

Consent for organ donation

A. Vincent^{1*} and L. Logan²

¹ Department of Anaesthesia, Royal Victoria Infirmary, Newcastle upon Tyne NE1 4LP, UK

² Donor Care and Coordination, NHS Blood and Transplant, UK

* Corresponding author. E-mail: angus.vincent@nuth.nhs.uk

Editor's key points

- There is wide international variation in rates of consent.
- Only 28% of the UK population are registered on the organ donor register.
- Increasing UK consent rates beyond the current 60% is a realistic aim.
- Many factors can improve the rates of consent; each needs to be addressed in a systematic fashion.

Summary. Improving the consent rate for solid organ donation from deceased donors is a key component of strategies in the UK and other countries to increase the availability of organs for transplantation. In the UK, the law is currently clear on what forms consent may take, with the views of the individual expressed previously in life taking priority. Such views may have been expressed prospectively, via membership of the Organ Donor Register or by talking to family members. The factors determining such actions include both positive altruistic motives and negative psychological responses. Studies have examined why some families of potential donors refuse consent, while others have demonstrated a key set of 'modifiable' factors relating to the family approach. These include ensuring the right timing of a request in an appropriate setting, providing emotional support, and imparting specific information, particularly concerning the nature of brain death. If these are optimized and the right personnel with adequate training are involved in a planned process, then consent rates may be improved as reported in other countries with organized donation systems.

Keywords: consent; donation attitudes; organ donation

The comparatively low rate of consent for solid organ donation in the UK is the single largest factor limiting the so-called 'conversion rate' of identified potential, to actual organ donors. Published data from the potential donor audit of deaths in the UK, from 2003 to 2005, demonstrated a consent rate of 59% for donation after brain death (DBD),¹ and this figure remains largely unchanged with a consent rate of 63% for DBD and 57% for donation after circulatory death (DCD) for the period 2007–9.² As a result, the goal of improving consent/authorization rates was identified by the UK's NHS Blood and Transplantation authority as the first of their six 'Strategic Big Wins' aimed at increasing the number of organs for transplantation.³ Suggesting that rates of consent can be improved implies that there are factors within our current practice of seeking assent from the family, which, if done differently, could be more likely to lead to the family agreeing to organ donation. Before considering this assertion, an understanding of the relevant legislation and sometimes confusing and overlapping terminology is necessary.

Consent, organ donation, and the law

In England, Wales, and Northern Ireland, the relevant legislation relates to the Human Tissue Act 2004 and the Mental Capacity Act 2005. In Scotland, the equivalent acts are the Human Tissue (Scotland) Act 2006 and the Adults with Incapacity Act (Scotland) 2000. Of interest in this context is the use of the word 'consent', which is the

actual term used in the England, Wales, and Northern Ireland Human Tissue Act. The term usually implies adherence to principles of informed medical consent related to normal clinical practice, and this forms the foundation of much of the act relating to, for example, tissue use and storage. However, for the purposes of organ donation, there appears implicit acknowledgement that consent in this form is impossible or difficult to achieve in many scenarios due to loss of capacity and differing levels of consent expressed earlier in life. It is for this reason that in the Scottish Act, the term 'authorization' is used to differentiate the process from what may be understood by 'usual' consent.

Occasionally, in the setting of proposed DCD, where brain injury is not a feature and capacity is retained, direct consent from the patient may be taken before planned withdrawal of life-sustaining treatments. However, in all cases of proposed DBD and in the vast majority of proposed DCD cases, this is not possible and consent must be obtained by other means. Valid and legal forms of consent for the purpose of organ donation, with regard to a deceased patient or a patient who lacks capacity, are detailed in the Human Tissue Authority code of practice.⁴ These include:

- a listing on the organ donor register (ODR), or another applicable advanced directive;
- consent from a properly appointed nominated representative, who is acting on the patient's behalf by prior agreement;

- witnessed statements of the prior views of the potential donor, usually by (but not confined to) an individual in a qualifying relationship;
- consent or refusal from individual(s) in a qualifying relationship, where the views/wishes of the patient are unknown or cannot be ascertained.

