Modified mandated choice for organ procurement

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Presumed consent to organ donation looks increasingly unlikely to be a palatable option for increasing organ procurement in the UK following the publication of the report into events at Alder Hey and elsewhere. Yet, given that the alternative to increasing the number of cadaveric organs available is either to accept a greater number of live donations, or accept that people will continue to die for the want of an organ, public policy makers remain obliged to consider other means of increasing the procurement rate.

In this paper, we meet the main objections to mandated choice (namely that it undermines autonomy and that mandated donation is preferable). We have modified the traditional approach to mandated choice to take into account the force of the objection that mandated donation is preferable, by accepting that people can and do make bad decisions about organ donation and proposing that all accompanying public education and information about cadaveric donation should be directed in favour of donation.

The need for organs for transplantation continues to be greater than the number donated. Other methods for increasing the availability of organs for transplantation being explored. Of these, advances in stem cell technology seem promising, but there are considerable obstacles yet to be overcome, as is the case with xenografting. Financial incentives for donation have also been considered, but the sale of any human tissue is likely to fall foul the Council of Europe’s Convention on Human Rights and Biomedicine. Given the present limitations on such alternatives, the failure to secure sufficient numbers of cadaveric organ donations has led to a noticeable increase in live donation of certain organs such as kidneys, as well as lung and liver lobes. Even if the risks and harms to live donors are statistically acceptable however, and this is not always the case, it would still be ethically preferable to use cadaveric organs, if only there were sufficient of these available, since no risk or harm to a living person is better than even a small risk or harm. There is, therefore, an ethical imperative to increase the number of cadaveric organs available before pursuing other options for saving life (and quality of life) that aim at increasing the number of donations from living persons. This remains the case, even if it is unlikely that there will ever be sufficient numbers of cadaveric donations to completely negate the need for live donation.

Furthermore, some organs or tissues, such as hearts and corneas, can, at the present time, only be obtained through cadaveric donation.

The UK currently operates an opting in system where those who wish to donate register this preference and carry a donor card. But signing a donor card is no guarantee that one’s organs will be used, even if one dies by an appropriate (in transplant terms) method. Relatives have to be given the opportunity to object (though in reality they are asked to consent), and to do this a member of staff has to approach them with the request. If a person dies without having their card in their possession, staff may not be prompted to approach relatives, and even when they do, relatives may override the wishes of the deceased person. The currently escalating shortage of cadaveric organs clearly illustrates that this system is failing. In an attempt to address this problem, the British Medical Association (BMA) produced a report in which they called for an integrated approach to organ donation centred on a system of presumed consent, and voted to lobby the government to adopt this system. Presumed consent (sometimes referred to as opting out) is a system that allows staff to presume that a person wants to be an organ donor unless they have registered a view to the contrary. Although the BMA would still like relatives to be given the opportunity to object (though not to consent), the presumption is that an unregistered person is a willing donor, thus permitting organs to be removed without further ado. This is a system that has found favour in some other countries. After the passing of a presumed consent law in Belgium, the number of kidneys available for transplantation increased by 114 per cent over the ensuing five years. There was no similar increase experienced in other countries without presumed consent laws in the same geographical region. Interestingly, donation rates in Denmark fell by almost half after the introduction of an expressed consent law in 1986, even though Denmark previously had one of the highest cadaveric organ procurement rates under the presumed consent system that was operated prior to 1986. Singapore also experienced a sharp rise in donation rates after instituting presumed consent. Incidentally, the publicity campaign before the introduction of the presumed consent law in 1987 had the added effect of causing an increase in the number of donations under the pre-existing expressed consent system. In Belgium too the implementation of presumed consent was supported by a strong publicity campaign, which may have influenced donation rates. Whilst there is still much to debate about the efficacy of a presumed consent system, such a system was rejected by the American Medical Association’s (AMA) Council on Ethical and Judicial Affairs.

