Tackling the organ donor shortage effectively: optimism or realism?

There continues to be a growing disparity between the demand for and supply of organs for transplantation. This article reviews the status of current strategies in the UK to tackle the organ donor shortage.

The NHS Organ Donor Register was created in October 1994, in response to a campaign by the Cox family, whose son wished to donate his organs, following his death from a brain tumour. The idea was to create a confidential, national computerized database, similar to that for those on the transplant waiting list, which identifies individuals willing to donate and can be accessed 24 hours a day by health-care professionals. Currently in the UK there are about 16 million donors on the Organ Donor Register, but with numbers on the transplant waiting list reaching 8000 and increasing by 8% annually, there remains a shortfall between supply and demand (UK Transplant, 2009). More than 3000 transplants are performed in the UK each year, but around 1000 potential recipients die while waiting for a transplant (Kmietowicz, 2008; UK Transplant, 2009). This article explores the current crisis in organ donation and reviews the efforts in effectively tackling the challenge in the UK.

In 2000, UK Transplant, a branch of NHS Blood and Transplant, launched the UK national potential donor audit to identify potential donors and reasons for opposition to donation (Barber et al, 2005, 2006). Building upon this, the UK Organ Donation Taskforce was established in 2006, to address barriers to donation and try to improve organ donation rates (Organ Donation Taskforce, 2008a). Ways of increasing organ donation in the UK include expanding the current donor selection criteria, changing organ donation legislation, improving national services infrastructure and coordination (British Medical Association Medical Ethics Committee, 2000), and engaging the public in active awareness. However, many ethical, clinical, legislative and social issues surround the practicality of such improvements, particularly in relation to a proposed 'opt out' system.

The current UK system

An informed consent or 'opt in' system for organ donation operates in the UK, in which fully informed individuals express a wish for organ donation by carrying a donor card or registering on the Organ Donor Register (Organ Donation Taskforce, 2008a; Rithalia et al, 2009). Currently, individuals on the Organ Donor Register produce an advance directive stating their wishes to donate and are encouraged to discuss these with their family (Jackson and Poppitt, 2001). The Human Tissue Act 2004 states that appropriate consent must be given for the removal of human tissue after death from an individual during life, or by a nominee or someone with a 'qualifying relationship' in the event that death occurs before this can be discussed (Human Tissue Authority, 2006).

The Act permits 'minimum steps' for organ preservation, e.g. cold perfusion of kidneys (Raftery and Delbridge, 2006), while seeking consent for donation from next-of-kin. Legally, if a fully competent adult consented to organ donation in life relatives cannot overrule this following his/her death (Human Tissue Authority, 2006), which could increase organ availability (Human Tissue Authority, 2007). However, this must be handled sensitively, and in practice qualifying relatives are encouraged to reach a decision with the wishes of the deceased in mind (Jackson and Poppitt, 2001; Human Tissue Authority, 2006). In such cases objection to donation may be reduced if family members know the deceased's wishes.

Although 70–90% of individuals are willing to be organ donors, only around 26% actually hold donor cards or are on the Organ Donor Register (Carnall, 2000; Kmietowicz, 2008; Organ Donation Taskforce, 2008a). This may relate to a reluctance to think about personal mortality or simply a lack of awareness (British Medical Association Medical Ethics Committee, 2000). Furthermore personal interpretation of religious and cultural doctrine may play a role in hesitancy (UK Transplant Co-ordinators Association, 1998; British Medical Association Medical Ethics Committee, 2000). Many options have been suggested to counteract this including increasing direct appeals for donors, increasing resource availability and doubling the number of transplant coordinators (British Medical Association Medical Ethics Committee, 2000; Rithalia et al, 2009). Other suggestions include a change to the 'presumed consent' system used in countries such as Spain and Austria (British Medical Association Medical Ethics Committee, 2000; Rithalia et al, 2009) or 'elective ventilation' (British Medical Association Medical Ethics Committee, 2000).

