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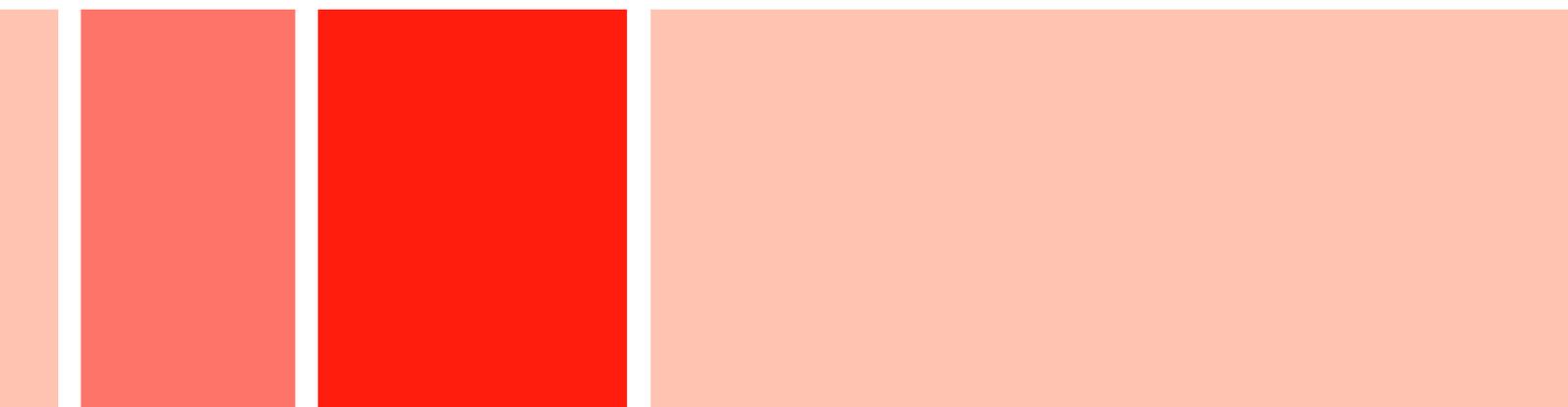
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The role of families in organ donation: International evidence review



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International evidence review

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Glossary

Brain death	Irreversible brain damage causing the end of independent respiration, regarded as indicative of death.
Cardiac death	Death resulting from the cessation of heart function.
CLOD	Clinical Lead for Organ Donation.
DBD	Donation after brain death.
DCD	Donation after cardiac death.
ICU	Intensive Care Unit.
Informed or explicit consent system	The individual authorises the removal of their organs after death, for example, by carrying a donor card.
NHSBT	National Health Service Blood and Transplant.
NHSBT Potential Donor Audit	Collects information on patient deaths in ICUs and emergency departments, with the aim of determining the potential number of solid organ donors in the UK.
NHS ODR	National Health Service Organ Donor Register.
Opt-in system	An informed or explicit consent system.
Opt-out system	A presumed consent system.
Organ donation	The process of removal and transplantation of viable organs from donor to recipient.
Presumed consent	Legislation that allows the organs to be used for transplantation after death if there is an opportunity to do so, unless the individual has objected during their life.
SNOD	Specialist Nurse for Organ Donation.

Executive summary

- This report provides a general overview of extant research involving the families of potential organ donors (both those who consented to donation and those who refused donation).

Factors associated with family consent to organ donation

- Research highlights a number of potentially modifiable factors which are associated with family consent rates. Many of these relate to the approach made by medical staff to the family, such as the timing and experience of professional(s) making the donation request.
- Many of the reasons for family refusal to donate documented in the research literature stem from misinformation or misunderstandings. For example, due to fears of unfair organ allocation or organ selling (Vincent and Logan, 2012).
- Certain demographic characteristics have been found to be associated with higher family consent rates. For example, consent rates have been found to be higher when the donor is male (Siminoff et al., 2001), younger (Rodrigue et al., 2006; Van Leiden et al., 2010) or of white ethnicity (Rodrigue et al., 2006).
- Arguably the most important factor in determining the family's decision to consent or not is their knowledge of the deceased's organ donation wishes. When the deceased's organ donation wishes are known, in the majority of cases, family members will make consent decisions in accordance these wishes. Where the next-of-kin know that the deceased wished to be an organ donor, family consent rates are approximately 90 per cent (NHSBT, 2012).

Experience of families members of potential organ donors

- Qualitative research suggests that in knowing what the deceased would have wanted, relatives felt that they did not have to ‘make a decision’ but that they were fulfilling the wishes of the deceased by facilitating the donation (Sque et al, 2003).
- The experience of the next-of-kin of potential organ donors is highly stressful and sensitive. The health professionals with whom the family interact are important in shaping this experience. A UK-based qualitative study found that respondent’s positive or negative feelings towards the health professionals remain, long after the death of the organ donor (Sque et al, 2003).

Communication with family members about organ donation wishes

- A recent Welsh Government survey (2012) indicates that the majority of adults living in Wales have not discussed their organ donation wishes with their family.
- International studies have found that individuals who are well informed about organ donation and those who intend to be an organ donor are more likely to have discussed their donation wishes with they family, compared to those who are less well informed and those who do not wish to be an organ donor.

Conclusions

- This report highlights the complexity and multi-factorial nature of organ donation decision-making, which involves not only the deceased’s family members, but also the healthcare staff making the approach.
- The role of the family is crucial under opt-in and opt-out systems of organ donation. Given that relatives’ awareness of the donation wishes of the

deceased is one of the most important factors in determining the decision made, campaigns promoting familial discussion about organ donation wishes may be of value.

1. Introduction

This report aims to provide a general overview of the research involving the families of potential donors (both those who consented to donation and those who refused donation). The relatives of potential organ donors play a critical role in determining whether organs will be procured for donation. A recently published analysis of 54 countries – which included both presumed consent and informed consent systems – found that next-of-kin have the final decision-making power as to whether their relative's organs will be donated in the majority of countries (Rosenblum et al., 2012). The need for consent or 'authorisation' from family members is particularly important when the deceased's donation wishes are unknown. However, even when the potential donor has explicitly expressed a wish to donate post-mortem during their lifetime, healthcare professionals will very rarely go ahead should the family strongly object.

For the period 2010-2011, data from the Potential Donor Audit of deaths in the UK demonstrated an overall family consent rate for donation of 65 per cent for donation after brain death (DBD) and an overall family consent rate of 51 per cent for donation after circulatory death (DCD). In cases where the potential donor was known to have expressed a wish to donate, the DBD consent rate was 94 per cent and the DCD consent rate was 80 per cent. (NHSBT, 2011)

At present, an 'opt-in' system for organ donation operates across the UK, under which individuals can express and record a wish to donate their organs after death by signing up to the Organ Donation Register (ODR). When a potential donor has been identified by medical staff, this register is consulted to determine whether the individual recorded a wish to donate their organs for transplantation. In the majority of cases when the wish to donate has been explicitly registered by the deceased, the relatives in question will agree to organ donation. However, it has been reported that of the potential donors who have signed up to the ODR, in one out of ten cases the family of the deceased objects, thereby preventing donation from going ahead (Shaw,

2012). The current opt-in legislation does not give the family the *legal* right to overrule the wishes of the deceased (where they are known). However, in practice, medical staff are unlikely to proceed with organ procurement should the family members object (Welsh Government, 2012). This disjuncture between legislation and practice in organ donation is by no means unique to the UK. Much of the research in other European countries also indicates that even if the law does not provide next-of-kin with the legal right of veto over their deceased relative's organ donation wishes, in practice, organ donation will not occur when health professional are faced with family refusal (Rosenblum et al., 2012; Boyarsky et al., 2011).

