

## **An update on initiatives to increase organ donation: A UK perspective**

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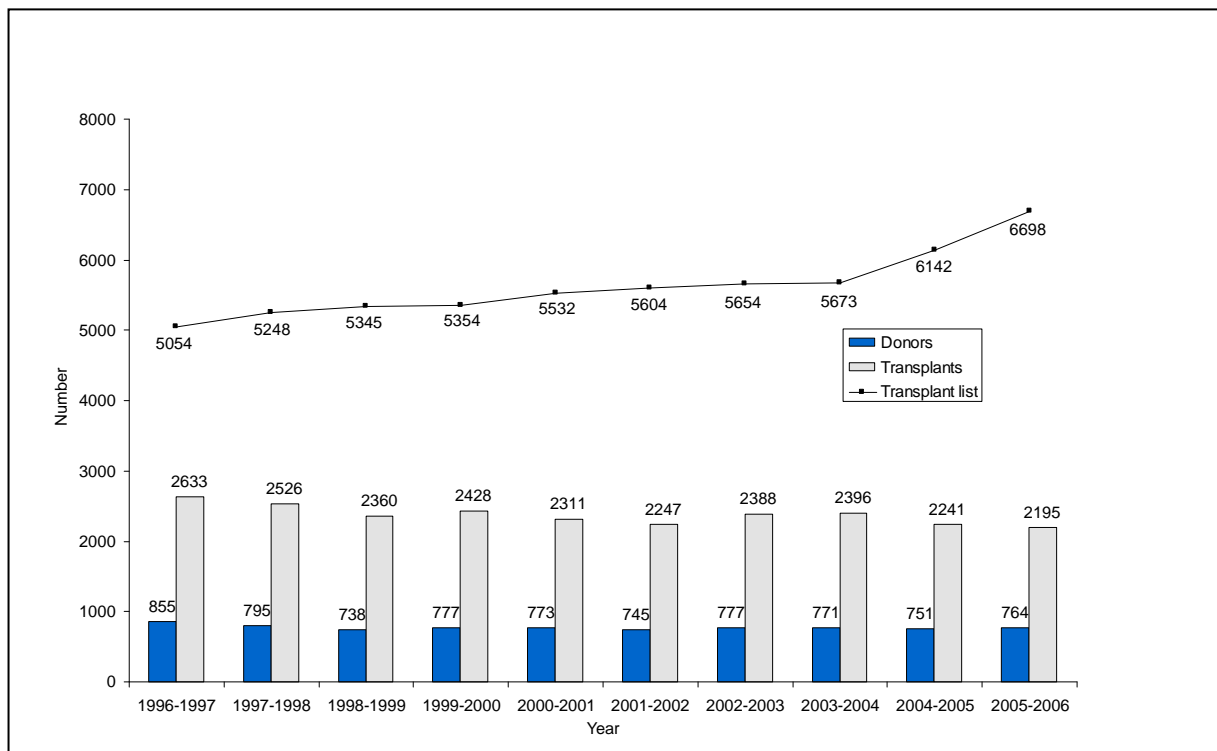
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## Introduction

In the UK there is a widening gap between the number of organs required and the number of organ available for transplant operations. According to figures presented in the annual report of the NHS Blood and Transplant service 2005-2006<sup>1</sup> despite increases in overall donation figures for 2005-2006 of 3% [NHSBT, 2006:4], the number of people listed for transplant is now at its highest figure of 8,315; representing a 9% increase from 2004-2005 [Figure 1]<sup>1 †</sup>.

