

# Transplantation and consent

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## Abstract

This is an overview of issues relating to consent in donation and transplantation, including the types of consent currently in use in organ donation. There is a discussion of altruistic consent, opt-in, opt-out and deemed consent, and mandated choice. Donation of organs after cardiac death and after brain death is described. Reference is made to current guidance from the UK National Health Service, the Human Tissue Authority, the UK Government and the Spanish model of Organ Donation and Transplantation.

**Keywords** Consent; renal donation; transplantation

## Introduction

Transplantation is one of medicine's success stories: gradual progress has enabled longer and better quality life for these patients, and technological success has yielded impressive dividends. The biggest challenges have arisen from infection and from adverse immunological incompatibilities, but the management of these technical issues has also improved in both intensive care and medical science. Developments in intensive care medicine have optimized the quality of the organs to be transplanted. The most important issue is understanding the types of consent used to obtain organs for transplantation.

### Donation after brain death (DBD) and donation after cardiac death (DCD)

The number of DCDs in the UK has increased. The potential number of DBDs depends on trauma or acute brain disease.

In 2001/02 most donors in the UK were on ventilators and had been declared dead after brainstem testing. The latest data from 2022/23 show that there were 5251 adult patients on the kidney transplant list, a 13% increase on the previous year. In addition there were 102 paediatric patients, representing an increase of one child on the previous year.

In 2022/23 3012 adult kidney transplants were performed, an increase of 4% on the previous year. Of these 1163 were from DBD donors, 1001 from DCD donors, and 848 from living donors. There were 127 paediatric transplants.

Given the shortfall in renal donation, the challenge is to assess every patient, whether as a prospective donor or an altruistic live donor. It is essential that organs that could be available are not 'lost'.

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## Key points

- Clinicians should understand the development of consent used in organ donation

## Seeking consent

Standard practice consists of establishing whether the prospective organ donor might have indicated with a donor card that they are willing to have their organs retrieved. If no indication is given, organs from the brain-dead patient can be used by establishing whether best interests are thought by a next of kin to be fulfilled. Requesting organs at the time of unexpected death requires a well-trained and motivated specialist nurse, and does not come without ethical challenges.

A smaller but growing number of kidneys are sourced from living donors giving their organs altruistically. Legislative change has made it possible for family members or altruistic strangers to donate. The most recent guidance for living donation ensures that potential donors are not being exploited but genuinely wish to donate.

Two memorable influential cases were of a Ugandan bus conductor who wished to donate his kidney to his bishop as an unrelated living donor, and a retired consultant physician, Dr Chris Burns-Cox in Bristol, who simply said that he only needed one kidney and successfully donated his spare one. Publicity of events of this sort can affect the altruistic wishes of other people, even among family members, who are then more likely to undergo living donation.

## Opt-out consent

Issues of consent for organ retrieval may improve the relatively poor record of UK practice, compared with, for example, Spain. In 2022 Spain was the world leader in organ donation, with 5383 transplants, representing a growth of 13% in the number of transplants and a 15% growth in the number of donations since 2021. The donation rate was 46.3 deceased donors per million population (PMP); the rate in the UK is 19.8.

The Spanish model also shows that it is possible to increase numbers via asystole donation and from patients who request assistance in dying. These developments have come about simply because adult citizens are automatically considered as donors unless they opt out in writing.

## Deemed or presumed consent

Societies approach organ retrieval differently and moves towards so-called 'deemed consent' do make a difference. In the UK, following an initial debate in the Welsh Senedd, an organ donation can now be considered as deemed if there is support from a family member. This is sometimes referred to as 'presumed' consent — not a satisfactory label if one notes that it is the nature of 'consent' to be a process in which the donor is able to consent.

## Mandated choice

A further approach has been to mandate expressing an opinion. The argument is that the patient must declare a preference by law, in the same way that Australians are mandated to vote in elections. The patient would then at least make a choice that is

theirs. For example in the USA there are two states that have a system of mandated choice and there are continuing debates about 'opt-in' and 'opt-out' registries across the country. Mandated choice has not attracted large support in the UK.

In Wales deemed consent is now legally enforceable. It is not clear whether this has led to an increase in kidney retrieval rates, as the accompanying publicity and public debate about the introduction of this policy may have had a positive effect. Society may be accepting that organ retrieval should be the norm. Accounts of the benefits of organ retrieval and transplantation can be very effective.

### Organ trafficking

Organ trafficking is a growing problem in the UK, and investigation into this illegal trade is being pursued under modern slavery legislation. Worldwide it is thought to make up approximately 10% of all renal transplants.

### Motivation

In the UK the ability to sell or pay for an organ is not thought to be an acceptable principle for a scarce resource and legislation prevents payment for organs.

In addition to issues of consent there is, of course, the matter of ideas of the common good. Unless the UK decides to follow the Spanish model of opt-out consent, the motivation to consent will always be the deciding factor in organ donation.

Sir Roy Calne (1930–2024) carried out the first liver transplant in the UK in 1968. He said:

Personal accounts supplemented with government action can make a significant contribution. Awareness of the problem of organ shortage can be in part ameliorated by the altruistic actions that can lead to responses like this example: "... I would love you to know that my family will now have a wife and a mother who they would have lost due solely to your bravery and compassion in making the decision you did, enabling me to live ..."



### FURTHER READING

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