Presumed consent for post mortem organ retrieval in England

The following is a copy of the Anscombe Bioethics Centre’s submission to the Department of Health’s consultation on introducing “opt out” consent for organ and tissue and donation in England. These responses were submitted electronically on 6 March 2018.

Consultation questions and responses

Question 1: Do you think people should have more ways to record a decision about organ and tissue donation? (yes / no)

Yes – there should be as many ways as possible to record a decision, including when people are doing other things, such as registering with a GP

No – you should only be able to record your decision directly onto the NHS Organ Donor Register online or on the phone

Yes.

The question of where and how to express one’s wishes or decisions about organ transplantation is independent of the proposed change to an “opt out” system (a system which provides for taking organs without express consent of the donor or of his or her representative). Indeed, the stronger one’s commitment to a system of genuine express consent, the stronger the reason to find ways in which people’s wishes or decisions can be expressed and communicated, after the person has a chance to inform him/herself and consider what is being decided.

The possibilities of doing more work in this area, for example by allowing the Organ Donor Register to flag the presence of further information in the patient record, show that “doing nothing” is not the only alternative to shifting to an “opt out” system. It is doing all manner of other things. Indeed, the debate over “opt in” vs “opt out” may be a distraction from the other interventions for which there is very good evidence. It is noteworthy that the Organ Donation Task Force which expressed caution about moving to an “opt out” system proposed other recommendations, many of which have been implemented and have resulted in an increase in donation and a decrease in the numbers waiting on the transplant list.

Question 2: What do you think are the advantages or disadvantages of including personal information on someone’s organ donation decision?
At a minimum the standard way of recording a wish to be an organ donor after death should enable others to be sure that this was an informed decision and not simply a box that was ticked unthinkingly. For example, it would help if people had to show that they had had a chance to discuss this decision with a medical professional, that they had some awareness of how death was determined before organ retrieval and the state their body would be in when the organs were retrieved, and that they had thought about how the process of organ retrieval might affect their grieving relatives.

If the personal information about wishes and decisions in regard to organ donation is stored in more than one place then there could be some places (e.g. within the patient medical record) which allow more detail.

Scope for more information would allow the ability to record conditional decisions or desires. Conditional decisions are possible currently in regard to wanting to donate some organs but not others, for example, kidneys but not hearts. However, it is not currently possible to express other kinds of conditional decisions, for example, for people to express a willingness to be a donor if this is supported by family or if agreeable to some religious authority, or if death is declared by cardiac criteria.

The ability to create such conditional decisions or alternatively, nonbinding expressions of desire might allow some people with religious or ethical concerns to express in principle support for donation, while giving a place for relatives and religious authorities to have input too. This might have the added advantage of increasing engagement with organ transplantation by people in minority communities.

It is increasingly common for Catholics to express their views about the provision or non-provision of future treatment in written statements. A desire to donate after death might therefore be made in the context of expressing views about treatment options and about access to the sacraments while one is dying. Having these different concerns stated in one place may make it more likely that they are addressed.

**Question 3: How can we make people more aware of the new rules on organ donation?**

This question assumes that there should be “new rules on organ donation” (rules permitting the taking of organs without the express consent of the donor or of his/her representative). In fact, such rules undermine the very idea of “organ donation”, that is, of giving organs freely, and contradict the clear teaching of Pope John Paul II and of the Catechism of the Catholic Church, both of which are strongly in favour of organ donation in principle. Nor is there evidence that such a change would lead to more organs being available for transplantation. Further evidence in relation to both these points will be given in answer to the final question.

In relation to the possibility and limits of making people more aware of a change to an “opt out” system, evidence is available from Wales. Debate over the possibility of a change in the law in Wales was very high profile and after the law had passed, the Welsh government made great efforts to advertise the impending change. As a result, immediately after the law came into force (March 2016) awareness peaked at 84% of the eligible population. However, in less
than two years this has slipped to 79% and there is no sign that this decline in awareness is levelling off (See Survey of Public Attitudes to Organ Donation: Waves 13 and 14, page 8

Currently more than one in five of the eligible Welsh population are thus not aware that, if they died, their organs could be taken and used on the basis of “deemed consent”. The number unaware of the law is likely to rise over time as the debates over the law recede in the collective memory. It should be noted that the challenges in establishing or maintaining even this level of awareness are much greater in England which has a much larger and much more diverse population.

Behind this question lies the more fundamental one: does awareness of the law, at the levels achieved in Wales, make it reasonable to “deem consent” where someone has not opted out? To put this in another way: does the absence of an explicit decision to opt out provide good evidence that the person wished to donate?

It should first be noted that it is not the case, despite being much repeated, that “8 out of 10 people say they would want to donate their organs and tissue after their death”. This figure represents general supportiveness towards organ donation in principle as a good or admirable practice, but does not imply a wish or a decision to donate oneself. An ICM survey in the Daily Mirror on 27 February 2017 (https://www.mirror.co.uk/lifestyle/health/two-thirds-back-mirrors-call-9930752) indicated that 66% wished to donate at least some organs after death but this fell to 55% if all potential organs and tissues (such as corneas) were included. These are more realistic figures for the wish to donate.