**Fig 1. Number of deceased donors, transplant operations, and number on active list [as of 31 March 2006] in the UK, 1 April 1996 – 31 March 2006 [NHSBT, 2007].**

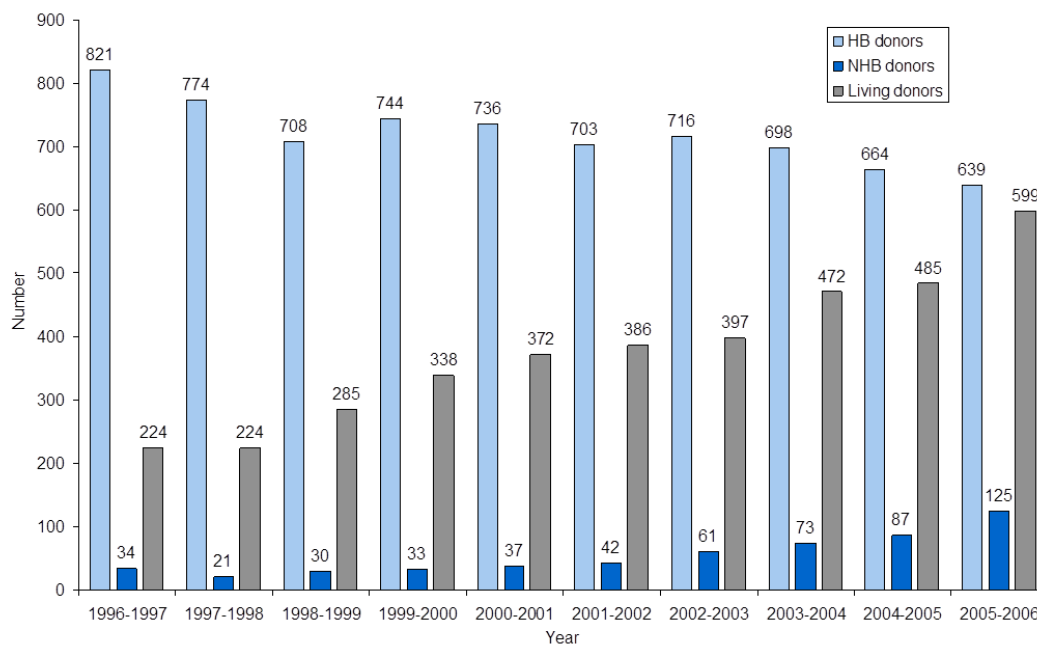


Whilst donation from non-heartbeating [125 donations] and live donation [599 donations] is at its highest level for 10 years, the number of donations from cadaveric heartbeating donors has fallen to its lowest level, with only 639 donations being reported in 2005 – 2006 [Figure 2].

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<sup>†</sup> 1,617 of these are temporarily suspended

**Figure 2. Number of deceased and living donors in the UK, 1 April 1996 – 31 March 2006 [NHSBT, 2007]**



These figures are of concern to the transplant programme as the number of patients needing a transplant in the future is set to rise [NHSBT, 2006]<sup>1</sup> and currently UK figures of 10.7 cadaveric donors per million population fall below those achieved in some European countries such as Belgium [22.8 pmp] and Spain [35.1 pmp]<sup>2</sup>. Arguments that Spain, for example, has high donation rates due to the number of traffic accidents are no longer tenable as, according to Rafael Matesanz, Director of the Spanish National Organisation for Transplants, the profile of organ donors has changed due to a reduction in fatal road traffic accidents from a high of 43% in 1992 to 14% [of 44.1 million population] in 2006<sup>3</sup>. Despite this reduction in fatal road traffic accidents, donation rates have been increased and maintained. The rise in donation rates appears to be linked to a complete overhaul of all the systems implicit within an organ donation and transplantation service, but fundamentally, an increase in the number of families giving consent for organ donation to proceed. Whilst the factors influencing how many transplant operations take place are multifaceted, there are two overriding influences on the potential number of cadaveric organs that are available for donation: i) the number of people who die in circumstances that facilitate donation, and ii) the willingness of the ‘nominated’ or ‘qualifying person’<sup>4</sup> to allow organ donation to proceed. In the case of live donation

the main influence is the willingness and suitability [in terms of meeting specified assessment criteria- see later] of potential donors to undergo surgery.

