Increasing Consent for Organ Donation in the UK

The Case for Action

There has been no significant increase in the consent rate for organ donation over the last 5 years, and evidence suggests there is a need for further changes to both clinical and societal attitudes to organ donation.

In 2010/11 the National Potential Donor Audit found that just 54% of potential donation after brain death (DBD) donors with no medical contraindication to organ donation went on to become donors. This figure is significantly lower for potential donors from Black, Asian, and Minority Ethnic (BAME) backgrounds.

8% of DBD donor families were not formally approached for consent for organ donation, and 35% of those who were approached declined to give consent for donation to occur.

The approach and consent rates are significantly lower for donation after circulatory death (DCD) donors, although this is an evolving area of clinical practice.

There is significant variation in consent rates for organ donation across the UK, ranging from 40% amongst DCD donor families in Northern Ireland to 81% amongst DBD donor families in the East Midlands.

People from BAME groups remain under-represented as organ donors, but can be more likely to need an organ transplant. About 95% of organ donors are white, suggesting there is an ongoing need to overcome religious and cultural barriers to organ donation.

About These Recommendations

The recommendations were produced by Transplant 2013 following a seminar on increasing the consent rate for organ donation chaired by Glyn Davies MP in Parliament on 22nd May 2012.

The speakers were Professor Magi Sque (Professor in Clinical Practice & Innovation, University of Wolverhampton), Jane Griffith (Regional Manager of Organ Donation for London and Northern Ireland, NHS Blood and Transplant), David Nix (Chairman, Donor Family Network) and Chris Rudge (Chair, Transitional Steering Group for Organ Transplantation). A written statement was read out from Dr Paul Murphy (Clinical Lead for Organ Donation, NHS Blood and Transplant) who was unable to attend.
Recommendations

1) Implement NICE Guidance

NICE published guidance on *Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation* in 2011, which applies in England and Wales.

The guidance recommends that potential donor families are approached by a multidisciplinary team including the medical and nursing staff involved in the care of the patient, a specialist nurse for organ donation, and a faith representative where appropriate.

International evidence suggests that when this approach is followed donor families are 7 times more likely to consent to organ donation. At present, however, the NICE guidance is implemented in just 50% of cases.

▶ NHS Blood and Transplant should audit the implementation of NICE guidance in England and Wales. A report on the audit should be published and each incident of the guidance not being followed should be reported to the Board of the relevant local NHS organisation.

▶ Adherence to the NICE guidance in each NHS organisation should be published in NHS Blood and Transplant’s annual review of organ donation and transplantation activity in the UK.

▶ The NHS Medical Directors in England and Wales should write to Medical Directors of relevant NHS organisations to confirm that specialist nurses for organ donation should be involved in the consent process in all cases in line with NICE Guidance.

▶ UK Health Ministers should include adherence to the NICE guidance within the Commissioning for Quality and Innovation (CQUIN) payment framework in England.

▶ The Potential Donor Audit should be modified to accurately capture ethnicity data to allow more detailed analysis of reasons why donation does not proceed within each ethnic population. NHS Blood and Transplant should seek the views of the National BAME Transplant Alliance in implementing this recommendation.


2) Enhance the Role of Organ Donation Committees

UK NHS organisations have Organ Donation Committees that are responsible for developing and implementing local policies to maximise organ donation. They are accountable to NHS organisations via local clinical governance arrangements.

▶ The role of Organ Donation Committees should be enhanced to include promoting the importance of consent for organ donation in the wider community served by the NHS organisation.
Organ Donation Committees should engage with local groups including patient groups, faith groups, schools, colleges, universities, and the media. They should be encouraged to host public awareness-raising events and produce information resources that are tailored to local needs.

NHS Blood and Transplant should produce guidance and resources for Organ Donation Committees to facilitate local engagement.

Responsibility for Implementation: Organ Donation Committees, NHS Blood and Transplant

3) Introduce National Organ Donor Day

The role of organ donors and donor families is not appropriately recognised by society as a whole. On average each donor saves or improves the lives of 3 people, and in total organ donors also save the NHS £500,000 each year compared to the alternative treatments costs for people waiting to receive a transplant.

Societal change is required so that people aspire to become organ donors after their death and discuss their wishes with their families.

UK Governments should introduce a National Organ Donor Day to commemorate the role of organ donors and facilitate societal change.

UK Governments should introduce official national memorial services for organ donors and their families in each nation that should be attended by senior Government representatives to demonstrate their commitment to organ donation.

Responsibility for Implementation: UK Governments

4) Enhance Education on Organ Donation

NHS Blood and Transplant has introduced educational resources including a teachers pack and website to educate children and young people about organ donation and transplantation and ensure they discuss their wishes with their families.

However, these educational resources do not form part of the national curriculum and their use is not compulsory.

NHS Blood and Transplant should set targets to increase the uptake of the teachers pack in schools across the UK as part of its strategy for organ donation and transplantation from 2013 onwards. Progress against these targets and information about which schools are using the teachers pack should be published as part of an annual implementation report.

UK Health and Education Ministers should write to all head teachers to encourage them to use the teachers pack in their schools.
UK Education Ministers should consider adding organ donation and transplantation to the national curriculum to reduce local variation in the use of the educational resources.

University Vice-Chancellors and Students Unions should ensure that students are given the opportunity to sign the NHS Organ Donor Register and be provided with information about organ donation and transplantation during Freshers’ Fairs.

Universities should be encouraged to include organ donation in undergraduate medical and nursing syllabuses, and opportunities for postgraduate training should be available.

Responsibility for Implementation: Schools, Colleges, Universities, NHS organizations, NHS Blood and Transplant, UK Governments

5) Integrate Organ Donation with End of Life Care

As set out in the NICE guidance on Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation, it should be usual for a multidisciplinary team to approach the families of potential organ donors.

This principle should be supported by all Government and NHS frameworks relating to end-of-life care across the UK.

UK Governments should ensure that the principles of the NICE guidance are included in NHS end-of-life care strategies in each of the UK nations.

UK Governments should monitor the number of potential donor families who are approached in accordance with the NICE guidance and include this as a measure within relevant frameworks (e.g. NICE Quality Standards and the NHS Outcomes Framework in England).

Research on end-of-life care should include a focus on how consent rates for organ donation could be increased, particularly amongst people from a BAME background.

Responsibility for Implementation: UK Governments