RCN Policy Unit
Policy Briefing 01/2009

Organ Donation Consultation

January 2009
1. Introduction

The issues surrounding organ donation are highly sensitive, and it is anticipated that members will hold many varied and strong viewpoints. This paper is not intended to argue for or against an opt out system for organ donation, but is intended solely to provide as balanced a summary as possible of the current debate, so as to aid members in preparing their responses.

1.1 In 1954 the first Kidney transplant took place in Boston USA and in 1967 the first heart transplant was undertaken by Dr Christian Barnard in South Africa. Since those early days organ transplantation has become one of medicine’s great success stories and transplant technology has increased as has the survival rates for patients. Organs are now transplanted from both live donors (e.g. kidneys) and deceased donors. However the gap between the supply of organs for donation and the numbers of people requiring a transplant is increasing at approximately 8% per year.¹

1.2 It is clear that with dramatic advances in medicine transplants can now save and transform lives. But the success of organ transplants cannot be separated from the fact that the availability of organs often follows tragic circumstances and the death of a human being. Therefore organ donation remains an extremely sensitive and emotive issue where many factors need to be carefully taken into account.

1.3 The question of whether an ‘opt out’ system of organ donation, often referred to as a system of ‘presumed consent’², should be introduced in the UK has received a lot of attention recently, particularly with the recent release of a report from the government’s Organ Donation Taskforce, wherein the recommendation was made that an opt out system should not be introduced.³ The question was also considered during the RCN 2008 Congress where it was suggested as part of the Congress discussion that RCN members should be consulted in relation to the issue.

1.4 The aim of this paper is not to provide a comprehensive assessment of the medical, legal and other issues associated with an opt out system of organ donation, or to present a preferred position in relation to the issue. Instead the main purpose of this document is to stimulate a wide-ranging debate with RCN members and throughout the profession about the options in relation to consent and organ donation.

² It has been suggested that the term “presumed consent” is inappropriate for describing an opt out system since, in situations where a deceased has not indicated any feelings in relation to their organs being donated, there is strictly speaking no possibility for any form of “consent”. As such, the term has been avoided where possible in this briefing.
2. The current ‘opt in’ system

2.1 In the United Kingdom we currently run a system of ‘opt in’ for organ donation. Individuals are asked to register their willingness to be a donor after their death. Current organ donor legislation (see chapter on the legal position below) requires that an individual gives his or her informed consent to donation.

2.2 Surveys show that between 65% and 90% of the UK population are willing to donate organs after their death, yet only 25% have signed up to the NHS Organ Donor Register.4

2.3 The reality is that demand is easily outstripping supply and this is an increasing concern that Governments are attempting to address. Examples of some of the latest figures are listed below:

- In 2007/08 more than 8,000 people where on the waiting list to receive an organ transplant in the UK.
- The median (average) waiting time for an adult kidney transplant is 841 days. Adults wait an average of 103 days for a heart and 406 for a lung. Children wait an average of 143 days for a heart.5
- Around 1,000 people died in 2007/08 in the UK while waiting for a transplant, and each year many more die before they even get on to the transplant list.6

2.4 It has been suggested that an ‘opt out’ system, where it is assumed that individuals are willing to donate their organs after death unless they have stated otherwise, would increase the numbers of organs available for transplantation. However, calls for a change in the law to allow for an opt out system of organ donation have been criticised for failing to acknowledge the importance of individual autonomy and informed consent to the organ donation process.

3. Arguments in favour of an opt out system

- It creates a default position that life should be saved;
- It could help make many more organs available for transplantation and save lives that are currently being lost when individuals die before having a transplant;
- It may assist during conversations with relatives. When raising the issue of donating organs, it has been found helpful to begin from a presumption that donation will occur;7

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• It encourages informed decision making by potential donors during life as opposed to what is inevitably subjective second-guessing by grieving relatives after death;
• It treats relatives more fairly by not imposing life-and-death decision making upon them at a very difficult and distressing time;
• It provides reassurance to the living, the majority of whom would want to donate, that their wishes will be respected following their death, while still allowing conscientious objectors to do so (retaining protection in law for their objections);
• Spain has one of the most successful organ transplant systems in the world and their opt out system may have been an important contributing factor to this success (although note that views differ on the significance of the Spanish example, as noted in the arguments against below). There are also opt out systems in Belgium, Austria, Norway, France, Sweden and Greece.