The Welsh Government's proposed Human Transplantation (Wales) Bill will change the current 'opt-in' organ donation system in Wales to a 'soft opt-out' system, also known as 'presumed consent'. A soft opt-out system is one where consent to the removal and use of organs and tissues for transplantation is deemed as having been given unless the deceased objected during their lifetime, and where the next of kin will be involved in the decision making process. It is proposed that the legislation regarding the role of the family in providing consent in this opt-out system will remain unchanged in that, legally, the wishes of the deceased take precedence. However, under the new system, those who have neither opted in nor opted out will have had their consent 'deemed'. Therefore, those who have not opted out will be treated in the same way as those who had explicitly registered a wish to donate. As stated in the Welsh Government's (2012) Draft Explanatory Memorandum: "these people will be deemed to have made a positive decision, and that will take precedence" (p. 11).

Under the proposed legislation, the next-of-kin would still not be given the legal right to object to donation when the deceased has previously expressed a wish to donate (or has had that wish deemed through taking no action). However, despite the lack of a legal right of veto, the Welsh Government states:

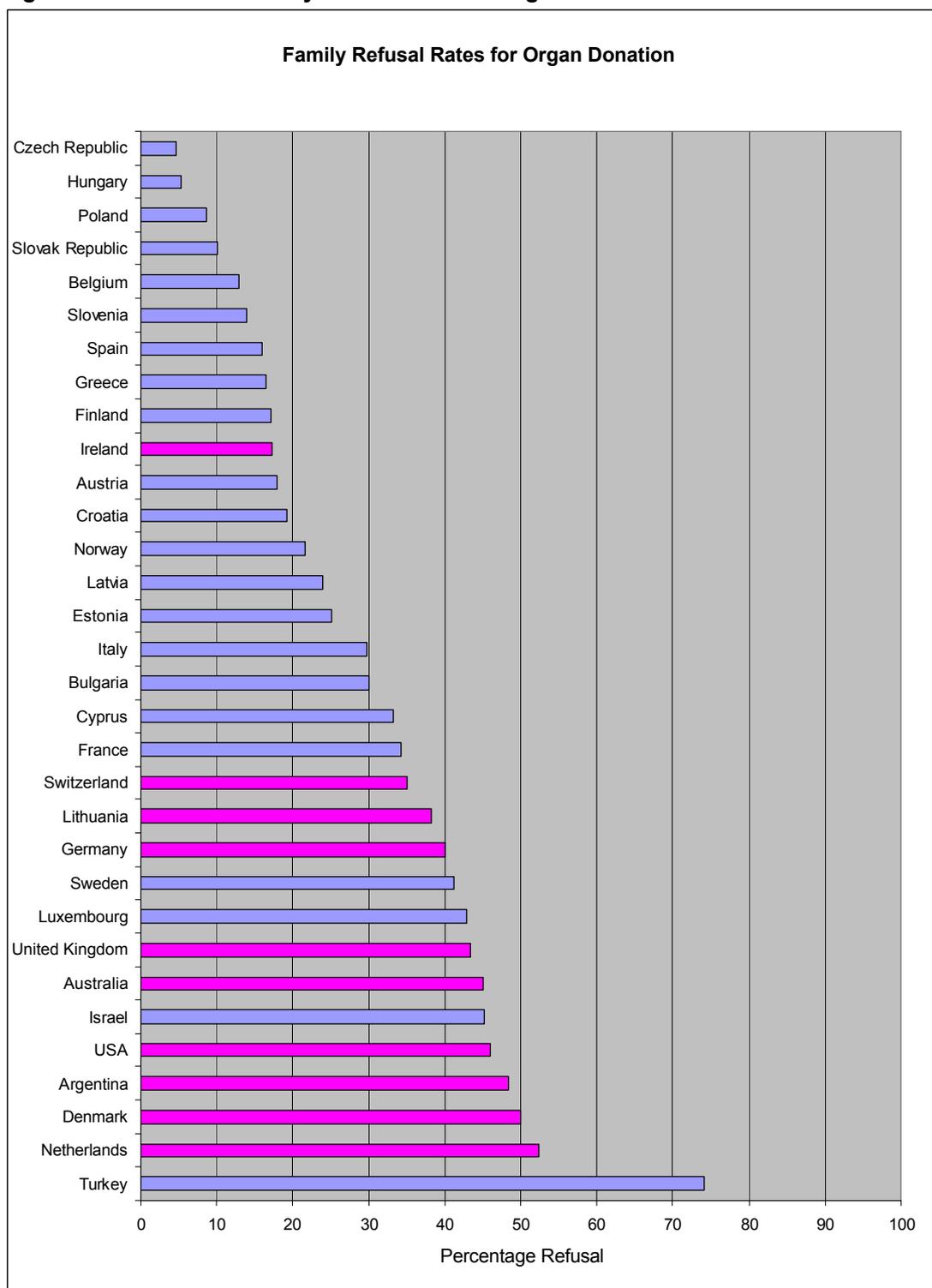
“It is essential to involve a deceased patient’s next of kin in any situation where organ donation may be a possibility because for safety and quality reasons, no donation can go ahead without their input [...] it is important to stress that the next of kin will be treated with sensitivity and their feelings will be carefully considered.”

Welsh Government (2012) Draft Explanatory Memorandum, p. 10-11

The remainder of this report is divided into a further six chapters. Chapter 2 provides an overview of international family consent/refusal rates for organ donation, looking at patterns and differences between countries that operate informed and presumed consent systems. Chapter 3 provides an assessment of the research concerned with identifying factors associated with family consent for organ donation – such as the way in which medical staff approach the next-of-kin – and the donor characteristics that increase or reduce the likelihood of organ donation proceeding. Chapter 4 focuses on what is known about family members’ communication about organ donation wishes prior to death. Chapter 5 reviews qualitative research literature focusing on the process that the next-of-kin of potential donors go through, including retrospective feelings about their decision to donate or not to donate their relative’s organs. In Chapter 6, the ethical implications of conducting this type of research with bereaved respondents is discussed. A final discussion is then presented in Chapter 7.