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Increasing public awareness

With a global deficiency in organ donation, and with individuals more likely to require a transplant than to become a donor (Mason, 2004; Lyall, 2005), increasing awareness is needed to facilitate donation. In 2004, a nationwide campaign was launched through an animated public display in Trafalgar Square, which marked the 10th anniversary of the Organ Donor Register, designed to increase the number of UK organ donors by 1 million (Mason, 2004). In 2005, the BBC offered television viewers the chance to join the NHS Organ Donor Register interactively by pressing a button on digital handsets (Lyall, 2005). Such campaigns increased donation rates (Mason, 2004; Lyall, 2005) and public enthusiasm for donation.

Similarly, initiatives such as the Driving and Vehicle Licensing Agency application forms or car tax renewals, which allow individuals to join the Organ Donor Register, have been successful in increasing donor rates (UK Transplant, 2009). The highest percentage of new donor registrations come from GP registration, Driving and Vehicle Licensing Agency access and Boots Advantage card applications (NHS Blood and Transplant, 2008). In response to the Organ Donation Taskforce findings and previous successes, the government provided an extra £4.5 million in March 2009 for a multimedia campaign promoting the importance of and need for organ donation in the UK (Johnson, 2008). This is part of the drive to increase donation rates by 50%, with a projected 25 million donors on the register by 2013 (Johnson, 2008; Organ Donation Taskforce, 2008b).

Presumed consent

Despite controversy and the government's decision to maintain the opt in system within the UK for the next 5 years, the British Medical Association was in favour of adopting an opt out system with safeguards as a method of increasing organ donation (British Medical Association Medical Ethics Committee, 2000). They argued that the established Organ Donor Register lacked systematic and continuous review, often relying on family members to communicate the wishes of the deceased to health-care professionals when the issue of organ donation arose (British Medical Association Medical Ethics Committee, 2000). In contrast, the opt out system, which presumes consent for organ donation after death unless the deceased actively objected to such donation during his/her lifetime (Rithalia et al, 2009), may be more rapidly accessed and, where possible, increase the number of non-heart beating donors through more efficient and rapid preservation on the basis of presumed consent (British Medical Association Medical Ethics Committee, 2000).

The extent to which presumed consent considers the views of relatives varies between the different countries which implement it. In Spain, active measures are taken to encourage relative agreement ('soft' opt out system), while the views of relatives in Austria are not commonly considered ('hard' opt out system) (Sipes, 1991; Rithalia et al, 2009). In practice it is unlikely that the views of close relatives would be dismissed, for example, legislation in Belgium states that although relatives are not required to give consent, they are informed about the donation and are permitted to object (Kennedy et al, 1998). Similarly in Spain, the consent of relatives is routinely sought, despite the supposed opt in system (Matesanz and Miranda, 1996), while relatives in the UK are encouraged to provide explicit consent rather than register objections to donation (British Medical Association Medical Ethics Committee, 2000).

Although countries which implement a presumed consent system show increased organ donation rates (Sipes, 1991; Kennedy et al, 1998; British Medical Association Medical Ethics Committee, 2000; Transplant Committee of the Council of Europe, 2007; Organ Donation Taskforce, 2008a), it is not clear whether this is the sole contributory factor or whether other factors may contribute to this increase (British Medical Association Medical Ethics Committee, 2000; Rithalia et al, 2009). In Spain, for example, which has the highest organ donation rates in Europe (Rithalia et al, 2009), a new and improved method of transplant coordination is considered to be responsible for such efficacy, rather than the current opt in system (Matesanz and Miranda, 1996). The British Medical Association Medical Ethics Committee (2000) concluded that if such a system were to be implemented in the UK, it would have to be accepted by the public and medical profession, as well as needing improvements in the multidisciplinary clinical infrastructure required to deliver organ transplantation. This supports the view that changing public attitudes, donor availability, health-care economy and infrastructure will all help to increase organ donation rates (Rithalia et al, 2009).