4. Arguments against an opt out system

• The recent organ retention scandals (at Alder Hey and Bristol) where organs were taken without proper consent has made a significant percentage of the public suspicious about opt out systems;
• There are concerns that clinicians will be able to bypass the wishes of family members and any last wishes expressed privately by the deceased before death;
• It would create a perception amongst some members of the public that the state has ownership of an individuals organs and Parliament can dictate to individuals who their bodies belong to after death;
• There are particular concerns about how vulnerable people, such as those with mental health issues, poor access to health services or a limited knowledge of English, would be protected under such a system;
• There is the potential for some sensitivities amongst certain religious groups in relation to an opt out system;\(^8\)
• The use of an individual’s organs would no longer be seen as a ‘gift’;
• An opt out system may divert attention from other steps that can have a more beneficial effect on organ donation rates;
• Any new system of organ donation will carry an associated cost, which needs to be considered in the context of prioritising health spending as a whole, and against potential expenditures in areas such as prevention.
• Health authorities in Spain have consistently highlighted that many other factors apart from their opt out system have been instrumental in achieving their high organ transplant rates (for example the number of

\(^7\) Evidence from the US has suggested that, in relation to discussion with family members of a deceased, simply phrasing questions using a ‘presumptive approach’ can result in an increase in consent rates. See Timely Referral of Potential Organ Donors, Ron Ehrle, Critical Care Nurse 2006 Apr; 26(2): 88-93.

\(^8\) For a helpful summary of the position of key religious groups in relation to organ donation please refer to the UK Transplant website: https://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/religious_perspectives.jsp
critical care beds available and improvements in their education programmes for organ donation). One of the key measures adopted in Spain has been a significant increase in the number of transplant co-ordinators. There are many countries that follow the opt in system in place in the UK including Ireland, the Netherlands and Germany.

5. Legal position

5.1 In England, Wales and Northern Ireland, the removal of organs after death is covered by the Human Tissue Act (2004) (Parliament, 2004) and in Scotland by the Human Tissue (Scotland) Act 2006 (Scottish Executive, 2006). This legislation reinforced the importance of providing consent for donation.

5.2 If an individual gives consent for their organs to be used following their death, as long as they are competent, that consent is sufficient for the donation to go ahead. Relatives have no legal right to challenge the decision. Consent may be given either by registering as a donor or discussing it with those close to you. If there is no record of what the individual may have wanted following their death, relatives or other relevant people may be approached to give consent. The Potential Donor Audit co-ordinated by UK Transplant (UKT), shows that the rate of refusal by relatives currently sits at around 40%.

5.3 Critics of the current system have argued that an opt out system would potentially bypass the requirement for informed consent, although it should be noted that a ‘soft’ opt out system would still take the views of relatives into account. Under a ‘soft’ opt out system relatives would be informed that the deceased had not opted out of donation; unless the relatives objected, the donation would proceed.

6. What organs can be donated and how do individuals register as a donor?

6.1 The manner, time and place of death determine whether a person’s organs are suitable for donation. Kidneys, heart, liver, lungs, pancreas and the small bowel can all be transplanted. There is also the possibility of tissue

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9 It should be noted that there is also a possible correlation between a country’s organ donation rate and, for example, its road accident mortality rate. Part of the UK’s low rate of donation could potentially be attributed to high standards of, for example, road safety.

10 Note that The Human Tissue (Scotland) Act 2006 is worded differently to the Human Tissue Act (2004). The Scottish Act uses the term ‘authorise’, not ‘give consent’.

11 UK Transplant. Potential donor audit, 24 months summary report 1 April 2006 – 31 March 2008. Of the 60% of families who agreed to organs being donated, around 90% of these approvals resulted in organs actually being donated.
donation: corneas, skin, bone, tendons, cartilage and heart valves can all be used by doctors to help others.