The AMA argued that unless a view has been registered, society has no way of knowing what the deceased’s preferences were, and presumed consent is therefore not likely to reflect the views of those who did not want to donate and did not register this preference. A survey of opinion in the USA, cited by the AMA, suggested this could amount to around 31% of the population, a figure similar to that found in...
surveys of opinion in the UK.\textsuperscript{13} Erin and Harris have argued that the concept of presumed consent is something of a fiction because although the term “consent” is used, in reality there is no consent at all.\textsuperscript{14}

Whatever the philosophical objections to presumed consent, events in the UK may have overtaken attempts to introduce this system of organ procurement. Since the BMA’s report was published, the public’s perception in the UK about the acceptability of removing organs without explicit consent has inevitably been affected by the public outrage at reports that thousands of dead children over a period of several decades were systematically and routinely stripped of their organs without the knowledge or consent of their parents. Moreover, the subsequent inquiry into organ retention strongly recommended that the law be tightened to ensure fully informed and explicit consent to removal of organs.\textsuperscript{15} The government quickly accepted all of the report’s recommendations, thereby effectively preventing any move towards a system of presumed consent for organ donation.\textsuperscript{16}

Where does this leave policy makers attempting to implement the ethical imperative to increase the supply of cadaveric organs for donation? It is clear that the current system is not only failing to deliver, but is also failing many people who would like to donate their organs. It is failing these potential donors in at least two ways. First, it does not necessarily honour the wishes of potential donors, as not only does it permit relatives to override these, it also allows these wishes to go unregistered if staff do not enquire about them. Second, it is not a system that potential donors themselves seem willing to use when only 20% of the 70% willing to donate actually register their wish to do so.\textsuperscript{17} Presumed consent, the favoured option of the BMA, is unlikely to be acceptable for reasons already given, so what other alternatives are there? One possibility, favoured by philosophers such as Harris\textsuperscript{18} and Menzel\textsuperscript{19} is that of simply taking organs without any consent, because on balance the good of providing organs to those to who need them outweighs any harms of frustrating the wishes of the donor, who is dead anyway. When seen from the relatives’ point of view this perhaps seems less acceptable, because relatives who oppose organ donation do have to live with the knowledge that organs were taken against their wishes. Irrespective of its philosophical attractions, this system is unlikely to be any more acceptable to the post Alder Hey public in the UK than presumed consent. Given the move towards very explicit and detailed consent before any tissue is removed, even that needed for a hospital postmortem examination, the time has come to consider other options, including the option that we favour—namely that of mandated choice.

**WHAT IS MANDATED CHOICE?**

Mandated choice requires competent adults to decide whether they wish to donate their organs after their deaths. Individuals are free to choose whether to donate, and even which organs they would like to donate; what they are not permitted to do is to fail to register their wishes. Individuals can also choose to let their relatives have the final say. Unless they are granted this right, however, the relatives have neither power nor opportunity to veto an individual’s decision, whether it was for or against donation.

How individuals are compelled to choose is a matter for policy makers—in this paper we are only going to argue that it is an ethically acceptable system for organ procurement. But by way of speculative illustration, questions about organ donation could form part of tax returns, vehicle driver’s licence application forms, state benefit claims, and so forth. It would be a requirement that before returns/applications/claims are processed, questions about organ donation are answered to the satisfaction of individuals who fail to donate would be penalised by not being able to drive, claim benefits, or would be subject to the penalties for failure to complete their tax forms properly. The system of registration must be as inclusive as possible to reach all the members of the population. So, for instance, tax forms alone would not suffice, as this would be unfair on those who do not earn enough to complete a tax return. Likewise, not all of the population drive cars or claim benefits. A move to mandated choice would also have to be accompanied by extensive public education so that when making their choices, people are sufficiently informed about both the need for choice and the implications of their decision. Finally, choices, though binding, would also be revocable: indeed, people could change their minds as often as they wished, and the most recent choice would prevail. In addition to granting individuals the opportunity to be proactive in revising their decisions, a system could also facilitate periodic but regular review. To avoid coercion, registered choices would be confidential and no privileges would accrue from the particular choice made.\textsuperscript{20}

Mandated choice has been widely debated in the USA. It was first proposed by Veatch,\textsuperscript{21} but Spital is perhaps its most ardent proponent.\textsuperscript{22} He conducted a survey in a population of young adults in the USA that indicated that an overwhelming ninety per cent would support mandated choice, while only sixty per cent approved of presumed consent.\textsuperscript{23} It is the preferred option of the AMA\textsuperscript{24} and the United Network for Organ Sharing (UNOS)\textsuperscript{25} but was rejected out of hand by the BMA in its report.\textsuperscript{26}

**ARGUMENTS AGAINST MANDATED CHOICE**

There appear to be two central objections to mandated choice. First, it is argued that it is unacceptable in a libertarian society to force people to make choices: compelling people to choose undermines their autonomy.