The validity of these forms of consent has been questioned.^{5 6} In particular, the equating of ODR registration with 'true' informed consent is a significant point of concern for some.⁷

The Mental Capacity Act sets in law a framework to guide healthcare professionals in the assessment of capacity, and how to assess and act in a patient's best interests, when they no longer have such capacity. It is made clear that best interests are not confined solely to medical conditions and may include religious, cultural, and social interests among others. While not specifically concerned with consent (which is strictly governed by the Human Tissue Act), the Mental Capacity Act provides a statutory framework for actions, which may be required to allow donation, such as delaying treatment withdrawal to allow DCD to take place.

The Human Tissue Act provides a structure for seeking consent in a sequential manner for organ donation from a patient who is deceased or lacks capacity. It is the duty of the healthcare team to seek evidence of the patient's consent in prior life, and if this is unknown to come to a decision with the family regarding donation. Up to 10% of families of potential donors, who are on the ODR, subsequently refuse to assent and at present it is an accepted UK practice to respect such wishes,⁸ despite the existence of valid consent which at law, the family has no right to overturn. A complete discussion of both the legal and ethical background to consent is covered elsewhere in this issue.^{9 10}

Consent in advance

Knowledge of a potential donor's prior consent or their expressed views and wishes is a key issue, so it is important to understand why people do or do not join the ODR or initiate discussions with their family.

Joining an organ donor registry

Currently, only 28% of the UK adult population are registered on the ODR.¹¹ A lack of awareness, lack of opportunity, an 'intention-behaviour' gap, or a specific decision not to join the ODR are all factors, but their respective importance is unknown. In the UK, membership of the ODR is highest in younger age groups (58.8% of ODR members are under 40) and in higher socioeconomic classes.¹² This contrasts with actual donors who tend to be older and less well off.

There are a set of much studied 'traditional' variables, which help discriminate why people are more likely to be on an ODR or not. These include: a positive attitude to organ donation,^{13 14} knowledge about donation,¹⁵ and religious beliefs and altruism.¹⁶ However, a growing body of more recent work has examined prevailing negative attitudes

to joining an ODR and suggests that these may be the most important barriers to address.¹⁷⁻¹⁹ In particular, a set of so-called 'non-cognitive' variables (beliefs and attitudes less amenable to change by rational argument) were identified by Morgan and colleagues¹⁸ in the USA as being key. These include:

- the 'ick' factor—a disgust response to organ procurement;
- the jinx factor—a belief that by registering on an ODR, an individual will hasten their own death;
- medical mistrust—often media-driven. This includes attitudes that if on the ODR, doctors will not try as hard to save the patient's life, so allowing the opportunity to harvest organs;
- body integrity—serious afterlife consequences will be faced if integrity is breached.

This study was replicated in the UK by O'Carroll and colleagues,¹⁹ who similarly found these variables to be a far greater discriminator between those on, or not on the UK ODR. They and others¹⁷ suggest that addressing such negative beliefs should be an important part of public campaigns to increase registration.

Family discussions

It is a consistent finding in the USA and Europe that only around 50% of those who would wish to donate after death have discussed this with family members.²⁰ This also holds true for those on an ODR.¹⁶ Given that families ultimately authorize donation, it may be argued that such communication is even more important than registering on the ODR, and it is clear that prior family discussion strongly predicts consent for donation from family members.²¹ Such discussions are made difficult by social taboos regarding death,¹⁵ and an unwillingness to discuss donation is very likely to have reasons much in common with those above for not joining the ODR.²² Prior knowledge regarding donation, holding a positive attitude towards donation, and holding altruistic views all predict the likelihood of having held a family discussion and willingness to do so.¹³ Publicity campaigns should target family communications, for example, the successful 'Share your life. Share your decision' campaign, which was run nationally in the USA in the 1990s. Such initiatives should provide detailed factual information on donation and dispelling the many myths surrounding it.

While it is acknowledged that ascertaining the views of the potential donor are important, ultimately it is for the relatives to authorize donation in most cases. This process has been studied in some detail.