6.2 Individuals can register to be a donor through the following methods:

- DVLA when you are renewing or applying for a driving licence;
- Boots when you apply for an advantage card;
- Through registration at a GP practice or;
- On line on the national transplant organisation’s web site.

6.3 This system allows the individual to carry an organ donation card and/or have their name placed on the NHS Organ Donation Register (ODR).

6.4 Although health departments in the four nations are responsible for the overall organ transplant policy UKT is responsible for all aspects of donation, matching and allocation of organs for transplantation across the UK as well as increasing the number of transplants.

6.5 There is no minimum age to join the organ donation register and parents or guardians may register on a child’s behalf. However, for children registered while they were under the age of 16 in Scotland, or 18 in the rest of the UK, it is possible for those children’s parents or guardians to request that a donation does not take place.

7. Current debate within the devolved nations

7.1 In January 2008 the Government in England announced it would back the initial recommendations of the Organ Donation Taskforce which could see a 50% increase in organ donation in the UK within five years. Although the Taskforce did not consider legislative changes, such as requiring that donors opt out, it was subsequently asked by the Secretary of State for Health Alan Johnson MP to consider whether a change to an opt out system would increase the number of organ donors. This was after the Chief Medical Officer for England expressed support for such a legislative change.

7.2 In response to the Secretary of State’s request the Organ Donation Taskforce established a series of expert working groups to help gather evidence and provide advice on this area. The Taskforce reported its findings in November 2008, recommending that the UK retain its current system and not move to an opt out system. Advice received from health professionals, including intensive care staff, was instrumental in the Taskforce recommending the maintenance of an opt in system.

7.3 The Secretary of State for Health accepted the conclusions and recommendations contained in the Taskforce’s report. However the Government has not ruled out further consideration of the issue or a future
change to the law, depending on the impact on donation rates of the recommendations in the Taskforce’s first report. Interest in the debate on presumed consent was increased early this year after the Prime Minister Gordon Brown spoke in favour of an opt out system and noted the success of the opt out system used in Spain.

7.4 Public support for an opt out system appears to be strong, with the Taskforce’s report indicating that around three quarters of participants questioned said they would support the law on organ donation changing to an opt out system.

7.5 The Scottish Government has fully supported the work of the UK-wide Organ Donation Taskforce, and has encouraged a wide public debate on the issue of presumed consent for organ donation.

7.6 The Welsh Assembly Government Minister for Health launched a consultation document on presumed consent and called for a debate across Wales on the issue. This consultation was launched earlier this year and the Welsh Assembly Government is now actively considering whether Wales should become the first UK Government to introduce a system of presumed consent. The Health minister in Wales has rejected the Assembly’s Health Committee’s recommendation that Ministers should not seek powers to introduce a presumed consent system. Although the consultation has now closed the Assembly Government called for a wider debate to establish the public’s view on a range of systems such as ‘hard’ or ‘soft’ presumed consent.

7.7 In Northern Ireland, the Department of Health, Social Services and Public Safety (DHSSPS) has recently endorsed the work of the Organ Donation Taskforce and its Health Minister has stated: ‘These UK-wide recommendations should go a long way to increasing the supply of donor organs to meet demand.’ The debate over an opt out system will be taking place in Northern Ireland, as elsewhere, within the framework of the taskforce recommendations.

7.8 The Chief Medical Officers in all four nations have indicated their support for presumed consent with the condition that the public must endorse it and there must be proper safeguards as well as good public information. The Chief Nursing Officers have not issued any definitive statements on the issue but have called for a wide-ranging debate.

8. Issues in relation to nursing practice

8.1 Nurses play a major role in supporting patients and families who are going through the transplant process. This includes patients who are going to undergo transplant surgery and potential donors and their families.

8.2 Nurses are often the first clinicians to broach the difficult subject of organ donation with families and act as the point of contact between the potential donor, their families and the transplant centre.
8.3 When a patient becomes critically ill and consideration is being given as to whether they will be a suitable for organ donation, it is often nurses who make the assessment to establish their suitability. A key component of this is to advocate for patients who are potential donors to ensure their end of life wishes are upheld. Not only do nurses provide emotional support to families and staff; specialist nurses also provide hands on expert care to potential donors to ensure that donation is possible.