Second, it is argued that people should not be permitted a choice in this matter at all. This kind of objection tends to be made by those who favour a system of compulsory “donation”, where it is automatically assumed that the organs of anyone who dies are available for transplantation purposes and a person has no right to refuse to “donate”.\textsuperscript{27} The main thrust of this argument in its traditional expression is that any harm done by mandatory donation is undoubtedly outweighed by the benefit of saving lives. A variation on this line of thought employs an argument that has not usually been associated with organ donation, but has been used in other areas, such as testing for HIV and genetic abnormalities. This is the argument that the range of choices available to individuals should be limited when individuals will do significant harm if the wrong choices are made. So, for instance, in the case of testing for HIV, an argument could be made for compulsory testing on the grounds that it is unreasonable for individuals to argue that they have the right to ignorance when the consequence of this ignorance is that other people are infected with this terrible virus.\textsuperscript{28} Clearly, a similar argument could be applied to organ donation, namely that if individuals are given a choice, some will choose not to donate, and as a result of this decision others may die. Thus, as mandated choice only requires that a choice be made and still permits people to choose not to donate, it will be viewed as a flawed system by those whose justification for mandated donation is based in utilitarianism.

We will now address each of these objections to mandated choice in turn.

**MANDATED CHOICE DOES NOT UNDERMINE AUTONOMY**

Being able to choose freely is valuable in many areas of life for, as Dworkin points out, having choices increases the probability of satisfying our wants and gives us greater control over our lives.\textsuperscript{29} Boddington has argued that the right to make choices in the context of organ donation can be compared to the right to give consent in the context of medical decision making for
therapeutic purposes. Because medical decisions tend to be crucial to a person's welfare, the right to consent is justified; it encourages effective compliance and allays public fears about mistreatment. In the current climate in the UK, it is all the more important to enhance trust in the medical profession and allay fears about mistreatment of the dead or dying and organs being removed without consent.

Another justification for gaining consent in the therapeutic context is that an individual has an interest in maintaining control over his or her own body. Whilst English law does not recognise any property rights in bodies or body parts, self ownership is presupposed because of the close relationship between the person and his or her body. Many of the claims made about violations of moral rights, such as those of assault or rape, are incomprehensible without some notion of self ownership and control over one's body. For the living, self ownership is the basis of the right to non-interference in one's body without consent—be this in a medical context or otherwise.

What is more controversial is the extent to which the dead can still be thought to own their bodies. Arguably, when one dies, one ceases to have an interest in what happens to one's body in the same sense that one has when one is alive and things that are done to one's body are done to oneself. Since the case of "ownership" of the body derives from this interest, rather than, say, some financial transaction, it is doubtful that one could be thought of as owning one's body after death. This is not of course to say that one ceases to have any interests after one dies. One's interest in medical confidentiality, for instance, continues after death. Interestingly, whilst making or executing a will is often cited as a useful parallel to organ donation, wills are sometimes contested after death, and relatives may be successful in overriding the wishes of the deceased.

All this seems to suggest that whilst one's autonomous decisions about one's body may have to be respected during one's life, they do not command the same respect after one's death. Translating this into policy would mean that individuals are entitled to make decisions about what happens to their dead body whilst they are alive, but once they are dead anything that they decided whilst alive can be ignored (if there is some imperative for doing so, such as the preservation of some vital interest of another—living—person). This is reminiscent of the argument for mandated donation since it is clearly in the interests of those who are living but dying for want of an organ to override the wishes of those who wished to be buried or cremated whole. We will return to this contention shortly. For now, what we have established is that it could be inappropriate to be concerned about self ownership and autonomous choice after death. In fact, however, it can be argued that mandated choice enhances the autonomous wishes of those who have died.