While uncertainty surrounds potential donor wishes post-mortem in the current opt in system (Organ Donation Taskforce, 2008b), ethical issues may be raised about presumed consent, such as the assumption that those who have not opted out wish to donate, rather than considering factors such as apathy, a lack of understanding (in terms of capacity) or a lack of awareness (Kmietowicz, 2008; Organ Donation Taskforce, 2008a,b). The UK Organ Donation Taskforce also noted that a proposed hard form of the opt out system could risk harming the doctor–patient relationship and destroy the trust which is paramount to successful transplantation (Kmietowicz, 2008; Organ Donation Taskforce, 2008a; Rithalia et al, 2009). It also concluded that such a system may pose clinical problems, trigger opposition from sectors of society (e.g. religious groups) previously not opposed to donation and may invite successful legal human rights challenges (Organ Donation Taskforce, 2008b).

This debate over a change in legislation has paradoxically increased awareness of organ donation in the UK, enabled the implementation of steps to improve the current system and facilitated discussion between different faith groups and communities (Organ Donation Taskforce,

2008b). Much focus will be placed on increasing awareness and tackling confusion surrounding organ donation, but options discussed below will also help to increase the donation rate (British Medical Association Medical Ethics Committee, 2000; Organ Donation Taskforce, 2008b).

Other strategies

Increasing the number of heart-beating donors

Heart-beating donation is donation of organs from patients who have suffered brainstem death as a result of serious and irreversible cerebral damage (Raftery and Delbridge, 2006). Health-care professionals working in intensive care units are encouraged, when appropriate, to identify these patients and facilitate organ donation once brainstem death has been confirmed (Department of Health, 2007). Any difficulties with this mainly surround obtaining consent from relatives (around 40% of families deny consent for organ donation) (Barber et al, 2006). Transplant coordinators and health-care professionals should therefore approach and discuss the possibility of organ donation sympathetically with relatives, addressing any concerns they may have (British Medical Association Medical Ethics Committee, 2000; Organ Donation Taskforce, 2008a).

Like the opt out system, this type of organ donation raises many issues such as what constitutes death and whether maintaining support after brainstem death is a form of elective ventilation (British Medical Association Medical Ethics Committee, 2000). Ethical consideration must be given to whether the potential benefit to others (transplantation) outweighs the potential emotional distress the relatives may experience (Barber et al, 2006) or, in cases of elective ventilation, the risk that such action could prolong life (without chance of recovery) leading to a persistent vegetative state or coma (British Medical Association Medical Ethics Committee, 2000).

Increasing the number of non-heart-beating donors

Non-heart-beating donation is also termed donation after cardiac death (Raftery and Delbridge, 2006), and is a potentially underused donor source in the UK. There are four categories of non-heart-beating donors (Rela and Jassem, 2007): category I – dead on arrival, category II – failed resuscitation, category III – awaiting cardiac arrest and category IV – cardiac arrest in brainstem-dead donor. Only category III is widely used in the UK. These patients do not fulfill the criteria for brainstem death but are expected to die of cardiac arrest upon withdrawal of treatment (ventilation and inotropes).

In the past there has been a reluctance to retrieve organs from non-heart-beating donors, because of concerns about censure or legal action (Department of Health, 2007). However, changes in the Human Tissue Act allowing 'minimum steps' for organ preservation and advances in preservation technique (Raftery and Delbridge, 2006) are increasing the use of such donors (Department of Health, 2007; NHS Blood and Transplant, 2008). In 1998, there were only 40 non-heart-beating donor kidney transplants in the UK. By 2008 this had increased ten-fold to 438 and in the same year an increase of 17% was seen (UK Transplant, 2009).

While non-heart beating donation would provide an effective method of increasing donation rates in the UK (Department of Health, 2007; NHS Blood and Transplant, 2008), increased awareness is needed in accident and emergency departments to identify potential donors and notify transplant coordinators, so that potential donors become actual donors (British Medical Association Medical Ethics Committee, 2000; Department of Health, 2007). The main logistical problem relating to category II donors is the availability of the retrieval team at the time of cardiac arrest. Currently only Newcastle upon Tyne Hospitals NHS Foundation Trust has a dedicated team on site permanently (Balupuri et al, 2000a) with improving levels of successful outcomes (Balupuri et al, 2000b).