This paper will present a summary of initiatives in the UK which aim to: increase consent for solid organ donation, and increase the availability of organs from less traditional routes of donation such as live donation, and from what has been termed 'back to the future' routes, namely, non-heartbeating donation<sup>5</sup>. Whilst the focus of this paper is the UK, where applicable, reference will be made to initiatives in other countries where they offer points for consideration or discussion. Tissue donation will not be addressed in this paper, nor will other issues linked to the gap between organ demand and supply such as the increasing numbers of people being listed for transplant operations<sup>1</sup>, intensive care bed provision and admission policy<sup>6</sup>, the shortage of transplant staff<sup>7</sup> or the non retrieval of organs<sup>8</sup>.

### **How many individuals could become organ donors?**

Perhaps the most significant development in focussing on the discrepancy between organ demand and supply has been the initiative by UK Transplant to assess the *actual* levels of potential organ donors resulting from deaths within intensive care units [ICUs] by auditing every patient death that occurs within UK ICUs. Until the commencement of the national Potential Donor Audit [PDA] in January 2003, the number of potential organ donors was based on figures that did not offer a comprehensive picture. The only systematic survey had been carried out over a two-year period, from ICUs in England and Wales<sup>9</sup>†. This survey reported that 1,200-1,350 people were diagnosed as dead post brain stem testing, and that about half of these individuals went on to become organ donors<sup>10</sup>. The most important reason reported for the loss of organs was a 30% refusal rate by family members of these potential donors. The second most important reason reported for missed kidney donation was that no discussion had taken place with family members regarding

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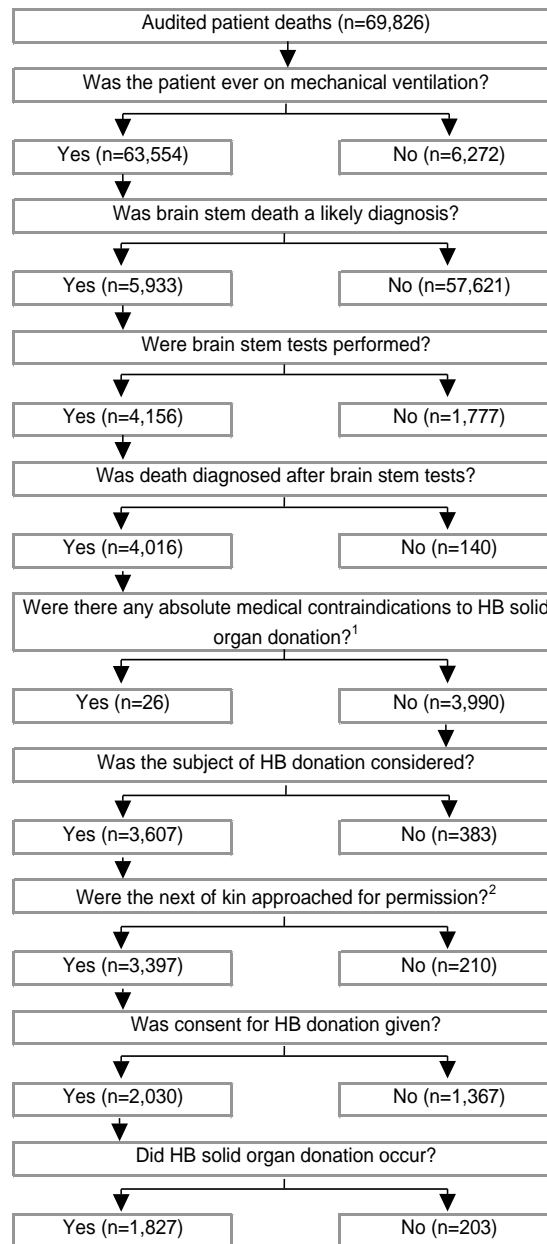
† Briggs et al, 1994 also carried out a five year survey [1989-1993], but this survey focussed on renal transplantation, and factors that were obstacles to better donation rates such as: inadequate ICU bed provision, neurosurgical provision and admission policy, low numbers of surgical transplant staff, poor transplant coordinator provision and inadequate reimbursement to ICUs for the extra work associated with organ donation. The survey recommends changes to all these factors and the expansion of the, at that time, embryonic asystolic and live donor programmes.

organ donation<sup>11</sup>. In view of subsequent changes (doctors are now required to request organ donation), more up to date information was needed about the state of potential organ supply. This was the aim of the national PDA, which reflects a similar initiative in Spain where all deaths that occur in ICUs and the outcomes, in regard to organ donation are audited.