2. International family consent/refusal rates

Figure 1: International family refusal rates for organ donation



Sources: Multiple (detailed in Annex 1)

Key	
	Informed consent
	Presumed consent

Figure 1 shows that there is a large degree of variation in family refusal rates for organ donation internationally. The graph has been colour coded to indicate the type of consent legislation in operation in each country: presumed consent or informed consent. The UK's family refusal rate, in excess of 40 per cent, ranks the eighth highest of the 32 countries represented.

Observing the graph, there appears to be a general pattern whereby countries with informed consent legislation are grouped with higher family refusal rates, while in general, countries with presumed consent legislation rates tend to have lower family refusal rates. While this apparent pattern may be informative of a true difference between countries with different types of consent legislation, there are likely to be other factors that contribute to the difference observed. Ireland and Turkey are notable outliers in the general pattern observed. Despite having informed consent legislation, family refusal rates are particularly low in Ireland, while Turkey is a presumed consent country with very high family refusal rates. A possible explanation for this is the religious make-up of these two countries – Catholicism tends to be associated with favourable attitudes to organ donation (Gimbel et al., 2003), while Anbarci and Caglayan (2005: 15) state that Islamic teachings 'emphasize the need to maintain the integrity of the body at burial'.

Comparisons of the data shown in Figure 1, however, should be considered relatively crude given the variety of sources from which data were extracted, the variation in the years from which the data applies to, and the issues with the different methods employed to calculate familial consent rates (Jansen et al., 2009). In addition, this selection of countries was limited according to which countries had family refusal data available. There is scope for further research employing multivariate regression analysis, which would allow the association between the type of consent legislation and family refusal rates to be assessed, while taking other influencing factors into account.

3. Factors associated with family consent to organ donation

A number of literature reviews have been published in recent years summarising the findings of quantitative research that identifies factors associated with family consent for organ donation. Arguably the most important factor in making this decision is whether the deceased expressed a wish to donate their organs during their lifetime. When such a wish is known, in approximately 90 per cent of cases in the UK relatives will agree to donation proceeding¹ (NHSBT, 2012). Additional factors associated with family consent to donation have been split into two distinct categories: modifiable (primarily concerned with factors related to the approach made to next-of-kin by health care professionals for organ procurement) and non-modifiable (mostly related to demographic characteristics of the family and/or donor).

3.1 Modifiable factors

Simpkin et al. (2009) conducted a systematic review to identify modifiable factors that influence relatives' decision to allow organ donation. No randomised control trials were identified and the results of 20 observational studies were summarised. The majority of studies were conducted in the US, and the remaining in Spain. Most relied on families' retrospective reporting. Therefore, the findings may be subject to recall bias in that those respondents who agreed to organ donation may remember their experience of the process in a more positive way than those who did not agree to the donation.

The factors identified by Simpkin et al's review as being associated with increased rates of relatives' consent for organ donation were:

- the provision of adequate information on the process of organ donation and its benefits;
- the perceived provision of high quality care of potential organ donors;

¹ Where the family knew that the deceased wanted to donate, consent rate was 94% for DBD and 80% for DCD in 2010/2011 UK Potential Donor Audit.

- ensuring relatives had a clear understanding of brain death;
- separating the request for organ donation from notification that the patient had died;
- making the request in a private setting; and
- using trained and experienced individuals to make the request.

Evidence from observational studies has suggested that ‘collaborative requesting’, involving the presence of a organ donation specialist (in addition to the usual medical staff) during the donation request process, increases relatives’ consent to organ donation. This observed relationship is illustrated in Table 1, showing the results of an analysis conducted by Vincent and Logan (2012) using NHSBT data from 2011. This analysis is crude in that it has not accounted for other potential factors that might affect consent rates, and therefore the results should be interpreted with caution. It does, however, shows a distinct pattern; approaches made by doctors alone (with no Specialist Nurse for Organ Donation (SNOD) involved) seem to have much lower consent rates (43 per cent) compared to those approaches that involved the resident SNOD and a doctor which resulted in a consent rate of 64 per cent. Interestingly, the highest consent rate is observed when a SNOD made the approach without a doctor (77 per cent).

Table 1: Vincent and Logan's (2012) crude analysis of the association between the professional who approached the family for organ donation, and consent rates

Who was involved in approach?	Number of cases	Crude consent / authorisation rate (%)
Doctor and no SNOD	827	43
Resident SNOD and doctor	276	64
Resident SNOD and no doctor	130	77
Neither SNOD nor doctor	44	21
On-call SNOD and doctor	540	67
On-call SNOD and no doctor	271	77

In an attempt to assess this relationship in a controlled manner, the UK ACRE (‘Assessment of Collaborative Requesting’) study was conducted (ACRE Trial

Collaborators, 2009). This involved randomly allocating the families of potential organ donors to either be approached by a doctor alone, or a doctor and the transplant coordinator, and assessing whether family consent rates differed between the group who received the routine approach and the group who received the collaborative approach. The trial was stopped after the recruitment of 201 patients into the study, as it showed no demonstrable difference between the groups in familial consent rates. These results were in contrast to the previous observational studies, but a number of criticisms of this trial have been reported (Vincent and Logan, 2012: 84): 14 hospitals where collaborative approaching was already undertaken as a matter of routine were excluded from the study; no proper definition of collaborative requesting was given other than the presence of the coordinator in the request room; over 100 relatives were excluded from the analysis, of whom, more than half of had been approached by the healthcare team prior to randomisation; and there was no control for registration on the Organ Donor Register even though 10 per cent fewer patients in the collaborative group were registered (or had expressed a prior positive wish) compared to the non-collaborative group.

According to the NHSBT's Potential Donor Audit, family consent rate is highest when the next-of-kin are aware that the deceased wished to become an organ donor. This relies on the donor, prior to death, having signed the NHS Organ Donor Register, carrying a donor card, or making their wishes known in writing or verbally to family members. It is therefore important that continued attempts are made to not only raise awareness about organ donation but to encourage individuals to make their wishes known to their next-of-kin.

Many of the 'modifiable' factors associated with family consent for organ donation centre on the approach made by health professionals to the grieving family. Specialist Nurses for Organ Donation (SNOD) are specifically trained in how to interact with family members and the positive effect these nurses can have on familial consent rates is illustrated in Vincent and Logan's (2012) analysis. However, the success of health professional's interaction with family

members must not be judged solely based on the family consent rate; it is important to emphasise that the role of these professionals is to fully inform families of their choices and the associated implications, so that they are enabled to make informed choices which are right for them.

3.2 Non-modifiable factors

The following 'non-modifiable' or 'scarcely modifiable' factors have been found to be associated with relatives' consent decision in the international research literature:

- Demographics: familial consent rates have been found to be higher when the donor is: male (Siminoff et al., 2001), younger (Rodrigue et al., 2006; Van Leiden et al., 2010) or of white ethnicity (Rodrigue et al., 2006);
- Certain religions are associated with lower rates of consent for organ donation, e.g. Jehovah's Witnesses (Radecki and Jaccard, 1997)
- Circumstances or cause of death: Siminoff et al. (2001) found familial consent rates to be higher when the cause of death was trauma, as opposed to a non-trauma related death.