Patient characteristics and other features associated with consent

Although not wholly consistent, there appear to be certain patient characteristic and other unmodifiable characteristics which are associated with a higher likelihood of family consent. The evidence is clear that where a potential

donor's wishes were known to be positive (in the form of registry on an ODR or prior discussion with family), that consent is much more likely to be obtained.^{21 23} Other characteristics associated with donation include a young age of the donor,^{24–26} ethnicity,^{21 24–27} prior religious beliefs, and trauma as a mode of death.^{21 26}

Why do families refuse to give consent for donation?

Understanding this complex question is a key issue if low consent rates are to be increased. Some work has attempted to address this as a primary research goal. Methodologies included:

- (i) structured interviews with donor and non-donor families either face to face, by telephone, or postal questionnaire;^{23 28–36}
- (ii) interviews with donor coordinators and healthcare professionals;^{25 37 38}
- (iii) prospectively collected registry data have also been examined.^{1 39}

By their nature, most studies are observational and qualitative in design.

Although grounds for refusal may have a basis in strong local cultural and religious beliefs in certain countries,^{28 39} there are many common themes to be found worldwide. The most frequent reasons that emerge, but by no means an exhaustive list, are shown in Table 1.

Other groups have attempted to describe the complex and conflicting emotional responses to death and requests for organ donation in a different way, concentrating on innate psychological responses and the modelling thereof.^{40–42} Sque and colleagues⁴⁰ performed a fascinating interview study of the family members of 23 potential organ donors who had all declined consent. They identified an essential conflict between the ‘gift of life’ (the prevailing view of healthcare professionals and perhaps society) and the ‘sacrifice’ required at both a personal emotional (relief of ‘guardianship’ and ‘protection of the body’) and physical (perceived mutilation to an otherwise viable looking body) level. In the case of DBD, this group describes an emotional ‘dissonance’ set up by a failure to resolve a poor understanding of brain death and the proposed donation procedure.⁴¹ Other important innate responses include the perceived relation between ‘body’ and ‘self’ (strong belief in some that the physical body is inherently part of identity),⁴³ and common ‘death anxiety defences’ including the ‘feeling of immortality’ reinforced by the appearance of a still warm well-perfused potential brain-dead donor.⁴² It is suggested that in some individuals, such responses overcome the more rational or altruistic motives necessary for consent.

Table 1 Common reasons for family refusal to consent for organ donation

Reason	References
Relatives not wishing surgery to the body/ concerns regarding disfigurement	1,23,25,29–33,37
Feelings that the patient had suffered enough	1,25,37
Uncertainty regarding the patient's wishes	1,23,28,32,34,37,39
Disagreements among the family group	1,28,29,32,34,36,37
Religious/cultural reasons	1,28,29,37,39
Dissatisfaction with healthcare staff and process	25,28,31,32,34,35
Concerns over delay to funeral/burial process	28,30,38
Unable to accept death, lack of understanding of brain death	29–32,34,37,39
Concerns regarding integrity of process, e.g. unfair organ allocation, organ selling	29,32,37
Relatives had decided on their own that organs would not be suitable	25,33
Longstanding negative views on organ donation	1,25,34
Relatives were emotionally exhausted	25

Modifiable factors within the family approach, which influence consent

It is accepted that the above responses may not be overcome in some individuals. There does although appear to be a strong signal from the evidence base that there are factors relating to the consent process, including the relatives' experience and their interaction with staff, which correlate strongly with a decision to consent or refuse. The assumption made is that optimizing the relative experience with regard to these factors is likely to lead to better consent rates. Perhaps the strongest evidence for this assertion comes from the US 'Organ Donation Breakthrough Collaborative', launched in 2003 by the Department of Health. This initiative was based on the principles of implementing best practice with regard to likely modifiable factors (amongst other interventions), and resulted in a 10% increase in conversion of potential to actual donors compared with control hospitals in the first 2 yr,⁴⁴ with more than one-third of participating hospitals achieving a conversion rate of 75% or more by the second year.⁴⁵

In addition to the benefits to wider society, there is some evidence that this increase may also benefit donor families in the longer term, with studies generally demonstrating higher levels of later regret about donation decisions, among families who refused consent.^{27 35 46 47} Concerns about requesting strategies becoming coercive in nature have been raised, particularly in the USA.⁴⁸ However, many would consider that the important modifiable factors in fact represent principles of good medical practice, regardless

of their effect on consent, namely being sensitive to the family needs, giving them time and privacy and ensuring they have sufficient information in an understandable format to allow them to make an informed decision.