According to the PDA carried out by UK Transplant from 1 April 2003 to the 31 March 2006, there were 69,826 audited patient deaths in ICUs throughout the UK. Of these patients, 63,554 were on ventilators at some point. In the case of 5,933 of these ventilated patients, brain stem death was considered a 'likely' diagnosis. Testing to certify brain stem death was carried out in 4,156 cases and of these; brain stem death was confirmed for 4,016 patients. Heartbeating donation was considered possible for 3,607 of these individuals and the next-of-kin of 3,397 potential donors were approached about organ donation. Of the 2,030 positive consents to donate, 1,827 actually ended in the donation of organs, therefore 203 consented donations did not result in organ retrieval [Figure 3] <sup>8</sup>.

The results of the PDA have also indicated that the earlier reported refusal rate of 30% underrepresented the refusal rate of those next-of-kin who were asked to consider donating the organs of their deceased relative. Refusal rates are nearer 40% for cadaveric organ donation, 46% for non-heartbeating donation; rising to 70% for 'non white groups' <sup>8</sup>.

**Figure 3 A breakdown from audited patient deaths to HB donors**



<sup>1</sup> Either known or suspected CJD or known HIV

<sup>2</sup> Includes cases where the next of kin made the approach

The results of the PDA are the foundation upon which initiatives to increase consent to donation and the availability of organs are based [personal communication with Falvey, 2006]. These initiatives include: the establishment of hospital ‘in-house’ donor transplant coordinators [DTC], a trial of collaborative requesting [see later], a re-focusing of the donation discussion so that it prioritizes the wishes of the

deceased, the funding of research to explore the decision making of family members who were approached about organ donation and declined to donate and the expansion of non-heartbeating organ donation and live donation programmes. We discuss these initiatives in the following sections. In addition to the initiatives carried out by UK Transplant, the Department of Health [2006] <sup>12</sup> has set up a multidisciplinary Organ Donation Task Force to: identify barriers to organ donation; analyse factors militating against organ donation; identify current issues that may have a bearing on donation rates; recommend action to be taken to increase organ donation and procurement; and consider options for improvement. The Taskforce is expected to report spring 2007

### **Hospital 'in-house' donor transplant coordinators [DTCs]**

Placement of DTCs is initially aimed at those ICUs and neurological units where there are documented higher numbers of potential organ donors, or where, 'historically', there have been greater numbers of family members declining organ donation<sup>1</sup>. The expectation is that having a coordinator available at all points along the potential donation trajectory will facilitate: early identification of potential donors, access regarding the wishes of the deceased as per the NHS Organ Donation Register; appropriate approaches to family members of potential organ donors, provide need specific care to family members [whether they agree or decline organ donation] and coordinate all aspects of any organ retrieval. The benefits of having an in-house coordinator have been directly linked to increased consent rates for organ donation in countries such as Spain<sup>3</sup> and the USA<sup>13</sup>, and appear related to the facility of having a specifically trained, knowledgeable, family focussed, motivated health professional who has the time to discuss all aspects of the organ donation decision-making process with family members.