The 2010/11 UK NHSBT Potential Donor Audit (NHSTBT, 2011) also conducted some statistical analyses to assess whether there were any differences in family consent rates according to demographic characteristics. The analysis found no statistically significant difference in consent rates for male and female donors for donation after brain death (DBD), but that for donation after cardiac death (DCD) the consent rates for male donors was slightly higher (54 per cent) than that for female donors (46 per cent). No statistically significant difference in consent rates between donors of different ages was detected. However, statistically significant differences in consent rates for donors of different ethnic groups were detected: for DBD, the consent rate was 71 per cent for white potential donors and 23 per cent for known non-white potential donors. For DCD, the consent rate was 54 per cent

for white potential donors and 30 per cent for known non-white potential donors. For the purpose of the analysis, all the non-white ethnicities were grouped into one category in order to maintain a large enough sample size for robust statistical analysis. However, this does not allow for the detection of potentially important differences in consent rates that may exist among different ethnic minority groups. Further research which focuses on the different ethnicities that make up the 'non-white' group may therefore be valuable in order to better understand reasons for refusal among different ethnicities where the refusal rate is particularly high.

3.3 Families' reasons for refusal to consent

Vincent and Logan (2012) provide a list of common reasons provided by family members themselves for refusal to consent to organ donation, which was compiled from the reviewed literature:

- Not wishing for surgery to the body/having concerns regarding disfigurement
- Feelings that the patient had suffered enough
- Uncertainty regarding the patient's wishes
- Disagreements among the family group
- Religious/cultural reasons
- Dissatisfaction with healthcare staff and process
- Concerns over delay to funeral/burial process
- Unable to accept death, or lack of understanding of brain death
- Concerns regarding integrity of process e.g. unfair organ allocation of organs and organ selling
- Relatives deciding themselves that organs would not be suitable
- Longstanding negative views on organ donation
- Relatives were emotionally exhausted

Many of these reasons are based around misunderstanding or misinformation – for example, the concerns regarding unfair organ allocation or organ selling,

or that there is an upper age limit for organ donors. In reality, the quality of organs are judged on a case by case basis (NHSBT, 2012). Communicating this to the public may encourage older people who previously assumed their own ineligibility to make their donation wishes known.

Given that some refusals are based on a lack of understanding of brain death, further efforts may be needed in order to communicate this type of death in a way that is accessible to persons with no medical training. Qualitative research suggests that for some individuals, more visual explanations of brain death are helpful in increasing understanding. The British Medical Association (BMA) has also suggested that there is a need for research concerning whether there would be any advantage in giving families a short death certificate, confirming that death has occurred before organs are removed (BMA, 2012).

4. Sharing organ donation wishes with family

The literature reviewed above indicates that family members' knowledge of the deceased's organ donation wishes is arguably the most important factor determining the families' consent decision. Thomas et al. (2009) conducted a qualitative study in Australia with family members of organ donors and the staff who work with organ donation cases. An apparent key factor in family members' decision to donate was their prior knowledge of the deceased's wishes. This led one staff member to comment that "the key community message about donation should be to encourage people to discuss donation rather than urging people to sign donor registers" (p.588).

Much of the organ donation literature focuses on improving consent for organ donation and encouraging those who wish to donate, to register. There appears to be far less research concerned with the communication of one's wish to donate, or not donate, and ensuring that family members are aware of these wishes. The Wales Omnibus Survey, conducted with a representative sample of adults resident in Wales in 2012, indicates that 62 per cent of respondents have not discussed their organ donation wishes with their family. (Welsh Government, 2012b). Talking about posthumous organ donation with family involves the uncomfortable acknowledgement that at some point, our relatives or ourselves may die in a way that is conducive to organ donation. Even in the absence of the question of organ donation, generally, death is a taboo subject and discussing it may cause upset or be felt to be tempting fate (Newton, 2011). Despite this, there is evidence (discussed later) to suggest that this knowledge may offer families the comfort of knowing that they carried out the deceased's wishes, facilitating the donation decision-making process, and minimising stress and family conflict during a period of extreme sensitivity and emotional burden.

Wenger and Szucs (2011) conducted a population-based survey in Switzerland, from which data were analysed to identify factors associated with participants having informed their family members of their intention to

donate organs after death. The results of the multivariate logistic regression found that having signed an organ donor card was the strongest predictor of having communicated donation wishes to family members; respondents who had signed an organ donor card were ten times more likely to have discussed their wish with relatives, compared to respondents who had not signed a card. This suggests that individuals who are more favourable about organ donation and have 'opted in' are more comfortable in also sharing this decision with family members. Respondents who felt that they were sufficiently informed about organ donation and transplantation were more than twice as likely to have discussed their wishes with family members, compared to those who did not feel sufficiently informed. Similarly, respondents who had engaged in a family discussion about organ donation or transplantation in general were over seven times more likely to have shared their donation intentions with their family, compared to those who had not had a general conversation about organ donation with family members. It seems plausible that families who have already discussed issues relevant to organ donation and transplantation in general may also be more confident in sharing their wishes.

Similar findings have been reported by Morgan and Miller (2002) whose study of a US sample also indicated that respondents with more favourable attitudes to organ donation, and who were more knowledgeable about organ donation, were more likely to report having discussed their donation wishes with family members. This finding prompts the authors to speculate that when people are more favourable towards and knowledgeable about organ donation, they are able to respond to family members' potentially negative views on organ donation.

The apparent association between favourable attitudes towards organ donation and communication of wishes to family members has implications for intervention efforts aiming to encourage familial discussion about donation wishes. On the one hand these findings may be taken to suggest that by increasing favourable attitudes, through positive campaigns which debunk common myths, this may help to increase family discussion. However,

maximising positive attitudes to organ donation does not guarantee that all that hold such attitudes will discuss their wishes. Guadagnoli et al. (1999) found that in their study of randomly selected US participants, of those who said that they wanted to donate their organ after death, only 50 per cent had shared this wish with their relatives. Even when individuals do not have favourable attitudes to organ donation and do not wish to donate, it is still valuable that these wishes are shared with family members, so that if faced with the request they are able to make a decision that is in accordance with the deceased's wishes.

Pitts et al. (2009) conducted a qualitative study of college students in the US, who were given an audio-recorder and instructed to take part in and record a family discussion about their organ donation wishes. One of the important insights provided by this study was that it captured people's natural responses to a common recommendation of organ donation campaigns, to "talk to your family about organ donation". The assumption underpinning this message is that people will discuss their organ donation wishes with their next-of-kin, which for most college students would be a parent. Although the majority of discussions did involve a parent, some students chose to discuss this topic with their siblings, grandparents, in-laws and even cousins. Thus, although following the instructions to discuss their organ donation wishes with family, many of the resulting discussions did not involve the person who would make the actual final organ donation decision at the time of death. Where discussion did involve a parent of the student participant, another issue was raised; parents (even those who were in support of organ donation) voiced concern that they would find it difficult to consent to the donation of their child's organs, even if doing so was consistent with the child's wishes. Fears expressed concerned the potential for being rushed into a decision when the child's prognosis would be difficult to understand or accept (e.g. brain stem death) to allow them to make a clear decision. An additional finding was that during the process of discussion, it became apparent that families in the study wanted all members to be in agreement in their wishes and views concerning organ donation, and when a consensus could not be reached, varying degrees of familial conflict emerged. These findings led the

authors to recommend three specific potentially problematic issues that future communication campaigns should seek to address:

- family members may fail to discuss organ donation wishes with the appropriate relative;
- family members might decide that they will not follow the expressed wishes of their deceased relative; and
- families use different strategies to address diverging opinions and consensus, some of which may result in familial conflict.

