

Improving family consent in organ donation could save lives

December 22 2011

Research published today in the *British Journal of Anaesthesia* suggests that organ donation rates in the UK could be increased if the current issues affecting declined consent are improved. At present, only 30% of the UK population are registered on the NHS Organ Donor Register (ODR). From 2003 to 2005, the overall consent rate for donation after brain death (DBD) was 59%. This figure remains largely unchanged with a consent rate of 63% for DBD in 2007-2009. The low consent rate for organ donation in the UK is the largest factor limiting actual organ donor.

Currently, organ donation consent is established by views expressed prospectively via membership of the ODR or views expressed to a family member. However, when a patient is deceased and has not previously expressed a wish to their relatives about organ donation the health care professional will discuss donation with the family. Up to 10% of families of potential donors, who are on the ODR, still refuse assent to donation. At present, it is accepted practice to respect the family's wishes despite the existence of valid legal consent.

The paper 'Consent for Organ Donation' by Vincent and Logan, published in a special issue regarding organ donation for the [British Journal of Anaesthesia](#), calls for action on the concerns and issues that affect consent.

Make Your Donation Wishes Known:

Findings have consistently shown that only 50% of those that wish to donate after death have discussed this with a family member. It is extremely important that donors discuss their wishes with their close relative because ultimately it is the family which authorizes organ donation. Research has found that family discussion strongly predicts consent for donation from [family members](#).

Recent research has examined the [negative attitudes](#) felt in joining the ODR and suggests that these may be the most important barriers to address. These include a level of disgust felt in the idea of [organ procurement](#), a belief that registering for organ donation will jinx the individual; and mistrust of the medical profession. Addressing such negative beliefs should be a key component in public campaigns to increase donation.

Staff Care and Interaction:

The relative's experience and interaction with staff can have a huge impact on the decision to consent or refuse donation. The basic principles of medical practice should always be in place. However, a wider treatment of care for the family itself can have a very positive or negative effect on consent. Provisions of physical support in the form of comfortable accommodation, staff availability throughout the patient's admittance, empathy to the family, and a respectful and dignified treatment, are all factors that can have a positive impact on donation rates.

Make Sure the Family Understands

Understanding brain stem death is an important factor in organ donation. Studies have consistently found that an astounding amount of relatives do not fully understand [brain death](#), even after it has been explained by

the attending doctors. It is extremely important that brain stem death is explained so that a relative can fully understand that their loved one is dead before donation takes place. Once this understanding has been reached discussion and consent for organ donation can then begin. Specialist Nurses in Organ Donation are also trained and have the time to make sure families understand this. It has been suggested that allowing a family to witness tests or providing imaging or diagrams to explain concepts could help to improve a family's understanding of brain death.

Who should request consent?

It is intuitive that a specialist coordinator, with systematic training, a skill set that understands the modifiable factors and grief reactions of the family, and a day-to-day experience of dealing with such encounters, may perform better than a physician who may be involved in donation infrequently. Studies carried out by Shafer and colleagues suggest that early contact with families and interaction before any conversation about donation increased consent and authorisation rates. The study showed 75% consent rates for groups that had contact with a coordinator for more than 3 hours. Since 2009, the UK has expanded its pool of coordinators from 100 to 250. It is anticipated that the value and expertise the specialist nurses bring to the intensive care unit will become accepted more widely in areas where the model has not already been embraced.

Practical steps for improving consent:

- Promote the need for families to discuss their wishes regarding organ donation
- Discuss donation at a time separate to that when the family are informed of the death or its inevitability, in an unhurried manner

- Ensure the family are given specific information and that in particular, concerning DBD, the concept of brain stem death is fully explained
- Use an approach pre-planned by the coordinator/specialist nurse and healthcare team that considers specific individual circumstances

Dr. A. Vincent, author of 'Consent for organ donation', comments that "Only 60% of families when asked, give consent for organ donation from a loved one. Research would suggest that adopting a best practice model with respect to the process involved in consent for organ donation could improve this rate. It is an improvement in consent rates, more than in any other area, that would see a real increase in donor numbers in the UK."

Paul Murphy, National Clinical Lead for Organ Donation at NHS Blood and Transplant said: "Organ transplantation is made possible through the generosity of people who donate their organs so that others can live on, but also through the skill and dedication of a great many clinical staff. There has been much progress in recent years in transforming the systems and processes across the UK to increase rates of [organ donation](#) and transplantation, and there is more work needed to improve rates further.

NHS Blood and Transplant plays a key part in overseeing and managing donation and transplant processes and is privileged to have been involved in producing this supplement which brings together the professional views of many highly respected and experienced clinicians and showcases the work being done in the UK to increase [donor](#) numbers."

More information: 'Consent for organ donation' by A. Vincent and L. Logan. *British Journal of Anaesthesia*. [doi:10.1093/bja/aer353](https://doi.org/10.1093/bja/aer353)

Provided by Oxford University Press

Citation: Improving family consent in organ donation could save lives (2011, December 22)
retrieved 4 May 2024 from

<https://medicalxpress.com/news/2011-12-family-consent-donation.html>

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