Spital has consistently rejected the claim that mandated choice undermines autonomy. Instead he asserts that mandated choice actually promotes autonomy, since it ensures that one's preferences for what happens to one's body after death are respected. He points out that under an opting in system, relatives are given the opportunity to override the wishes of the deceased, whilst under presumed consent, incorrect assumptions in favour of donation may occur around 30% of the time. Spital further argues that consulting relatives results in delays, creates additional stress for the family who are already under considerable strain, can lead to tension because the time. Spital further argues that consulting relatives results in delays, creates additional stress for the family who are already under considerable strain, can lead to tension because the time. 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1) The act makes a great difference to Y who is at risk of loss of life or health or some other major interest.

2) The act would not present significant risks or costs to X: the rescue must be relatively easy.

Registering a decision about organ donation clearly meets the requirements. If someone decides to donate, her organ(s) can confer huge benefits on the recipient(s), and unless she has a religious or ethical objection against transplantation, contributing is a very easy thing to do in terms of time, effort, and effects on other responsibilities. If, on the other hand, a person decides not to donate, at least her survivors will be aware of her wish, will be spared the uncomfortable situation which might arise when hospital staff approach them about donation and they refuse. And furthermore, they may be comforted in knowing that the deceased’s wishes are being honoured. Thus, even registering a preference for not donating is an easy rescue: an easy emotional rescue of relatives.

The main problem with the application of the duty of easy rescue to the issue of mandated choice, is that, as Menzel himself argues, the duty of easy rescue once again points to mandatory donation rather than mandatory choice. It is therefore important to tackle the second objection to mandated choice, namely that it is an ethically inferior system to mandated donation: since it is good to donate and bad not to donate, why allow people to make a bad choice?

**SHOULD WE PERMIT “BAD” CHOICES?**

The system of mandated choice requires that people make their own decisions about organ donation and that these decisions should be respected whatever they are. There could be two reasons for holding the view that these decisions should be respected. The first is that they should be respected because they are the decisions of autonomous agents, and respecting them is an integral part of respect for persons. The second is that the idea of there being “good” and “bad” decisions in this context is simply wrong. Neither of these reasons strikes us as decisive.

In the first place, if it is accepted that autonomous decisions should be respected simply because they are autonomous decisions, then why not respect the autonomous decision of people who do not register a preference? Why have mandated choice at all? If, however, the public polls we have previously cited are correct, it is not obvious that the failure to register is in fact an autonomous decision since the majority of us are in favour of organ donation but only a minority of us register our approval. Most people, it seems, are too lazy, ignorant of the need, busy, or otherwise preoccupied to make a serious decision. But even if it were accepted that the failure to register was an autonomous decision, we have already argued in favour of limiting autonomy when its exercise causes avoidable harm to others: this is the basis for mandating choice in the first place.

The second objection, that there is no such thing as a “good” or “bad” choice in this context also seems wrong as donation is clearly the “good” choice given that the duty of easy rescue can apply equally well to donating organs as it does to registering a preference.

So why are we arguing for mandated choice rather than mandated donation? Firstly, the easy rescue argument for mandated donation draws no distinction between “choice” and “reasons for choice”: “good” or “bad” reasons for choosing may operate independent of the consequences of the choice made. In addition, it gives no weight to the process of choosing itself. Secondly, the duty of easy rescue should be conditional on relative harms and benefits of all possible systems. Let us explore each of these points in turn.

While it is true that cadaveric organ donations save life and improve quality of life, these goods have to be balanced against other goods. One of the most difficult areas here is the good of preserving the freedom to form one’s own religious beliefs. This is considered so important that it is a right, alongside the right to life, in the International Declaration on Human Rights. Many objections to organ donation have come from those holding religious beliefs incompatible with burying a body less than whole. It has been argued that these beliefs are misguided, even from the point of view of the religions thought to support them. But this is not a good reason to abandon toleration for religious difference as such. The argument that supports the right of individuals to form their own religious beliefs is also an argument for accepting the choices that individuals make in deference to their beliefs.