In summary, there is limited research concerned with the communication of organ donation wishes to family members and none of the studies reviewed above involve respondents from the UK. UK-based research may be useful in understanding what factors motivate or impede individuals from discussing their organ donation wishes with family members, thereby informing interventions aiming to encourage these types of discussions. In addition to public communications campaigns which promote awareness and positive attitudes towards organ donation, efforts could also focus on encouraging family discussions of organ donation intentions. The above research suggests that individuals with more positive intentions to donate their organs after death are more likely to have communicated this intention to their next-of-kin, compared to those who do not wish to donate their organs. Specific attention could be given to the promotion of discussion of donation wishes, whether these are to donate or not, thereby ensuring that family members can feel comforted by the knowledge that they made a decision in accordance with the deceased's wishes.

5. Experiences of families of potential donors

Multiple qualitative studies involving in-depth interviews with families who have consented or refused for their relative to be an organ donor have been conducted. In general, these studies provide narrative accounts of how families' reflect on their experiences of the organ donation process, including how they feel months after the decision was made to donate or not donate their relative's organs. This section seeks to give an overview of the process of organ donation as experienced by the next-of-kin of the deceased.

Particular focus is given to a number of studies conducted by Magi Sque and her team; these qualitative studies are judged to be of high quality and they are specific to the experience of donor/non-donor families living in the UK.

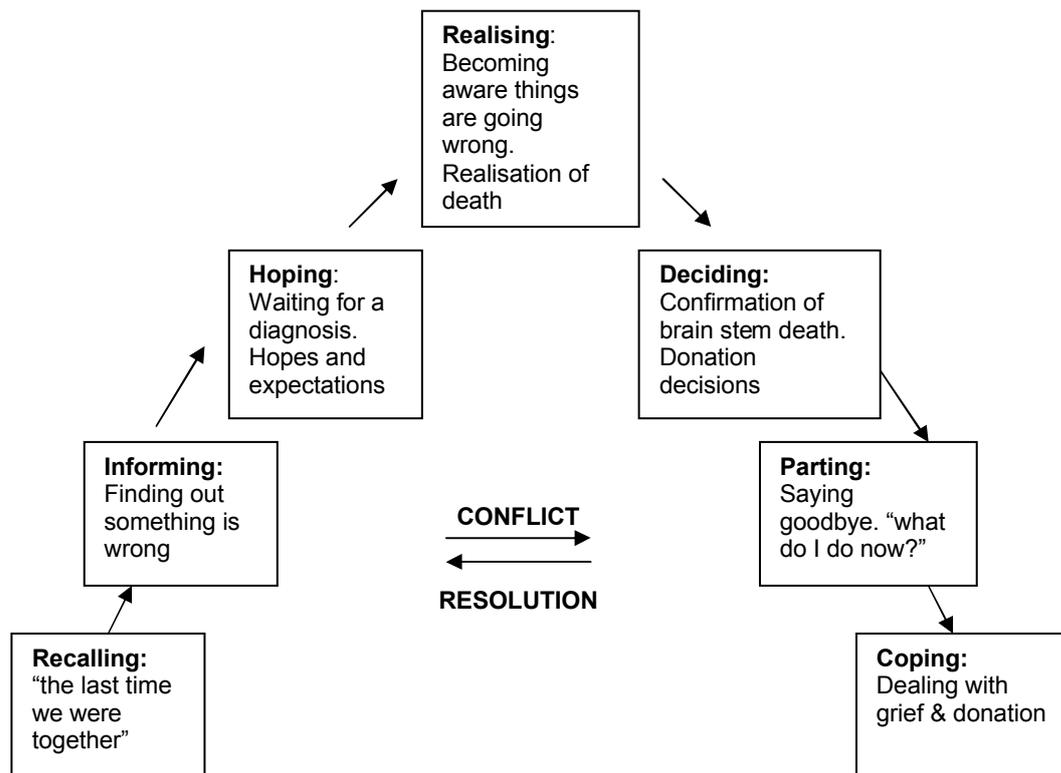
Sque and Payne (1996) propose a theory of 'dissonant loss' to explain donor relatives' experiences of the donation process. The authors define dissonant loss as:

“a bereavement or loss which is characterised by a sense of uncertainty and psychological inconsistency [...] dissonance occurs as the loss is encompassed by a series of complex decisions.”

Sque and Payne (1996: 1367)

Next-of-kin's experiences were found to revolve around a process of conflict and resolution. Conflict unfolds as a chain of extraneous events over which the family has no control, such as the realisation of their relative's death and the donation decisions which must be made in an emotionally provocative environment. Relatives may feel under pressure to honour the wishes of the deceased, even against their own convictions. Such decisional conflict is particularly exacerbated when relatives are faced with accepting brain stem death as confirmation of actual death. The experience of donor relatives is illustrated by a model proposed by the authors (Figure 2).

Figure 2: Sque and Payne's (1996) model of donor relatives' experiences



5.1 Understanding brain death

The critical injury and subsequent death of individuals who are eligible to become organ donors is usually sudden and unexpected. While more and more donations are being made after cardiac death (after the heart has stopped beating), the majority of organ donations still come from patients who have been declared ‘brain dead’ (NHSBT, 2012b). The difficulty of understanding and accepting brain death when one’s relative is on a ventilator is a common theme arising in the literature on families’ experience of the organ donation process (Ormod et al., 2005; Long et al., 2008).

Considering organ procurement from the seemingly ‘alive’ body of a relative is a particularly challenging component of the organ donation process for next-of-kin (Ormod et al., 2005). Long et al. (2008) report that the ‘visually alive’ relative being diagnosed as brain dead seems to trigger an emotional and cognitive conflict which may only be resolved when the body is consistent with

the conventional schema of a dead body. In line with this is that respondents in Kesselring et al's (2007) study, conducted in Switzerland, gave great importance to having the opportunity to say their final goodbye after the organ procurement procedure, which provided certainty that death had really occurred: "you cannot say goodbye when he is still breathing" (respondent quote: p.214). In Sque et al's (2003) study, three of the 46 respondents remained in the hospital to see the deceased after the donation operation. A larger number returned the following day to see the deceased in the Chapel of Rest. Most participants who had seen their relative after the donation operation were relieved that they had not been disfigured, as this was a common theme of concern.