9. RCN Congress discussion - 2008

9.1 The most recent RCN debate on presumed consent was at the 2008 Congress. There was an in depth and passionate debate that acknowledged the emotive nature of the issue.

9.2 A resolution – ‘that this meeting of RCN Congress opposes any attempt to make consent to organ donation presumed’ – was defeated by a show of hands. The debate was opened by David Mathis from the RCN Pain Forum who said that while the Forum is fully supportive of the need to raise levels of organ donation, the ‘opt-out’ system would not acknowledge the importance of individual autonomy and the right to self determination.

9.3 Dominic Walsh from the RCN Critical Care Forum was one of the few speakers who urged members to vote against the resolution. Dominic spoke of his personal experience as a charge nurse working with liver transplant patients.  

10. Stakeholder perspectives

10.1 Several patient groups, including Patient Concern, are against an opt out system, arguing that it is not up to the state to decide how people's bodies are used after they die. The Patients Association have also stated that the key to increasing organ donors is to raise public awareness and access to the register rather than imposing an opt-out system. A public campaign would highlight the shortage of donors and allow people to register a personal choice in an easily accessible forum.

10.2 The BMA has stated that their members support a ‘soft’ system of presumed consent in which relatives' views are always taken into account. In October 2007 a YouGov survey commissioned by the BMA showed that 64% of respondents would support a soft system of presumed consent. The Royal

An online poll conducted at the same time as the Congress and asking the same question produced the following result: Yes: 36, 28.8%; No: 89, 71.2%.

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College of Surgeons, the British Transplant Society and the Royal College of Pathologists have all declared their support for an opt out system.\textsuperscript{15}

11. Options available for consideration

11.1 In order to facilitate discussion of this issue, below are listed a number of potential options that have previously been considered as ways to improve organ donation transplant rates.

11.2 It should be remembered that the options described below shouldn't necessarily be considered as mutually exclusive, nor are they intended to be an exhaustive list of potential responses to the issue:

**Option 1** – Retain the current system of consent and:

a) Launch a major national campaign involving all stakeholders to encourage national awareness of the ‘opt in’ system;
b) Increase the number of organ donor transplant co-ordinators, increase the number of critical care beds as well as strengthen the network of organ retrieval teams so they can have 24-hour ready access to acute medical units. Many countries that have benefited from successful organ transplant systems have emphasised that the number of critical care beds is a critically important factor in achieving progress in this area.

**Option 2a** – A ‘hard’ opt out system. Move to a full opt out system where everyone is automatically placed on the donor register. This would mean that, unless people opted out of the register, hospitals would be allowed to use their organs for transplants, regardless of the views of relatives.

**Option 2b** – A ‘hard’ opt out system with some specific groups not covered. This would be the same as Option 2a, however people who are members of certain groups (for example religious groups\textsuperscript{16}) would not have their organs removed without consent first being obtained.

**Option 3a** – A ‘soft’ opt out system. This would make donation the default position from which people may opt out during their lifetime if they so wish. This ‘soft’ opt out system would ensure that relatives’ views are also taken into account. Instead of being asked to consent to donation, they would be informed that their relative had not opted out of donation. Unless they object (either because they are aware of an unregistered objection by the individual or because it would cause major distress to close relatives) the donation would proceed. Under this option it would be a requirement that doctors actively contact relatives and obtain consent to the removal of organs.

**Option 3b** – This would be the same as Option 3a, however, it would be made the responsibility of relatives to inform the doctor that they do not

\textsuperscript{15} The Royal College of Surgeons of England also recently announced the creation of twenty new fellowships for organ donation specialists.

\textsuperscript{16} See note 8.
consent to donation (rather than it being the responsibility of the doctor to contact the patient).