In repeated surveys the Welsh government has asked about attitudes to organ donation. They found that, after the change in the law, in 65% of cases people were either already on the register or had “done nothing as they were happy for deemed consent to apply” (See Survey of Public Attitudes to Organ Donation: Waves 13 and 14, page 17). As 38% are on the register (NHSBT Organ Donation and Transplantation Activity Report 2016/17, page 116) and 5% (of those surveyed) had opted out, this leaves 27% happy for their consent to be deemed but 30% who are undecided or do not know (Survey of Public Attitudes to Organ Donation: Waves 13 and 14, page 17). Thus, if the person is not on the register and has not opted out, and consent to donate is “deemed” then in most cases they would not have been “happy for deemed consent to apply”. In most cases eligible for “deemed consent”, therefore, it is not the case that the person is likely to have made a decision to donate.

Question 4: If the law changes, would this affect your decision about organ donation? (no difference / want to donate / want to opt out)

This is an institutional submission rather than an expression of the views, or donation intentions, of individuals.

Evidence of the effect of such a change in the law on popular attitudes is ambiguous and difficult to assess. Clearly some people have opted out in Wales (around 6%) despite the
potential for stigma if this were to become known, for example, if personal data on those opting out were to be leaked or hacked.

England is very different from Wales, with a much larger and more diverse population, and the rate of consent to organ transplantation is lower in BAME communities. It seems likely, therefore, that there would be a higher percentage in England who would be inclined to opt out, but other factors (such as a lower level of trust in the system or engagement with services) might mitigate against these wishes being expressed.

There is no evidence that a change in the law away from express consent would make people more confident in or more favourably disposed to the practice of organ transplantation. Inherently this seems unlikely.

**Question 5: If the law changes, people would be considered willing to be an organ donor unless they have opted out. Do you think this change could have a negative impact on people from some religious groups or ethnic backgrounds?**

Yes.

The is evidence that members of Black, Asian and Minority Ethnic communities have, on average, a greater need to receive an organ but are less likely to register as an organ donor and less likely to consent to donation of organs from a relative. This may be for a variety of reasons, social, cultural and religious, and the pattern is not the same in all groups. Nevertheless, the need to address the disparity between need and engagement with organ donation among BAME communities has been acknowledged since the Organ Donation Task Force report of 2008.

Successive governments have therefore had a policy to engage positively with minority communities on organ donation, which they have done with some success. However, this work requires great sensitivity and the system relies on trust. It is necessary to identify what are the factors that inhibit donation and to acknowledge the validity of concerns.

For example, in some faith communities there are diverse views about the determination of death. This is a serious scientific, philosophical and ethical question (whether one is religious or non-religious), but the fact of diversity among some religious authorities further complicates the question. When trust breaks down (as it can in healthcare, especially in times of emotion and when services are under pressure) then differences of professional or scientific opinion can be interpreted as hiding questionable ethical opinions. Where the person asked to approve organ retrieval is unsure, for example, about whether brainstem death is the death of the person, then it will be no help for doctors to say that the relative’s consent is not necessary as the donors consent can be “deemed”. Such a response would just reinforce the impression that neurological criteria for death are a convenient invention to facilitate the taking of organs.

Similarly, people have different attitudes about what is necessary to show respect for a human body, and religion often plays a part in the how such respect is understood and expressed.

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The Anscombe Bioethics Centre  
17 Beaumont St Oxford OX1 2NA  
tel: +44 (0)1865 610212; fax: +44 (0)1865 610213  
email: admin@bioethics.org.uk  
website: www.bioethics.org.uk  
Registered Charity No. 274327
The cultural acceptability of post mortem organ donation depends on showing that this practice is compatible with the human meaning of the body: that it is not disrespectful to the dead. Where some concern or dispute arises about whether respect requires, for example, the consent of the relatives, it would be counterproductive to seek to resolve this by appeal to “deemed consent” or to the force of law. The very attempt to marginalise the involvement of close relatives or religious authorities is liable to be seen as expressive of a lack of respect which threatens the legitimacy of using the body.

The greatest danger for religious minorities is that a case or cases occur where there is a dispute and that “deemed consent” deepens this dispute and becomes a kind of lightening rod. It is not difficult to imagine a dispute where the family felt they have been misled or not properly consulted, or where it later emerges that organs were taken from a person who was religiously opposed to it. The legal power to overrule relatives at a time of grief merely by appeal to “deemed consent” could easily lead to the kind of emotional reaction that occurred at Alder Hey Hospital and that led to the Human Tissue Act. Those most harmed by such a backlash would be people within the community who needed an organ and those who wished to speak, within their tradition, for the possibility of ethical and respectful organ donation.