Health professionals have a vital role to play in ensuring relatives have a full and clear understanding of brain death. In Sque et al's (2003) study, researchers found that while some relatives struggled in understanding what the brain injury meant in relation to the quality of life for their relative, others who were provided with a more 'visual' explanation (involving scans or models of brains, or more relatable analogies) exhibited greater understanding of the injury. It has been recommended that the delivery of information about injury and brain death should involve a variety of communication strategies, such as visual aids, verbal information and written information. Sque et al. (2003) also suggest the possibility of sending follow up written information at a time when relatives are more mentally receptive to it, such as after the funeral.

5.2 Interacting with health professionals

The research provides accounts of respondents' experience of communication with health professionals, both positive and negative. Respondents who felt that the staff had recognised them as 'important' people in the deceased's life and communicated well, provided more positive accounts of their interactions with the health professionals (Sque et al., 2003). This study interviewed families at three time points post-donation and found that even at the last interview visit (18-24 months following bereavement) the

negative or positive feelings towards the interaction with health professionals remained. Nurses were pivotal to families' overall experience in the Intensive Care Unit (ICU); participants specifically identified individual doctors if their communication was seen as good or poor, but no nursing staff received poor reports from participants.

Families' perceptions of the care provided to their deceased relatives was important in their experience, as was having final dedicated time to say goodbye before the donation procedure went ahead. A small number of respondents recounted that their quiet time to say goodbye had been disrupted by the entry of the organ retrieval team made up of medical staff not previously involved in the case (Sque et al., 2003).

Sque et al. (2003) recommend that, in order to enhance information processing and maximise the positive impact of initial care on subsequent grief, relatives need:

- **Time:** to absorb the nature of brain injury, and to discuss this with other family members and seek reassurances for any concerns;
- **Attention:** to the special role they have as next-of-kin, attention to their inner turmoil and the understanding that this could impact on how they process information;
- **Care:** in the way, and where, information is presented and the understanding that this will 'live' on in their minds for years to come.

5.3 Deciding whether to donate

In accordance with the quantitative research, qualitative studies also highlight that knowledge of the deceased's organ donation wishes is often the most important factor in relatives' decision-making about whether to consent (Thomas et al., 2009; Tymstra et al., 1992). Nineteen of the participants in Sque et al's (2003) study knew the wishes of the deceased in relation to organ donation, and so made decisions in line with those wishes. It is

suggested that participants who knew the wishes of the deceased did not feel that they had to 'make a decision', but that they were fulfilling the wishes of the deceased by facilitating the donation:

"That's the way she wanted it. It's an obligation to her."

"It was S's wish my own personal views on the matter didn't, just weren't relevant, they weren't an issue. It wasn't for me to alter anything that S wanted."

(Sque et al., 2003: 27)

Where the deceased's wishes are not directly known (i.e. there has not been explicit communication before death), the deceased's desire may be indirectly inferred, because the family believe that the deceased was the kind of person who liked to help others (Pearson et al., 1995). Sque et al's (2003) study found that in such cases, the decision to agree to donation was influenced by the perceived attributes of the deceased, and the opinion of them held by the family members as an 'altruistic person' who 'cared for others'.

The opportunity to help others and for something positive to come out of such a negative experience also motivates family members to agree to donation (Muthny et al., 2006). Martinez et al's (2008) qualitative study of families in Spain reports similar reasons given by the next-of-kin for agreeing to donate; predominantly respect for deceased's will, but also:

- **Usefulness:** in that the organs are no longer of use to the deceased and they could save multiple lives;
- **Generosity:** wanting to help others;
- **Reciprocity:** thinking about other relatives who may one day need a transplant; and
- **Transcendence:** the idea that the donor "may live on in another person" (p. 133).

Another study by Sque et al. (2006a) involved qualitative research specifically with the families of individuals who had been eligible to donate their organs

but consent had been refused. In some of these cases, it was known that the deceased had not wished to be an organ donor and so the family considered that the decision had already been made.

Some qualitative studies have attempted to compare the experiences of donor and non-donor families to shed light on what factors account for the different decisions regarding organ donation. Jacoby et al. (2005) report that the main differences in their study (involving the 11 families of donors and 5 of non-donors) was that, according to those families who refused consent, there was little prior preparation for the donor request, insufficient time to cope with the crisis and make the decision (in the case of non-donors), and the existence (in the case of the donors) or absence of a person who acted as an intermediary with the doctors who had treated the deceased. The 'no' decisions reported in Sque et al's (2003) study were characterised by poor communication and rapport with the health professional involved. Martinez et al. (2008) conducted a qualitative study with three non-donor families and six donor families in Spain, whereby donor families recalled the health professional's information and communication strategies positively because in making the family aware of the severity of the situation they were able to accept their relative's death more easily and quickly. The three non-donors families reported that they considered their interaction with the health personnel negatively because of its "coldness, and hardness" (p. 131). Also, either by not emphasising the severity of the situation or through the lack of comments related to the prognosis, families felt that the health professionals had raised their hopes, only to be disappointed later, which led them to suspect that the staff had not done all that they could.

Martinez et al. (2008) also report on the differences in nature of the reasons provided for the families' decision to donate or not donate; the authors report that donor families seem to give more internal reasons for donation, such as the wish for something good to come out of tragedy, while non-donor families gave more external causes, often relating to the experience of the health service, as reasons for why they did not donate.

Martinez et al. (2008) found there were not only differences in the medical professionals' approach in the accounts of donor and non-donor families, but pre-held views of the relatives concerning organ donation that also played a role: "in all the interviews that concluded in donation, at least one person was found among the main deciders who was in favour of donation, and there was nobody who maintained the opposite viewpoint a priori" (p. 131). There may be some degree of interaction between a family's a priori viewpoint regarding donation and their perception of the health professionals' approach, whereby those with more favourable attitudes towards organ donation reflect more positively on the approach made. It seems plausible that the family members' pre-held views regarding organ donation affects the extent to which the behaviour of the medical professionals impacts on the final organ donation decision. Martinez et al posit that the likelihood of granting consent for donation is partially determined by the beliefs and attitudes of the family of the potential donor and that the more positive the beliefs and the more clearly known the donor's wishes regarding organ donation, the higher the likelihood that the family will agree to the donation, independently of hospital and medical factors. When the next-of-kin are not clearly inclined towards organ donation, the behaviour of the health professionals is more critical in shaping the final decision, and there appears to be a greater incidence of reports of conflict with the healthcare personnel in the final decision.

In Sanner's (2007) qualitative studies of the families of potential donors in Sweden and the physicians who treated each case, the doctors were categorised as 'pro-donation' or 'neutral' based on their type of approach to the family. Although this was a qualitative study with a very small sample size, the author still highlights an interesting pattern concerning the cases for which donation did and did not occur. Table 2 shows that when the prior wish of the deceased was unknown, only those relatives who were met by a physician with a pro-donation approach consented to organ donation (seven of nine cases where deceased's wish was unknown and physician took a pro-donation approach resulted in consent for donation). In the five cases where the deceased's wishes were unknown and the family were met by a physician with a neutral approach, none consented to donation.