Such aspects reflect the nexus of beliefs, fears, concerns, poor knowledge base and assumptions, that arise when a family is approached about organ donation, issues that are not solely based on the wishes of the deceased regarding organ donation. There is a belief, supported by the literature<sup>14 15</sup> that family members will agree to

organ donation if their deceased relative stated in life that they wanted to donate, and this is true for many situations, but not all. Research funded by UK Transplant which explored the decision-making of family members who declined organ donation reported situations in which both the family members and deceased, in life, were pro-donation and yet donation did not take place<sup>16</sup>. Findings indicated that of the 23 deceased potential organ donors, nine had expressed positive views about donation whilst alive. Of the 26 family members 12 were positive about donation and four were ambivalent. Therefore in situations where the decision-makers' views were positive and the expressed views of the deceased were positive, one might expect donation to proceed. However, Sque, et al [2006]<sup>16</sup> reported that in six cases of positive pairings, no donation took place. Non donation was reportedly linked to: family members' reluctance to relinquish their guardianship and ability to protect the deceased body, concerns about the nature of the donation operation, and that instead of family members' views embracing the notion of 'the gift of life', which Sque et al [2006] describe as a dominant discourse in relation to organ donation, these family members may have been more influenced by the 'sacrifice' that is essential to facilitate organ donation; i.e. the 'sacrifice' of the often unmarked, viable looking body to what family members perceived to be a potentially mutilating operation.

These findings underpin the critical nature of the psycho-social dynamics involved in family decision-making. Decision-making that is influenced by many issues such as: the meaning of the human body and the human person, of death, of the meaning of a gift<sup>17</sup> and a gift relationship<sup>16 18 19</sup>, of individuality and of community, of self-interest, generosity and compassion<sup>20</sup>. It is these types of issues that contribute to a, 'No', decision, a decision that may be regretted later<sup>21</sup>, and therefore a decision that needs careful exploration by someone with the necessary skills. These skills can be learned as has been shown by work carried out by Verble and Worth<sup>22 23</sup> in the USA. These authors were engaged by UK Transplant to carry out 3 day workshops, attended by all donor coordinators, which focussed on the donation discussion and techniques whereby any fears, questions and concerns that family members may have could be i) elicited, ii) acknowledged, and iii) addressed. Instead of just



answering questions and providing information, DTCs will be better equipped to explore the decision-making process of family members, thereby increasing the likelihood that family members will leave the hospital confident in the decision that they make<sup>†</sup>. As NHSBT intends to maintain current investment in the 12 established hospital in-house coordinator teams and invest in a further 20 [focussed on neurological ICUs] by 2009/2010, this may pay dividends with a decrease in the number of families declining organ donation.

What about those ICUs where there are no in-house coordinators? Another initiative, collaborative requesting, which has been tested in the USA, is currently being trialled by the Oxford Regional Transplant Team and linked ICUs] <sup>24</sup>.

### **Collaborative requesting**

Collaborative requesting is where the family, following the death of the critically injured relative, is approached about organ donation by an ICU clinician **and** a donor transplant coordinator. Empirical evidence suggests that having a coordinator at the initiation of discussions regarding organ donation carried out with family members, is linked to lower refusal rates, potentially as a result of what this individual can bring to the discussion in relation to specialist knowledge<sup>25 26 27 28</sup>. Even when the approach to families is not made collaboratively, but is made by a health professional and followed by a meeting with the transplant coordinator, family members were more likely to agree to organ donation as opposed to when other health professionals [physician, nurse, social worker, transplant coordinator] requested organ donation<sup>29</sup>. These findings underpin the need for a skilled, well-informed, motivated, individual, who has time to spend with the family, in early discussions. The trial being carried out in Oxford may need to continue for up to two years, depending on potential donor numbers, but could have wide-ranging implications for future policy and procedure regarding approaching family members and discussing organ donation, therefore the outcomes will be of great interest.

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<sup>†</sup> Margaret Verble and Judy Worth also facilitated clinical workshops throughout the UK, in which other health professionals were involved

## **Non-heartbeating donation**

Whilst some see non-heartbeating donation [NHBD] as a new initiative, NHBD was the norm before the introduction of the diagnosis of brain stem death<sup>30</sup>. Numbers of non-heartbeating donors have increased over the past decade to a high of 125 donors in 2005-2006 [Figure 3]. An argument supporting non-heartbeating donation is that some family members struggle with the diagnosis of brain stem death, and may believe that their family members is not dead as their heart is still beating, their chest is still moving, and they look alive<sup>31 32</sup>.

