN-ODs are working above and beyond, in overstretched conditions, to meet patient need.

SN-ODs lead the clinical donation process, and offer support to and gain consent from the families of each potential donor. SN-ODs are Agenda for Change at band seven, are employed to work Monday to Friday, 09:00-17:00 with all other hours being covered by on-call. The current on-call requirement for the SN-ODs means that they are on call for a 24 hour period for approximately 7 occasions in a 30 day period, during which time they could be physically working for the entire 24 hours. This is in addition to their contractual working hours. Added to this excessive workload could be final travel home time of up to an additional 3 hours following their facilitation of a donation process. This is the same structure and workload which has been in place in excess of 20 years and is no longer fit for purpose.

If the outcome of this consultation is favourable to a soft opt out for organ and tissue donation, significant current pressures on NHSBT will need to be addressed. There are currently 12 teams working across the UK, but our own estimates suggest that the SN-OD workforce may have to manage an increase in organ donors in the region of 100-120 per annum across the country if opt out was to be implemented. **NHSBT's own statistics show that in 2017, to achieve their final number of 1413 proceeding donors, 8280 potential donors and families were seen and approached by a SN-OD.**² Therefore, to achieve a potential increase of 100 donors in England, it is estimated there would need to be 550-600 extra approaches being made per year.

¹ Nursing and Midwifery Council, "New figures show an increase in numbers of nurses and midwives leaving the professions", July 2017. Available [here](#).

² NHS Blood and Transplant, 'Organ Donation Statistics by Country', Accessed March 2018. Available [here](#).

An increase in SN-ODs, and expanding the specialist workforce was a significant factor members had based their view on organ and tissue donation upon. For those respondents who have no fixed view on a change to an opt out system for organ and tissue donation, 69% would be more in favour, if more SN-ODs trained and recruited before an opt-out system is introduced.

Funding is vital for health and care transformation and innovation. Funding granted to NHSBT for organ and tissue donation across the four devolved countries is assumed to remain flat until 2022.³ If the decision is taken to move to an opt out model for organ and tissue donation in England, funding decisions must be based on a genuine analysis of expected demand, what services will be provided, and how they will be delivered. Organisational transformation cannot be achieved safely and effectively without funding to ensure that standards of patient care are maintained.

2. Moving to an opt out system: raising awareness among the public and upskilling healthcare professionals.

Raising awareness and educating the public

If an opt out system for England is introduced, respondents were clear that an important condition for this change, is the need to raise awareness amongst the general public, and healthcare professions. Nursing staff, and others working with potential donors and their families, need reassurance that any changes to the organ donation system will be effectively communicated. We would recommend that a change to an opt out system has an implementation period of one year, to enable both the public and healthcare professionals to understand the impact and any potential implications of the new legislation.

At the moment, the majority of nurses who work outside of intensive care units, critical care, emergency departments, or specialist organ transplant units do not regularly spend their working time treating or supporting potential donors and their families. As these staff don't have high levels of exposure to potential donors, and don't witness organ donation in practice, they are unlikely to feel confident to discuss the issues.

From our survey, the majority of respondents reported having little to no engagement with potential donors and their families regularly. There is much more to be done to ensure that nursing teams, and wider healthcare workers are upskilled to understand organ and tissue donation practices, and to increase their confidence to speak to potential donor families. Delivering this sort of outreach work with staff is part of the SN-OD's job description, but as the donor numbers increase, the SN-OD will likely have less time to spend on development and teaching. It is the responsibility of the Department of Health and Social Care to build support for changing the law in England, and for all devolved governments to ensure that the public and healthcare professionals are adequately informed, and trained.

Among members in England, Scotland and Wales who were either against opt out or felt unsure about the change, members felt more favourable to an opt out system if **an education programme for all health care professionals would be run for at least a year before any change was implemented.**

The Health Education England budget for "workforce development", which is largely used for Continuing Professional Development (CPD) for nurses, has been cut from £104.3m to £83.49m in 2017-18, after it was almost halved from £205m the year before. The "future workforce" postgraduate medical and dental budget will be increased by 2.7% in 2017/18.⁴ We are calling for the CPD budget for nursing staff to be reinstated. Training is important for

³ NHS Blood and Transplant, 'NHS Blood and Transplant annual report and accounts 2016-2017'. Accessed March 2018. Available [here](#).

⁴ Health Education England, *HEE Proposed Budgets for 2017/18*, Accessed 28/11/17, available [here](#).

nursing staff to gain confidence, maintain standards and understand emerging issues in healthcare like organ and tissue donation.

Co-producing guidance with SN-ODs

We welcome the UK Government supported Private Members Bill on Organ Donation (Deemed Consent) before Parliament sponsored by Geoffrey Robison MP, which would legislate for an opt out system in England.⁵ Clause 2 of this Bill includes a consequential amendment which places a requirement on the Human and Tissue Authority (HTA) to produce guidance on the ways in which an opt out system will work in practice, and on the detail of information provided to relatives of the deceased donor. We recommend that this guidance is clinically led, patient focused, and, made easily accessible to all working in, or caring for anyone involved in, organ and tissue donation. Any guidance drafted and developed by the HTA, must be co-produced with the SN-ODs leading the donation services, as they are well placed to advise on best practice, patient pathways and service design.

Conclusion

Our members' conditional support for introducing a soft opt out system for organ and tissue donation in England is reliant on the following recommendations as well as the above safeguards:

1. Awareness campaign aimed at the public for one year;
2. A training and educational programme for nursing staff for one year before implementation;
3. Funding and investment to match transformation in the service, including for the recruitment of additional SN-ODs, and any associated extra resources.

We look forward to working with the UK Government - once the outcome of the national consultation is known – on any future measures, guidance or legislation that may be required if a change to an opt out system for organ and tissue donation is recommended for England.

About the Royal College of Nursing

The Royal College of Nursing is a professional body and trade union representing over 430,000 registered nurses, midwives, nursing students, health care assistants and nurse cadets. Our members work in a variety of hospital and community settings in the NHS and independent sector.

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⁵ UK Parliament, *Research Briefing: Second reading, The Organ Donation (Deemed Consent) Bill 2017-2019*. Accessed March 2018. Available [here](#).