

RA statement on Government proposal for opt-out consent for organ and tissue donation in England

Executive Summary

The UK Renal Association is the professional representative body for renal doctors and scientists in England. The views of the membership were canvassed through a survey of all members. This statement represents the consensus of views expressed and the position of the RA in respect of the consultation for opt-out consent for organ and tissue donation in England.

The summary view of the RA is that the RA supports an increase in organ donation and the promotion of a transplant first approach to ESRD through KQuIP implementation. The RA believes that opting-out would need a significant campaign of public education, and that opt-out may not make a difference to transplant numbers without additional initiatives. Its membership believed that opt-out should be applied to adults with capacity and that various ways of recording an individual's preference should be promoted e.g. when registering with a GP, at other NHS premises and through a web based registry. As regards reversal of decisions by family members or feeling that certain groups may be disadvantaged members were equally split or uncertain. On an individual level the overwhelming majority felt that a change in law would not affect their decision about organ donation.

See <https://www.gov.uk/government/consultations/introducing-opt-out-consent-for-organ-and-tissue-donation-in-england>

Background

The waiting list for transplantation in the UK remains significantly greater than donor numbers, resulting in deaths while waiting for a transplant. There were 3155 transplants in 2016/7, and of the donors 1177 were deceased donors, while there were approximately 5400 patients on transplant waiting lists. With specific regard to kidney transplantation in 2017 there were 5197 adults and 80 children on waiting lists, and in 2016/7 there were 3347 kidney only transplants (127 in children), of which 2160 were from deceased donors (55 in children), as well as 178 multi-organ transplants (which included a kidney). In addition to deaths on the waiting list for kidney transplantation, there is an impact on long term health (including length of survival), for patients who have a long wait before kidney transplantation.

The majority of the public are in favour of organ donation after death, however, many do not register on the organ donor register (opt-in). Approximately 40% of potential organ donations do not proceed because of family refusing consent, commonly due to previously expressed wish not to donate, uncertainties of potential donors' wishes, not wanting further surgery to the body, and religious or cultural beliefs. This proportion is significantly higher for donors from ethnic minorities compared to white donors (65% vs 34% respectively).

Currently, patients are considered as donors if they have consented during their lifetime (signed on to the donor organ register or made their views known to family members). Families can also agree to donation after death of relatives, however, fewer families do so in UK than other countries.

There is a current proposal in process to consider opt-out consent, if accepted this would mean that all potential organ donors would be considered to have agreed to donation unless they specifically opt-out. People will still be able to record their decisions, be it opt in, opt out, or nominating a representative to decide. However, if no decision is recorded, the default decision would be that the patient supports being a donor. An opt-out system has been in place in Wales since 2015, with high levels of support among public and healthcare workers, but without evidence yet of changes in rates of donation. Other countries with opt-out systems have variable rates of organ donation in relation to the UK, some higher, some lower; there may be additional factors that are responsible over and above the consent process for maximising organ donation rates (such as the framework for identification of donors, communication to the public, and support for the donation process). There is evidence that an opt-out system does not reduce rates of donation, but it is unclear on its own how much of an increase it would result in.

The government is now seeking opinions on this proposal and the Renal Association is canvassing the opinion of the membership so that we can contribute to the consultation by providing a report that reflects the views of the membership

There are specific issues to be considered in the consultation: they include

Potential

1. Impact on families: will they be able to overrule the decision? Currently, around 100 donations a year are reversed by families despite the deceased having consented on the organ register. In Wales this can be overcome if family show that the deceased was opposed to donation, while in France they need to sign a refusal register or tell a relative who signs a declaration of refusal.
2. The impact on certain ethnic/religious groups in which there are real or perceived difficulties in talking about organ donation, the concept of brainstem death, wish for informed consent.
3. Exceptions to opt out rule: children (possibly under 18), people lacking capacity, tourists, overseas workers.

Implications

1. Financial: There would be a cost for communication of the changes and managing the potential increase in people opting-out and managing the opt-out registry (estimated at £15m initially and potentially £5-6m annually). Increased costs of more transplants, but this should be more than offset by the potential financial benefits of getting patients off dialysis (or other medical support in the case of other organs), and potential return to work. Potential QALY benefits of transplantation.
2. Will it increase donation? Evidence unclear, but not likely to reduce rates.

3. The potential increase in donors has been estimated to range from 0 to 142 to 422 per year depending on whether consent rates remain unchanged or increase from current 62% to 70% or 80%, translating to increases of between 0-1080 transplants per year, with between 0-680 increased kidneys transplanted per year.
4. More transplants, means more people off waiting list with reduction in waiting times
5. Modelling the changes predicts significant QALY gains to the health system, and a net positive value if rates of consent increase from 62.4 to 63.5% or more.

The questions being asked in the consultation include:

Should there be alternative ways to register decision apart from organ donor register?

Should more personal information be included?

What are best ways to inform the public of changes?

Should families be able to make the final decision if the deceased has not opted-out?

Should families be able to overrule decisions made by patients prior to death?

Who should be excluded from the opt-out system?

Results

We asked for members' opinions and 115 responded to the survey which closed in February

<https://www.surveymonkey.co.uk/r/FKBXSL9>

Q1. Do you think someone's family should be able to decide if their organs are donated, if it is different to the decision they made when they were alive?

44% thought there were sometimes circumstances where this should happen, while 48.5% thought this should never happen.

Q2. Should any of the following groups not be included in the proposed new rules about organ donation?

The majority of respondents agreed that children under 18 years, people lacking capacity and visitors to the UK should be excluded, while a minority believed that people living in England under 12 months should also be excluded, while others suggested a lower age cut off of 16 years.

Q3. If the law changes, people would be considered willing to be an organ donor unless they have opted out. Do you think this change could have a negative impact on people from some religious groups or ethnic backgrounds?

Here people were almost equally split, with a third saying yes, a third no, and a third uncertain.

Q4. If the law changes, and someone has died and they have not opted out of organ donation, should their family be able to make the final decision?

Here the majority believed that sometimes there may be such circumstances, while a small minority believed the family should always have the final decision.

Q5. If the law changes, would this affect your decision about organ donation?

Overwhelming majority said no it would not.

Q6. Do you think people should have more ways to record a decision about organ and tissue donation?

Vast majority believed that there should be more ways including when registering with a GP.

Q7. Do you have any other opinions about opt-out consent for organ donation?

<50% responded with a number of points: many did not think that it would increase donation, however, acknowledged that it would increase awareness and discussion around donation, while a few individuals were strongly in favour.

Q8. If implemented, how could we make the general public more aware of the new rules for organ donation?

50% answered: through press, radio, TV, social media, on NHS premises, but many were worried about the costs of such a campaign.

Q9. What are the advantages or disadvantages of including personal information on someone's organ donation decision?

<40% answered: anxiety about data governance, and potential to put off donation if other data were asked for. Question was a little ambiguous, but was intended to ask about adding information regarding donors wishes regarding donation.

Conclusions

Of the members who replied the feeling was that opting-out would not change their opinion about donation, may not make a difference to rates of donation, would require a significant campaign of education, and should be applied to adults with capacity. With regards the difficult questions of reversal of decisions by family members or feeling that certain groups may be disadvantaged members were equally split or uncertain.

Professor Alan Salama

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