Consistent with findings from Franz et al [1997]<sup>33</sup> and the Gallop Organization [1993]<sup>34</sup>, Siminoff, et al [2003]<sup>31</sup> found that a sizable number of participants, 30% of 385 respondents, agreed with the statement that a person is dead only when the heart has stopped beating. Therefore the argument goes that family members may be more comfortable with the procedure of non-heartbeating donation as it fulfils their social expectations of death in that family members can observe the last breath and cessation of the heartbeat [not an option if the deceased is a heartbeating donor] if they wish. But could this use of the newly dead impact on donation rates, in the opposite way to which it is intended? So far the PDA indicates that for the 27 months from 1<sup>st</sup> January 2004 to 31<sup>st</sup> March, 2006 the refusal rate for non-heartbeating organ donation was 45% of 518<sup>35</sup> potential non-heartbeating donors, suggesting that there are also barriers to this means of increasing organ donation. As there has been no research carried out exploring families' experiences of participating in non-heartbeating organ donation it is perhaps premature to suggest that this will have a major impact on the number of organs available for transplantation as there are many questions arising from this initiative, which have implications for both family members and health care professionals.

The NHSBT plans to continue funding the 14 current non-heartbeating renal programmes, and to expand this initiative to cover all neurological and general ICUs<sup>1</sup>, with the aim of increasing consent to retrieve organs from individuals who are ventilated, and seen to be irredeemably injured, but do not meet the criteria

required for a determination of death based on brain stem testing [controlled non-heartbeating donation], and to retrieve more lung and liver lobes.

### **Live donation**

Whilst living related donation is not the norm in the UK, in some countries it is. In Mexico, Norway, and Japan, for example, the majority of renal transplants are sourced from, usually, blood relatives, or partners of the patient with end stage renal disease. For reasons linked to the illegality of cadaveric organ donation [until 1997], and continuing concerns regarding the diagnosis of brain death in Japan<sup>36</sup>, inaccessibility of dialysis centres in Norway<sup>37</sup>, and factors related to a lack of infrastructure, low levels of health service funding, and a cultural preference, in Mexico<sup>38</sup>, live related organ donation programmes have been established to address the problem of people dying for the need of a kidney. In the USA, more kidneys are now donated via live donation than by cadaveric donation<sup>38</sup>. In the UK, the NHSBT strategic report indicates that funding of existing live donor schemes will be maintained, and that there will be funding for live donor transplant coordinators to be placed in renal units where there are more than 400 patients with end stage renal disease<sup>1</sup>, due to the extra demands that live donation makes in relation to assessing, listing and supporting potential related and unrelated donors. The aim is that all renal transplant units will transplant 15% of patients on their waiting lists from living donors<sup>40</sup>.

With the implementation of the Human Tissue Act [2004]<sup>4</sup> and the Human Tissue [Scotland] Act [2006]<sup>41</sup> on September 1<sup>st</sup> 2006, the potential for both paired live donation and altruistic non directed donation became available as methods that could potentially increase the number of kidneys available for donation operations. Paired donation is where a family member indicates that they would wish to donate an organ to their ill relative. In some cases these pairings are incompatible and in such cases it is planned to offer the potential donor and their intended recipient a pairing from a pool of other potential live donors and recipients. Therefore the potential donor would be offered the opportunity to donate to someone they are not related to, and their intended recipient would have the opportunity to receive an

organ from a non related, but matched donor. This process will fall under the governance of the Human Tissue Authority [HTA] with the national list of assessed pairs or potential donors being held and managed by UK Transplant. This initiative is expected, as in the USA and Scandinavia to increase the number of kidneys available for transplantation<sup>42</sup>.