Using extended criteria donors

One of the main issues in understanding the discrepancy between the numbers of organs offered for donation and the numbers of transplant procedures performed are the number of kidneys that are 'discarded'. United States organ donation policy makers introduced a policy of 'extended criteria donation' in 2002 to try and reduce this number (Rosengard et al, 2002). Extended criteria donation kidneys are defined as those from donors over 60 years old or donors who are 50–59 years of age with any two of the following three criteria: 1) cerebrovascular accident as cause of death, 2) pre-existing hypertension or 3) creatinine on retrieval >3 mg/dl (130 mmol/litre). These criteria were defined in heart-beating donors or donors after brainstem death and are now termed as extended criteria donation or donors after brainstem death. Transplantation using these organs increased the relative risk of graft failure by about 1.7 (Merion et al, 2005; Sung et al, 2005). However, with careful patient selection and donor matching, the medium-term graft and patient survival is comparable to standard criteria donors (Stratta et al, 2006), and increasing numbers of UK centres are using such donors to meet demand.

Increasing live donors

Live donation is becoming increasingly popular for renal transplantation in the UK, with 40 live donor transplants performed in Leeds alone between 2007 and 2008 (NHS Blood and Transplant, 2008). New types of living donation have been introduced, such as paired and altruistic forms, which have the potential to increase the donation rate (Raftery and Delbridge, 2006; Human Tissue Authority, 2007). Historically, such donation was often reviewed by the Unrelated Live Transplant Regulatory Authority if the donor did not have a close relationship with the recipient (British Medical Association Medical Ethics Committee, 2000). However, under current policy, a close 'emotional

relationship' (e.g. friends or spouses), like those for directed living donation (Raftery and Delbridge, 2006), would not require such a review, and would be accepted if evidence of such a relationship could be presented to an independent assessor (British Medical Association Medical Ethics Committee, 2000; Raftery and Delbridge, 2006).

Improving the infrastructure

Integrated approaches to increasing organ donation within the UK have been introduced, e.g. the national Organ Donation Taskforce. The taskforce comprises those from transplantation teams, including surgeons, nurses and coordinators, ethicists, representatives of patients, minority interests and hard to reach groups, together with NHS management and the media. Improving coordination of both local and national organ donation identification and retrieval schemes, together with enhanced communication between regions and an increase in transplantation coordinators, would help to increase organ donation rates.

Conclusions

The British Medical Association and recommendations of the UK Organ Donor Taskforce (Kmietowicz, 2008; Organ Donation Taskforce, 2008a) suggest a 'consolidated approach' to increasing organ donation, including cooperation between the government and NHS Blood and Transplant in order to direct targets, while working in partnership with the public to raise awareness and promote organ donation within the UK (Organ Donation Taskforce, 2008a, b). More UK transplant centres are using donors from a variety of sources including expanding the donor selection criteria and live-related transplantation.

These strategies have helped begin the change needed to meet the challenge of the organ shortage and demand. However, the need for effective delivery of organs remains the Achilles heel of transplant surgery and society must continue to deliver if we are to reduce the numbers of patients dying on the waiting list every year. **BJHM**

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Balupuri S, Buckley P, Mohamad M et al (2000a) Early results of a non-heartbeating donor (NHBD) programme with machine perfusion. *Transpl Int* **13** (Suppl 1): S255–8

Balupuri S, Buckley P, Snowden C et al (2000b) The trouble with kidneys derived from the non heart-beating donor: a single center 10-year experience. *Transplantation* **69**(5): 842–6

Barber KM, Hussey JC, Bond ZC, Falvey SJ, Collett D, Rudge CJ (2005) The UK national potential donor audit. *Transplant Proc* **37**: 568–70

Barber K, Falvey S, Hamilton C, Collett D, Rudge C (2006) Potential for organ donation in the United Kingdom: audit of intensive care records. *BMJ* **332**: 1124–7

British Medical Association Medical Ethics Committee (2000) *Organ Donation in the 21st Century: Time for a consolidated Approach.* BMA Publishing, London: 1–34

Carnall D (2000) Transplant organs. *BMJ* **320**: 1678

Department of Health (2007) Organ Transplants. In: *On the state of public health: Annual report of the Chief Medical Officer 2006.* Department of Health, London

Human Tissue Authority (2006) *Code of Practice – Donation of organs, tissues and cells for transplantation.* Department of Health, London

