

# Introducing ‘opt-out’ consent for organ and tissue donation in England

## RCS consultation response

### Overview

The Royal College of Surgeons (RCS) welcomes the opportunity to respond to the Department of Health and Social Care’s consultation on introducing ‘opt-out’ consent for organ and tissue donation in England. Organ transplantation remains one of the most important advances in modern medicine, enabling the treatment of patients who have failed, damaged or missing organs. However we believe there is insufficient evidence that an opt-out system of itself increases rates of organ donation. If adopted, it should not be used to replace the role family members and healthcare professionals play in consent and in order to preserve this relationship, if families object to organ donation, they should be able to overrule it. We would also caution that introducing an opt-out system may harm the sense of donated organs as altruistic acts, thereby potentially damaging donation rates.

Aside from legislative change, we would encourage the Government to focus on other measures to improve organ donation. This should include investment in public awareness campaigns and infrastructure that supports transplantation services. We have provided further details on our position in response to question 9 of the consultation.

Below are our responses to the consultation questions to which we are responding.

### **Q1. Do you think people should have more ways to record a decision about organ and tissue donation?**

We strongly support the proposal for there to be as many ways as possible to record a decision about organ and tissue donation, including through routes such as registering with a GP, dental surgery or optician. It would be useful for these changes to be made whether or not the opt-out system of consent is introduced. Increasing public awareness of the NHS Organ Donor Register should help to increase the numbers of donors and knowledge of a person’s decision. This in turn would build confidence in the system and support healthcare professionals when they approach families for consent to proceed with a donation.

### **Q2. What do you think are the advantages or disadvantages of including personal information on someone’s organ donation decision?**

We support the opportunity for people to include certain information about their decision to donate on the NHS Organ Donor Register. For example, some people may prefer to specify which organs they would like to donate. However we suggest the amount of additional personal information should be limited to prevent unnecessary delays to organ transplantation if there is uncertainty about a patient’s wishes.

**Q6. 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?**

Family members should always be consulted to make the final decision on organ donation, and should also have the power to overrule it. This would help to support the relationship between healthcare professionals and donor families.

**Q9. Please tell us about any opinions or evidence you have about opting out of organ donation.**

As per our comments in the 'overview' section, the RCS believes there is insufficient evidence that an opt-out system of itself increases rates of organ donation. The consultation document itself highlights the recent Welsh Government report on the opt-out system that was introduced in 2015, which states a longer period of time is needed to draw firmer conclusions around the impact of the change.<sup>i</sup>

We support the British Transplant Society's analysis that "assessments of the effects of opt-out laws on donation rates are hampered by differences in cultural attitudes, economic conditions, availability of intensive care units, numbers of transplant co-ordinators, degree of governmental support and other factors, whose influence may be important but uncharted".<sup>ii</sup> For example, although Spain introduced its opt-out system in 1979 and has the highest donor rates in Europe, these rates only began to increase ten years after the law was introduced. Much of Spain's success is attributed to the establishment of a new national transplant organisation to coordinate the donation and transplantation process, including the appointment of transplant coordinators who instigate conversations with the family of potential donors.

As stated above, we would not wish the introduction of an opt-out system to have a negative effect on the relationship and feeling of trust between healthcare professionals and potential donor families, particularly if they object to donation. It is clear from best practice cases where organ donation has been achieved that this relationship is key to facilitating the process. Therefore we believe it is vital for the Government to increase investment in the resources and infrastructure supporting organ donation and transplantation services. This should include better training for healthcare professionals to approach potential donor families and an increase in the numbers of specialist nurses and transplant coordinators.

We also recommend the Government undertakes a public awareness campaign to highlight the need for more organ donors, whether or not the opt-out system of consent is introduced. In particular, we hope that increasing public awareness on organ donation will lead to an increase in donors from the BAME (black, Asian and minority ethnic) community who often refuse consent due to faith and cultural concerns.

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<sup>i</sup> Welsh Government (2017) Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report

<sup>ii</sup> British Transplant Society Ethics Committee (March 2017) Response to the Scottish Government's consultation on Organ and Tissue Donation and Transplantation