Altruistic non-directed donation, where an individual with no genetic or familial ties to anyone on the transplant waiting list may donate an organ is now facilitated within the Human Tissue Act. In these cases potential donors must be assessed [UK Guidelines for Living Donor Kidney Transplantation]<sup>43</sup> by an independent assessor, who is employed within the NHS, must not be linked to any transplant programme, and who has received specific training from the HTA for this role. Assessment includes tests that are aimed at determining an individual's 'fitness to donate' [Human Tissue Authority Guidelines]<sup>44</sup> examining medical, surgical, psychiatric and psychological domains. Despite research that indicates that individuals who have become live donors feel positive about this initiative, many saying that they would do it again<sup>42</sup> there are outcomes related to family dynamics, the reciprocity of the gifted kidney, obligation, and changing relationships that makes both the preoperative assessment and post operative support challenging<sup>45</sup>.

### **Changes in the law governing individual decision making**

In response to the gap between organ demand and supply new legislation enacted in many states in the USA now nullifies the option for the family to override the wishes of the deceased, documented whilst they were alive, regarding wishing to donate organs. First person consent or donor designation prioritizes the 'authorization' provided by the deceased, whilst alive, for their organs to be used in transplant operations. The legislation to adopt this stance has been available within the Uniform Anatomical Gift Act<sup>46</sup> since its revision, but few states were willing to override family members objections until recently [personal communication, Gunderson, October, 2006]. The view is that by 2007, 46 states in the USA will have some form of donor designation in place. It would appear that instead of focussing on the psychosocial barriers to organ donation the decision has been that this

obstacle can be overcome by prioritizing the donor's autonomous decision over the 'rights' of others. Despite research from the USA stating that informing a donating family that their relative wanted to be a donor, did not cause stress for the majority of donating families [479 of 569 respondents], this research did not report on what those families who did not want to donate, even in the knowledge of their relative registering their wish to be a donor, felt about the donation going ahead. This paper goes on to state that 'donation rates are increased when donor rights are honoured, without jeopardizing the care of the donor family'<sup>47</sup> [p:153]. How families, who do not want to donate, cope with donation in light of their objection being overruled is yet to be reported. The legislation is now in place in the UK to remove the need for the family to 'give consent' for organ donation to proceed. Families in the future may be informed of the wishes of their deceased relative regarding organ donation, and not asked for their lack of objection, and while this may lessen the burden of decision-making considerably for some, it may open up a whole new debate for those families who disagree.

In the USA the group who were frequently the 'strongest source of resistance' to donor designation were health professionals working within the organ procurement agencies [personal communication, Gunderson, 2006]. Now that the UK also has legislation to prioritise consent given in life regarding organ donation, over the wishes of the family, it will be of interest to see how health professionals interpret this change. If, with the publicity aimed at increasing the number of individuals on the Organ Donor Register from the present 13.8m to 16m [by 2010]<sup>1</sup>, more family members make their wishes known to each other regarding their views of posthumous organ donation, then this may make this potential change in philosophy, from 'requesting to informing'<sup>47</sup>, easier to implement.

## **Conclusion**

The most prevalent themes underpinning the above initiatives, and on which their success or failure may rest, is that they all rely on both the skills of the health professional involved in raising the issue of organ donation at a time and in such a way that facilitates well informed decision-making and on a well informed, trusting

public whose views regarding organ donation are known to family members. These skills may be gained from training and experience, but a lack of them will impact on the number of organs available for transplant operations. As the NHSBT Service Strategy 2006-2010 aims to increase the number of transplant operations from the current 2,700 per year to 3,150 per year by 2010; with a year on year increase of 150 transplant operations, by increasing spending for specific initiatives such as in-house coordinators, the expansion of non-heartbeating programmes and an increase in the number of coordinators available to facilitate live renal donation, this is no small undertaking. As cadaveric organ donation appears to be declining this places the emphasis firmly on non-heartbeating and live donor programmes, with their associated difficulties.

It may be that the time has come to not only focus on ways of increasing the availability of organs for transplant operations, but also make a more transparent link between lifestyle choices, end stage disease and transplantation. If the need for organ donation could be reduced alongside increases in organ supply, we may see a reduction in the length of time individuals spend on transplant waiting lists and a decrease in the numbers of people dying for the lack of an organ.

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