A recent systematic review of this topic⁴⁹ identified 20 studies that reported on modifiable components of the consent process relating to potential DBD donors, and were associated with a statistically positive or negative effect on consent. This work, and that by others, identifies broad categories for intervention, as outlined below.

Understanding brain death

Follow-up studies of the families of potential donors have consistently shown that poor knowledge and understanding of brain death is common among both donor and non-donor families.^{41 46 50 51} This is present to a remarkable degree, despite presumably some form of medical explanation, and is even more prevalent among the general public.⁵² It is a consistent finding that those families with a good understanding of brain death are more likely to consent.^{21 24 27 35 53 54} It appears (and is intuitive) that those relatives who truly understand that their loved one is dead can more easily consent. Sque and colleagues⁴⁰ observed that for some, being unable to 'witness the observable ending of life' was a barrier to consent. Some studies show a higher rate of consent in the DCD setting and relate this to greater family ease with the concept of cardiorespiratory death,⁵⁵ although this is not confirmed by the UK potential donor audit.² Suggestions to improve a family's understanding of brain death include allowing them to witness tests⁴⁶ or providing imaging or diagrams to explain concepts.⁵¹

Information imparted during the consent process

Both structured interview and qualitative studies have shown the importance of the inclusion of specific issues within the consent discussion.

- Description of the what the organ donation process actually involves.^{27 56}
- Emphasis on the benefits of donation and the potential to help others.^{21 35}
- Reassurances regarding funeral and burial arrangements.^{21 35}
- Reassurances regarding the fairness of organ allocation.^{35 57}
- In the USA, reassurances that becoming a donor does not require payment from family.^{21 35}

Time factors and setting

The timing of the request may be important. Separation of the request for donation from the discussion informing of the development of brain death or the inevitability of death (so-called 'decoupling') in particular has been examined. Although certain experts believe this to be unnecessary,⁵⁸ the majority of studies examining this question show that consent is more likely if requested at a time separate to the discussion informing of brain death.^{21 59–61} In

practice, decoupling may be difficult, if after being informed of their relative's death, the family immediately wish to know what happens next.

Many studies also demonstrate an association between consent being granted and the family being given sufficient time in an unpressurized manner to absorb the information they have been given, and then consider their response.^{21 24 35 43 47 56} Unsurprisingly, consent is also associated with a private and appropriate setting for these sensitive and difficult discussions.^{35 56 60 62}

Emotional support and empathy

Although subjective and difficult to quantify, a number of studies draw attention to the effect of the wider aspects of care for the family itself, both in terms of emotional and physical support and the manner in which interviews are conducted. In one of the best recent studies, Jacoby and Jaccard²⁷ in a telephone interview study with 199 families from across the USA showed consent being positively associated with:

- families who felt they had been treated with respect and dignity;
- staff who were available and showed empathy, understanding, and reassurance;
- provision of physical support in the form of accommodation, toiletries, and so forth.

It is a consistent finding among other work that a sensitive and empathetic manner (or lack of) during family discussions is a discriminator between donor and non-donor families,^{24 27 56 63} and that those families who feel pressurized or feel that staff are uncaring are less likely to donate.^{21 62}

Who should request consent for organ donation?

This question has been extensively studied and at its core is whether the approach is best made by a specialist donor coordinator, the healthcare professionals caring for the patient, or by a combination (collaborative requesting). It is intuitive that a specialist coordinator, with systematic training, a defined skill set including knowledge of modifiable factors and grief reactions, and day-to-day experience in performing requests, may perform better than a physician, who may be involved with donation infrequently and be lacking in certain skills and knowledge.