Table 2: Sanner, 2007 (p. 301), outcome of donation request in cases where deceased's prior wishes were unknown, according to whether prior wish was known and basic approach of physician making the request

Physician's approach while requesting	Outcome of donation request		Total
	Donation	No donation	
Pro-donation	7	2	9
Neutral	0	5	5

This study is one of very few which also examine the experience and account of the request for donation approach from the perspective of the physician who made the approach. This highlights that physicians have different approaches in how they request consent for organ donation from the family. The reasons for the differences in approaches are not clear, although the authors suggest that they may be associated with the health professional's own personal view of organ donation.

De Groot's (2012) review of the international literature highlights certain themes arising from studies with non-donor families when accounting for why they did not agree to organ donation. In line with the findings of the quantitative research literature, these included values related to integrity of body and the wish to avoid disfigurement. Protecting the body, in terms of keeping it whole and intact was a recurring theme in Sque et al's (2006) study, discussed in 15 of the 23 interviews with non-donor families, and was the primary reason reported for not donating. Again, in line with the findings reported in the quantitative literature, participants also expressed some incorrect assumptions about organ donation relating to the belief that due to the age or illness of the deceased, the organs would not be suitable for donation.

Conflict between family members in deciding whether or not to donate has been reported in multiple studies. Rodrigue et al. (2008b) found that families who were not in agreement were significantly less likely to donate. Similarly, Martinez et al. (2008) report that where disagreement occurs as a result of a family member expressing and maintaining views strongly against donation, the conflict is often resolved by the yielding of those family members who

favoured organ donation, due to the need to not add further anxiety to the situation, particularly for the closest relatives or those who are more emotionally affected. These findings are in line with previous research that indicates that where there is uncertainty, the 'non-decision' option is to refuse organ donation: "spontaneous reactions of the grieving and tired relatives to ward off provoking ideas and regard "no" as a non-decision can be regarded as an instinctive reaction" (Sanner, 2007: 304).

In 14 of Sque et al's (2003) cases, children were present and actively contributed to the decision-making about organ donation. This was an unexpected finding that the authors felt warrants further investigation into the role of children and young relatives in the organ donation decision-making process.

5.4 After donation

Relatives of organ donors often report that a degree of comfort was provided by organ donation (Bellali and Papadatou, 2006; Douglass and Daly, 1995; Ormod et al., 2005). Sque et al. (2003) found that at all time points interviewed, participants expressed how donating the organs of their relatives had, in different ways, been a comfort for them. Despite this comfort, respondents did not feel that donation actually mitigated any of the painful feelings experienced nor helped them in their grief.

Post-donation, many respondents in Sque et al's (2003) study expressed a desire for information regarding the fate of their relatives' organs. At the time of the first interview (3-5 months), not all respondents wanted contact from the organ recipients, but by the third interview (18-24 months) all the participants "would like to hear" or thought it "would be nice to hear" (p. 39). By the third interview 19 participants had received at least one letter from an organ recipient or a member of the recipient's family. Overall, the response from those who had received a letter was positive and it was felt that they provided an important recognition of the role the deceased had played in changing the

recipient's life. The contact was described as 'helpful', 'comforting' and some felt 'proud' of their relative's donation. Those participants who had not heard from recipients expressed emotions ranging from disappointment to anger. The need for contact with those involved in the process was not confined to the organ recipients. Some families expressed a desire for further contact with the transplant co-ordinator involved in their case but seemed reluctant to make the contact themselves, worrying that the co-ordinator would be too busy.

It has been reported that less regret is experienced by families who consented to organ donation, compared to those who had refused (Ormod et al., 2005; Rodrigue et al., 2008). A review of international research literature by De Groot (2012) also suggests that there may be differing levels of regret after the decision to donate or not to donate. The author found a number of studies which indicated that of families of non-donors, between one-third and 42 per cent reported that they would change their minds if given the opportunity. Conversely, regret among families of donors has been found to be far lower.

In contrast, none of the participants in Sque et al's (2006) study of non-donor relatives regretted the decision they made at the time of their relative's death. Seven participants did report being left feeling guilty or selfish, which they attributed to a number of factors, including the feeling that they were in the minority (and that most people donate); that they did not fulfil the wishes of the deceased; and due to media pressure to 'give the gift of life'. This indicates that even when relatives feel that the decision made at the time was right for them, the implicit societal pressure to donate may have a negative effect on the feelings of those who choose not to donate.

6. The ethics of researching the bereaved

This section focuses on the actual process of conducting research with the bereaved family members of potential donors. Relatives of potential donors are particularly at risk of aberrant bereavement outcomes due to the likely unexpected and sudden nature of their relative's death. Such a loss may be exceptionally difficult to come to terms with given that often, the donor was previously healthy, with no signs or symptoms to indicate a sudden death. In the majority of (potential) organ donor cases, death will have been defined by brain death criteria as opposed to cardiac death (when the heart stops beating) (NHSBT, 2012b). This may add an additional level of complexity to grieving relatives' experience. Given the degree of distress already experienced by the relatives of a potential organ donor, there are ethical considerations that must be taken into account when conducting research with the bereaved.

6.1 Recruitment

There is limited data on recruitment rates for research with the bereaved and the extent to which comparisons between studies can be made is limited given the variations in focus of the interviews, recruitment methods and lack of statistical information. In general however, recruitment rates seem to have ranged from around 30-70 per cent, though the studies that report the highest recruitment rates are generally those that were carried out in earlier years, when the donation procedure was newer. There may have been greater scope for access to local participants, and possibly a greater tradition of compliance with the medical profession.

While there are stringent procedures which researchers must go through in order to ensure the ethical validity of their research, there are reports that the 'gatekeepers' tend to err on the side of caution, thereby preventing bereaved people from participating in research (Parkes, 1995). Sque (2000) reports on

the 'blocking' encountered when trying to gain access to donor relatives, whereby four of the seven transplant co-ordinating units approached refused to facilitate the recruitment of relatives of donors owing to the sensitive nature of the research.

Sque et al's (2003) study recruited donor family participants from four transplant co-ordinating services; transplant co-ordinators sent out recruitment packs to families 6-8 weeks following bereavement. For access to non-donor families, approaches to Intensive Care Units (ICUs) were facilitated through two transplant co-ordinating services participating in the project, which collected data on families who declined donation. Meetings with senior ICU managers and collaboration with the Intensive Care National Audit and Research centre (ICNARC) also facilitated ICU recruitment. The research comments on the particular difficulty in recruiting the families of non-donors.

6.2 The respondents' experience of the research process

There appears to be little evidence to suggest that research with bereaved individuals will cause further distress or harm. Hutchinson et al. (1994) argue that people who cannot tolerate talking about a topic will not consent to taking part in an interview. Therefore, the recruitment process should filter out those who could potentially be at the greatest risk of distress or harm. Colin Murray Parkes, an experienced bereavement researcher agrees, stating: "Any bereaved people who are not ready to talk will decline the invitation to take part" (Cartwright and Seale, 1990: 36). This finding also indicates that researchers must respect first refusals and not push for consent to participate.