Human Tissue Authority (2007) *Statement on Chief Medical Officer's announcement: comments on presumed consent.* Department of Health, London

Jackson M, Poppitt E (2001) Current approaches to increasing organ donation: a brief review from the United Kingdom perspective. *Transplant* **7**: 9–11

Johnson A (2008) Organ Donation Taskforce. www.publications.parliament.uk/pa/cm200708/cmhansrd/cm081117/wmstext/81117m0001.htm#08111712000006 (accessed 22 January 2009)

Kennedy I, Sells RA, Daar AS et al for the International Forum for Transplant Ethics (1998) The case for presumed consent in organ donation. *Lancet* **351**: 1650–2

Kmietowicz Z (2008) UK taskforce rejects system of presumed consent for organ donation owing to lack of evidence. *BMJ* **337**: a2621

Lyall J (2005) Press red button, donate kidney. *BMJ* **331**: 461

Mason S on behalf of UK Transplant (2004) Launch of UK Challenge to increase organ donation. www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseId=96 (accessed 20 January 2009)

Matesanz R, Miranda B (1996) *Organ donation for Transplantation. The Spanish model.* Groupo Aula Medica, Spain

Merion RM, Ashby VB, Wolfe RA et al (2005) Deceased-donor characteristics and the survival benefit of kidney transplantation. *JAMA* **294**(21): 2726–33

NHS Blood and Transplant (2008) *Transplant Activity in the UK: 2007–2008.* UK Transplant, Bristol

Organ Donation Taskforce (2008a) *Organs for transplants: a report from the Organ Donation Taskforce.* Department of Health, London

Organ Donation Taskforce (2008b) *The potential impact of an opt out system for organ donation in the UK.* Department of Health, London

Raftery A, Delbridge M (2006) Organ and tissue transplantation. In: Raftery A, Delbridge M. *Surgery*. 3rd edn. Elsevier, London: 558–69

Rela M, Jassem W (2007) Transplantation from non-heart-beating donors. *Transplant Proc* **39**(3): 574–6

Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A (2009) Impact of presumed consent for organ donation on organ donation rates: a systematic review. *BMJ* **338**: 3162

Rosengard BR, Feng S, Alfrey EJ et al (2002) Report of the Crystal City meeting to maximize the use of organs recovered from the cadaver donor. *Am J Transplant* **2**: 701–30

Sipes DD (1991) Does it matter whether there is public policy for presumed consent in organ transplantation? *Whittier Law Rev* **12**: 505–35

Stratta RJ, Rohr MS, Sunberg AK et al (2006) Intermediate-term outcomes with expanded criteria deceased donors in kidney transplantation: a spectrum or specter of quality? *Ann Surg* **243**(5): 594–601; discussion 601–3

Sung RS, Guidinger MK, Lake CD et al (2005) Impact of the expanded criteria donor allocation system on the use of expanded criteria donor kidneys. *Transplantation* **79**(9): 1257–61

Transplant Committee of the Council of Europe (2008) International data on organ donation and transplantation, waiting list and family refusals: Year 2007. *Newsletter Transplant* **13**: 23–35

UK Transplant Co-ordinators Association (1998) *Religious and Cultural Issues. Information for healthcare professionals.* UK Transplant Co-ordinators Association, Bristol

UK Transplant (2009) Life-Saving organ donor register reaches 16 million early. www.uktransplant.org.uk/ukt/newsroom/news_releases/article.jsp?releaseId=223 (accessed 20 January 2009)

KEY POINTS

- In the UK demand for organ transplantation exceeds current donor supply, with 1000 potential recipients dying on the waiting list every year.
- Multimedia and government strategies have been implemented to raise public awareness and attempt to increase the number of people on the Organ Donor Register from 16 million in 2009 to 25 million in 2013.
- Extending the boundaries of conventional donor criteria has lead to an increase in transplantation from live related, non-heart-beating and altruistic organ donation.
- The UK has rejected an 'opt out' system of presumed consent citing ethical issues, potential harm to the traditional doctor–patient relationship and the need first to implement the infrastructure capability to ensure all potential organs are used.