A number of US studies seemed to demonstrate the beneficial presence of a specialist coordinator.^{21 24 26 60} In a prospective observational study of 707 donation consultations, Gortmaker and colleagues⁶⁰ found that the presence of the coordinator was one of three independent variables associated with consent and that a collaborative approach achieved the highest consent rate.

The UK ACRE trial (Assessment of Collaborative REquesting) undertaken in 2007/8 sought to determine any increase in consent/authorization rates for organ donation after brainstem death when collaborative requesting was used in place

Table 2 Crude consent/authorization rates for DBD and DCD by requestor(s) in the UK (October 1, 2009–September 30, 2010)

Who was involved in the approach?	n	Crude consent/authorization rate (%)	Odds ratio for consent/authorization	95% confidence limits
Doctor and no SNOD	827	43	1.00	
Resident SNOD and doctor	276	64	2.29	1.57–3.35
Resident SNOD and no doctor	130	77	6.87	4.00–11.77
Neither SNOD nor doctor	44	21	0.26	0.09–0.71
On-call SNOD and doctor	540	67	2.24	1.65–3.04
On-call SNOD and no doctor	271	77	4.54	2.98–6.91

Source: NHSBT Statistics and Audit, 2011 (unpublished data).

of routine requesting by the patient's physician.⁶⁴ This unblinded, randomized multicentre trial was stopped after recruitment of 201 patients showed no demonstrable difference between the groups. By methodology, it stands alone in the field and yet its negative findings, which contradict much other work, remain contentious.⁶⁵ The authors conclusion is that 'collaborative requesting confers little or no advantage in request for organ donation' and cite the trial as an example of a topic where observational data send a strong signal, which is subsequently negated in a randomized trial. Criticisms however include:

- 14 large UK hospitals where collaborative approaching was already maturing and undertaken as a matter of routine were excluded;
- no proper definition of collaborative requesting was given (for pragmatic reasons) other than the presence of the coordinator in the request room. Thus, the request was unlikely to have followed a true collaborative model with a process of prior planning and due attention to timing and other modifiable factors;
- 116 relatives were excluded from the analysis, more than half of whom had been approached by the health-care team before randomization;
- there was no control for registration on the ODR. Ten per cent fewer patients in the collaborative group were registered or had expressed a prior positive wish.

Ultimately, regardless of job title, the evidence supports that whoever is approaching the family is more likely to receive consent if they have the appropriate expertise and training.^{66 67}

The long contact and in-house coordinator model

'Long Contact' describes family involvement with the donor coordinator or specialist nurse before requests for donation, and there is evidence for this approach from the USA.^{68 69} Shafer and colleagues⁶⁸ described the daily presence of organ procurement organization staff in level I trauma centres. Early contact with families and interaction before any conversation about donation increased consent/authorization rates with the highest rates of consent (75%) in a group that had had prior contact with the coordinator for more than 3 h.

An 'in-house' coordinator describes the situation where an individual or small group is attached to one particular clinical area giving the advantages of relationship building with the clinical team, easy availability, time for planning an approach, education, and staff support. Since 2009, the UK has expanded its pool of coordinators from 100 to 250 specialist nurses for organ donation (SNOD) with this aim in mind. With the advent of specialist nurses partially resident in all UK intensive care units, it is anticipated that their value and expertise in requesting conversations will become more accepted over time, in those areas where this model is not already embraced.

Initial figures from NHS Blood and Transplant after year 1 of implementation of this model are suggestive that the presence of the SNOD is significantly associated with consent (Table 2).

Summary of practical steps

While acknowledging imperfections and inconsistencies within a very large body of work, the evidence would suggest a best practice model of family consent should include:

- an approach pre-planned by the coordinator/specialist nurse and healthcare team to consider specific individual circumstances—the 'team huddle';^{58 65}
- requesting by individuals known to the family;
- requesting by team members with the required training and expertise to provide the right information in a sensitive and empathic manner. In the UK, this should be the SNOD and a senior doctor;
- requesting at a time separate to that when the family are informed of the death or its inevitability, in an unhurried manner in an appropriate setting;
- use of unapologetic and positive language, emphasizing the benefits of donation;
- ensuring the family are given specific information as detailed above and that in particular, concerning DBD, that the concept of brain death has been fully explained.