There is also evidence to suggest that for those who take part in interviews concerning experiences of a sensitive nature, including the decision to donate or not donate the organs of a deceased relative, the interview process can actually be therapeutic. In Sque and Payne's (1996) qualitative study with relatives of organ donors, the authors state that their participants seemed grateful for the opportunity to express their sorrow and to talk about their deceased relative. Similarly, in Sque et al's (2006) interview study with non-

donor families, participants were asked to fill out post-interview evaluation forms concerning their interview experience; 14 of 21 respondents reported that they found the interview to be 'very' helpful, six reported that they found it 'a little' helpful and one respondent reported that they did not find the interview helpful. Some of the comments from the participants' evaluation of taking part in this study included:

"I found [the interviewer] a very sympathetic, sensitive interviewer and appreciated the opportunity to talk to someone at length about our experiences with the distance of time, and in my own way."

"Extremely sensitive, kind, and understanding questioner – put up with uncontrolled reminiscence and ready tearfulness. This was not a sign of distress but a relief and a chance to go through in words memories which are deeply felt. I much appreciate the chance to take part."

(Sque et al, 2006: 16)

A similar evaluation was completed by the donor and non-donor family participants in Sque et al's 2003 qualitative study. Participants were asked what it was like to be part of this research and responded by stating their desire to 'help' or to 'make a difference'; a reflection, perhaps, of the type of people participating in this research. After the first set of interviews, participants were sent a letter requesting an evaluation of the interview experience. Responses showed that the majority of participants found the interview helpful and reported that they felt the interviewer to be understanding. Omrod et al. (2005) also report on the value of the interview process to respondents, with particular reference to how, for some, the interview answered some unresolved questions concerning brain death, "the demonstration of pathology on CT scan being particularly helpful in this regard" (p. 1005).

Given the traumatic experience that the relatives of potential organ donors will have already been through, researchers must be especially careful to ensure that their research does not cause further distress. The experience of

interviewees will likely very much depend on the attributes of the researcher, and it is vital that they are sensitive and sympathetic. Researchers have suggested that potential respondents who are not ready to talk about their experience will not consent to partaking in such research, and therefore, the recruitment process effectively filters out those individuals for whom the research experience could cause particular distress. Many of the respondents to the qualitative research reviewed above actually seemed to find the interview process to be helpful, and even therapeutic.

7. Discussion

The proposed Human Transplantation (Wales) Bill, which will introduce a 'soft opt-out' system of organ donation in Wales, does not provide relatives with the legal right to override the explicitly recorded or deemed wishes of the deceased. However, the explanatory memorandum states, "it is important to stress that the next of kin will be treated with sensitivity and their feelings will be carefully considered" (Welsh Government, 2012:11).

Sque et al's (2003) qualitative study, which conducted in-depth interviews with 46 family members of potential organ donors, explored what the relatives of potential organ donors thought about opt-out legislation for organ donation. Participants were asked their opinion regarding 'presumed consent opt-out' and the majority (37 out of 46 respondents) felt presumed consent was a good idea and that it would facilitate discussions about organ donation. Respondents also felt that presumed consent should not replace the discussion with families regarding organ donation. Seven participants were not in favour of 'presumed consent opt-out' and two were not sure. However, as these findings could not be considered to be representative of a wider population, there may be value in conducting further research with individuals who have been through the organ donation decision-making process to explore how they think a system of presumed consent may have affected their experience.

In conducting this review, no research was identified concerning whether the interaction/discussion between healthcare staff and families differs according to whether the approach takes place in the context of an opt-in or opt-out system. As discussed above, current research indicates that if the next-of-kin know the donation wishes of deceased, in the majority of cases, the family will want to follow those wishes. Where deceased's wishes are not known, and if the family do not hold strong opinions against organ donation, then these are the cases in which the approach by health professionals is a particularly important factor in the decision-making process. Of interest, is

whether or how implementing opt-out legislation changes the nature of these discussions.

Also of potential significance in determining how well an opt-out system works to increase organ donation rates is how the next-of-kin perceive the deceased's consent according to whether it has been explicitly registered or deemed through lack of action. Coppen et al (2010) conducted an experimental study with a sample of Dutch adults to investigate how the type of consent given by the hypothetical deceased potential donor affects the reported consent rates of next-of-kin to allow donation to proceed. This study indicated that when the deceased's consent had been presumed, the level of familial consent is lower than when it has been explicitly expressed, but that when the deceased has not registered their donation wishes, there is a higher rate of familial consent in a system of presumed consent versus explicit consent.

In summary, this report highlights the complexity and multi-factorial nature of organ donation decision-making, which involves not only the deceased's family members, but also the healthcare staff making the approach. During this highly stressful and sensitive time, it is important that relatives are enabled and supported in making a decision that is right for them, whether that be to donate or not donate, so minimising the risk of regretting their decision. The relatives' awareness of the donation wishes of the deceased is one of the most important factors in determining the decision made; in the majority of cases, the family will follow the deceased wishes. A recent survey conducted among a representative sample of the Welsh adult population (Welsh Government, 2012b) indicated that that 62 per cent of respondents had not discussed their organ donation wishes with their family, suggesting that there is a need for efforts to increase family discussion about organ donation intentions in Wales. The role of the family in organ donation remains critical whether Wales adopts the new opt-out legislation or not. Therefore, campaigns promoting familial discussion about organ donation wishes may be of value, regardless of the status of the consent legislation.

Appendix 1: Sources of family refusal rates used to construct Figure 1

Country	Source
Spain	Council of Europe, 2012
Croatia	Council of Europe, 2011
Belgium	Gelder et al, 2008
Portugal	No data identified
USA	Jansen, 2012
France	Jansen, 2012
Norway	Council of Europe, 2012
Austria	Eurotransplant, 2010
Italy	Council of Europe, 2012
Ireland	Council of Europe, 2010
Latvia	Council of Europe, 2012
Luxembourg	Council of Europe, 2011
Czech Republic	Council of Europe, 2011
Finland	Roels et al, 2008
United Kingdom	Council of Europe, 2012
Estonia	Council of Europe, 2012
Slovenia	Council of Europe, 2012
Sweden	Jansen, 2012
Canada	No data identified
Argentina	Council of Europe, 2012
Australia	http://theconversation.edu.au/half-of-bereaved-families-refuse-organ-donation-3094 [accessed: 17/10/12]
Germany	Eurotransplant, 2010
Poland	Council of Europe, 2011
Netherlands	Council of Europe, 2012
Hungary	Council of Europe, 2012
Denmark	Jansen, 2012
Slovak Republic	Council of Europe, 2012
Switzerland	Council of Europe, 2009
Lithuania	Council of Europe, 2012
Israel	Council of Europe, 2012
New Zealand	No data identified
Greece	Council of Europe, 2010
Cyprus	Council of Europe, 2012
Turkey	Council of Europe, 2012
Bulgaria	Council of Europe, 2012

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