Question 6: If the law changes, and someone has died and they have not opted out of organ donation, should their family be able to make the final decision? (always / sometimes / never / other)

Always.

Where a person has not expressed a view in person one way or the other, it is only someone close to the person, their valid legal representative, who can express consent to the donation of organs. Some actions post mortem (for example, autopsy to determine cause of death), may be ethical without consent and even against the wishes of relatives, but these are not acts of “donation”. As stated earlier, taking organs without the express consent of the donor or his representative “would no longer correspond to an act of donation but would amount to the dispossessing or plundering of a body” (Pope John Paul II, Address to The Society for Organ Sharing, 20 June 1991).

Question 7: Do you think someone’s family should be able to decide if their organs are donated, if it is different to the decision they made when they were alive? (yes / sometimes / no / other)

Sometimes.

Donation is in the first place the act of the donor and only when he or she cannot act should it be the act of his or her representative. It follows that someone’s family should not consent and should not be asked to consent where the person has signed the opt out register or has otherwise indicated a decision not to donate.
Where a person has expressed a clear and informed wish to donate then the family should only have a right to block donation for sufficiently serious reasons. Absent such reasons, the family should still be consulted but not to obtain consent; rather so they are informed, included and involved in the implementation of their loved one's wishes.

On the other hand, a person may have expressed a wish to donate without this amounting to a definite decision to donate or may have made a decision premised on the family also supporting this (or at least, not being seriously distressed by it going ahead) or may have made a decision without giving it due thought or may have changed his or her mind. There should be scope for families to challenge such donation decisions giving their reasons for doing so.

Question 8: Which of the following should not be included in the proposed new rules about organ donation? (children under 18 / people who lack capacity / visitors to England / those living in England < 12 months / others).

None of the following should be included in the new rules because no one should be included in a rule permitting the taking of organs without express consent of the donor or of his or her representative.

Question 9: Please tell us about any opinions or evidence you have about opting out of organ donation.

The significance of this change in the law should not be underestimated. In practice doctors and specialist nurses may well act sensitively and not insist on taking organs on the basis of deemed consent in the face of family opposition. Such sensitivity accounts for the 40% or so of cases in 2016-17 in which deemed consent did not go ahead. Nevertheless, the law provides the opportunity for bad practice and the rationale of the practice has been altered.

The act of “deeming” consent is always and per se the act of another not an act of the person. In matters of human significance, such as the giving and receiving of gifts, deeming is no substitute for express consent. What is taken without express consent is not “donated” and those used as a source of organs without their prior express consent, or the express consent of a representative after death, are not “donors”. Their bodies are treated simply as material to be used as natural resources are used.

It is for such reasons that the opt out system in Wales was opposed in a joint statement of the Roman Catholic Church in Wales, the Church in Wales, and the Wales Orthodox Mission (On the Ethics of Organ Transplantation: A Catholic Perspective. Appendix IV, pages 63-72 http://www.bioethics.org.uk/Ontheethicsoforgantransplantationfinal.pdf).

The reason that policy makers are willing to undermine the very concept of donation and risk the real danger of creating ill feeling against the practice of organ transplantation, is the promise that an “opt out” system will increase the supply of organs and thus save lives. For example, in a press statement released in September 2016, just prior to the system coming into
effect, the Welsh government claimed that this “could lead to a 25% increase in the number of organ donors”.

However, there is no robust evidence of benefit.

In 2017 after the first full year of the opt out system in Wales, the post mortem organ donors rose in England (from 1134 to 1157) and rose in Scotland (103 to 137) but decreased in Wales (75 to 68). There are of course random fluctuations in the rate of donation and these variations are greater in a smaller population. Nevertheless, the contrast between this result and the promised 25% increase is striking.

The results from Wales are in line with the comprehensive review by the Organ Donation Task Force in 2008 which concluded that it was “not confident that the introduction of opt-out legislation would increase organ donor numbers, and there is evidence that donor numbers may go down.”

Even the government’s own impact assessment states only that “if moving to an opt-out system shifted consent rates from the current level of 62.4% to 63.5%, and that if this in turn led to a proportionate increase in organ transplants, then the policy would be good value for money”. However, the same IA acknowledges that there is “no unambiguous evidence” that changing the system of organ donation to opt-out itself has any positive effect on rate of consent or on rates of transplantation, let alone a specific effect of 1.1%.

In contrast there are some interventions that certainly make a difference. When a patient’s wishes in relation to organ donation are unknown, consent is given by relatives in 46.7% of cases. When deemed consent is applied (though this is based on a sample of only 33 cases in one year) the consent rate was 60.6%, but when the person was on the organ donation register the consent rate is 90.5% and when a specialist nurse was also involved 92.6% (NHSBT Organ Donation and Transplantation Activity Report 2016/17, page 126). Rather than deeming consent where it might or might not be present, the key to organ donation is to obtain consent and to encourage people to have the conversations that will enable people to make informed choices about their loved ones.