A National Institute for Health and Clinical Excellence (NICE) guideline in the UK aims to assist teams in implementing such a model.⁷⁰

Table 3 International consent rates for deceased organ donation in 2009⁷¹

	Total no. of donation requests	Total no. of assents	% consent rate		Total no. of donation requests	Total no. of assents	% consent rate
Estonia	63	33	52.4	Poland	500	444	88.8
Greece	110	92	83.6	Romania	112	42	37.5
Ireland	127	105	82.7	Spain	1922	1606	83.6
Italy	2328	1621	69.6	UK	1265	755	59.7
Latvia	24	13	54.2	Cuba	159	136	85.5
Lithuania	79	55	69.6	Israel	122	66	54.1
Malta	10	9	90	Turkey	952	298	31.3
The Netherlands	518	274	52.9	Venezuela	182	48	73.6

International perspectives

Consent rates vary significantly between countries⁷¹ (Table 3).

The reasons for such wide variation are not fully understood. In addition to the impact of cultural and patient characteristic differences, it may be seen that countries with highly organized donation systems such as Spain and Italy have among the highest consent rates.

Financial and other incentives to consent including directed donation

The arguments for a system which financially compensates a donor or their family are well rehearsed;^{72 73} it is, however, only in Iran that a legal, centralized system for payment to living donors exists. The debate primarily engages with the issue of payment (or equivalent incentives such as lifelong medical insurance) to a living unrelated kidney donor, yet work has also gone into studying the effect of a financial incentive on the families of deceased potential donors.

The Ethics Committee of the American Society of Transplant Surgeons concluded that direct cash payment to families violated the ideal standard of altruism upon which donation should be based; however, payment of funeral expenses or to a chosen charity was deemed acceptable and compatible with the concept of donation as a gift.⁷⁴ In an interview study of 155 next of kin (102 donors, 53 non-donors), 12% of non-donor families stated that they would have consented if an incentive had been offered, although interestingly 6% of donor families stated that they would have refused donation if an incentive had been offered, implying that it may offend some.⁷⁵

The Nuffield Council on Bioethics is conducting a UK consultation regarding attitudes to this question and expects to report in autumn 2011.⁷⁶ Israel has recently introduced legislation⁷⁷ that offers a non-financial incentive to consent, namely preferential access to transplantation for individuals who join the ODR, the first-degree relatives of individuals who are on the ODR, living donors, and the family members of deceased donors. Introduced in 2009, the Israeli authorities plan to assess the impact of these changes after 2 yr in use.

In the UK and other areas,^{78 79} there has been careful consideration of so-called directed donation or requested organ allocation. In certain unusual circumstances, family members may request an allocation of a deceased donor organ to a close relative or friend. A policy document drawn up by NHS Blood and Transplantation and the Human Tissue Authority⁷⁸ was adopted by the UK Health Administrations, which accepts in certain circumstances that this can be considered. It is made clear however that the fundamental principles that underpin UK organ donation, namely absence of conditionality and equity, must be respected. A requested allocation would not take priority over a potential recipient in urgent clinical need, for example, a patient on the super urgent liver list. NHSBT has established a 'Requested Allocation Oversight Group', which should be consulted by the medical and specialist nurse teams on every occasion that such a request arises.

Summary

By its nature, consent for organ donation has greater complexity than that for most medical procedures. Although some aspects remain contentious, the law is clear on what formats consent can take, and the sequence in which these should be considered, with priority given to views expressed by the individual in prior life. Although not wholly consistent, a large body of work suggests that teams can improve consent rates by attention to key aspects of the family approach. Increasing consent rates in the UK beyond the current rate of 60% is a realistic aim and would be a major step in addressing unmet transplantation needs.

Declaration of interests

A.V. is the clinical lead for organ donation at Newcastle upon Tyne Hospitals and was a member of the NICE short guideline development group 'Improving donor identification and consent rates for cadaveric organ donation', 2011. L.L. is a regional manager for Donor Care and Coordination for Scotland and Northern England, overseeing hospital and regional teams practice and performance relating to deceased organ donation.

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