**Option 4** – A system of ‘required request’ or ‘required referral’ similar to the one operated within the United States of America. Required referral is defined in the USA ‘that it shall be illegal, as well as irresponsible and immoral to disconnect a ventilator from an individual who is declared dead following brain stem testing without first making proper enquiry as to the possibility of that individual’s tissues and organs being used for the purposes of transplantation’. Under this system hospitals are required by law to refer all potential donors to the responsible organ donation organisation (this would be UK Transplant if the system was introduced in the UK). Even though the introduction of this scheme resulted in an initial rise in the availability of organs within the USA, the numbers have declined over time.

**Option 5a** – A system of mandated choice. Under this system all adults would be required by law to indicate their wishes regarding use of their organs after death. This can be done via the electoral role or be mandatory on registering with a general practice or another mechanism. This system has been promoted in particular by Professor John Saunders, the current Chair of the Royal College of Physicians’ Committee for Ethical Issues in Medicine. Individuals would be free to make whatever choices they preferred in relation to the use of their organs but they would nevertheless be required to make a decision.\(^{17}\)

**Option 5b** – This would be the same as Option 5a, however, whilst people will be able to indicate both whether they have opted in or opted out, providing such an indication would not be mandatory. Where no indication has been made, relatives would need to be consulted or a default position would need to be adopted.

**Option 6** – A ‘hard’ opt in system. This would require that people are listed on the Organ Donor Register before their organs are donated, and it would make it impossible for relatives to oppose the removal of organs where a person is registered.

**Option 7** – No change at all to the current system of consent for organ donation.

11.3 Once again it should be noted that a combination of one or more of these options may be the best alternative. A complex range of inter-related factors affect transplant rates and need to be considered including the organisation of transplant services, relatives’ refusal rates, and any shortage of transplant surgeons.

\(^{17}\) It should be noted that this system would potentially risk contravening regulation 94(3) of the Representation of the People (England and Wales) Regulations, since the material on organ donation has no connection with electoral issues. Therefore the Government would need to amend the relevant statutory instruments (and the equivalent regulations in other devolved nations) for this system to operate.
12. Conclusion

12.4 Organ donation, and specifically the issue of whether an opt out system should be introduced, remains a highly sensitive issue and one prone to significant diversion of opinions. As a result of the recently announced recommendations of the Organ Donation Taskforce, as well as recent statements made by the Prime Minister and leading health organisations such as the BMA, it is also a topic currently receiving significant media attention.

12.5 Whilst there is a wealth of evidence available from the systems currently in operation in other countries, it can often be a difficult task to identify the precise impact which opt out systems have in isolation from other measures adopted to improve rates of organ donation.

12.6 It also needs to be acknowledged that the introduction of a new system would need to occur alongside measures such as public education and infrastructure. Increasing the number of donors available is only valuable if the supporting infrastructure is able to cope with the additional workload, the nature and cost of which cannot be considered in depth here due to the limited scope of this briefing.

12.7 Please note that a template has been prepared in conjunction with this briefing paper to assist members in providing a response to the issues in this consultation, which can be accessed from the RCN internet site. However in referring to the template members should not feel restricted in the form of their response.
Further Recommended Reading

  

- Secretary of State for Health's response to the Organ Donation Taskforce’s report.
  

  

  
  [https://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/religious_perspectives.jsp](https://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/religious_perspectives.jsp)

- UK Transplant. Transplant Activity in the UK 2007-08.
  

  
  [http://www.parliament.the-stationery-office.com/pa/cm200708/cmhansrd/cm081120/hallindx/81120-x.htm](http://www.parliament.the-stationery-office.com/pa/cm200708/cmhansrd/cm081120/hallindx/81120-x.htm)

- BMA briefing paper on presumed consent.
  
  [http://www.bma.org.uk/ap.nsf/Content/PresumedconsentfororgandonationJuly08](http://www.bma.org.uk/ap.nsf/Content/PresumedconsentfororgandonationJuly08)

- The Patients Association’s campaign statement.
  
  [http://www.patients-association.org.uk/Presumed-Consent-for-Organ-Donation](http://www.patients-association.org.uk/Presumed-Consent-for-Organ-Donation)


  