Clearly, however, there are limits to the extent to which an individual’s practices have to be accepted just because they are religious in origin. Debates here range from the acceptability of an Islamic jihad against non-Islamic states through the permissibility of circumcision to the need for denominational schools. The limits are revealed by setting the benefits of tolerating religious beliefs against the seriousness of the consequences of tolerating a particular belief in a particular context. In this context, we would have to ask whether tolerating refusal to donate to organ transplantation is likely to undermine cadaveric transplantation in a given society. Ironically, the most vulnerable societies here are those where the religious beliefs against transplantation are strongest, but this might be a cost acceptable to the citizens of those countries. In European countries such as the UK, or in the USA or Australia—assuming that the majority of those who choose, choose in favour of donation—the refusal of a minority on religious grounds may prove no real threat to the transplant system as a whole. In this case, the benefits of not threatening the security of religious minorities by a public policy that is intolerant of their religious beliefs might be thought to outweigh the injustice of permitting freeriders in the transplantation system.

Another way of looking at the problem of religious objection is simply to accept that a policy that requires one to act against one’s religious beliefs is no “easy” rescue at all. Similarly, for others who have strong non-religious objections to organ donation, the proposed rescue will be less than easy. Here we again need to draw a distinction between what is chosen and the reasons behind a given choice. Mandatory choice takes into account that there are going to be some people for whom organ donation is no easy rescue (they still have a duty to make their preferences known, but they are guaranteed that these preferences will be respected). Mandatory donation, on the other hand, assumes that the good consequences of requiring people to donate outweigh the harmful effects on those for whom this will be no easy rescue. These tensions between mandated choice and mandated donation need to be set within the context of two broader philosophical problems that we cannot hope to resolve in this paper.

The first is how the boundary between the obligatory and the supererogatory is to be established. Cadaveric organ donation seems to fall right on the border between the obligatory and the supererogatory. The great attraction of mandated donation is that for many people cadaveric organ donation ought to be obligatory because it costs them nothing (it is an easy rescue). But for a minority of people it is more difficult to apply the duty of easy rescue because the costs are significant. The second broader issue is how we resolve the tensions between utilitarianism and Kantian ethics with the latter’s emphasis on absolute respect for autonomy and on the need for agents to deliberate and adopt policies of action in the light of the formulae of the categorical imperative: there are compelling reasons to donate but many people do not make the decisions that they ought to about donation. Some never get around to registering any kind of preference at all; others refuse to donate for irrational reasons, because of vanity or for some other self centred reason. Whilst we cannot address the broader question here, we do offer a system of modified mandated choice that takes into account some of the tensions
between Kantian ethics and utilitarianism. It also brings into play our second argument, that the duty of easy rescue should take all available systems into account. What we are recommending is a policy of mandated choice that is modified to take into account the view that all things being equal, people do have an obligation to donate, but is better than mandated donation because it also places a value on the act of choosing for oneself. The modification that we have in mind here is that the onus should be on people to justify their decision not to donate, if this is what they decide. Rather than concentrating, however, on the final decision that people make, we should concentrate on how and why this decision is made.

No moral weight needs to be given to an apparent decision that is made unquestioningly or for no reason at all since it is not clear how such a decision can be considered an expression of autonomy, or indeed, a decision at all. Furthermore, it is irresponsible for individuals to say “no” to donation simply because they could not be bothered to think about it seriously. The same would be true of shifting the burden for making the decision onto the family. On the other hand, a good reason for allowing one’s family to decide might be that they have strong objections to donation that, whilst not shared by oneself, are sufficient to suggest that donation would contribute significantly to the trauma of them coping with one’s death. Refusing to donate out of squeamishness, vanity, or a reluctance to contemplate one’s future death etc would all be bad reasons for refusing to donate, and the fact that they are bad reasons is sufficient justification for the choice itself to be morally questionable. Indeed, since there is a presumption in philosophy that autonomous choices are rational choices, any irrational reason for refusing to donate could make a decision questionable. Moreover, we tend to agree with, for instance Charlesworth, that an act that is freely chosen, regardless of whether it is objectively wrong, has greater moral value than an act that may be objectively good but has not been freely chosen.

MODIFIED MANDATED CHOICE

This leaves the question of how a system of mandated choice could accommodate the modification we have suggested—that is, the recognition of good and bad reasons for choosing with the onus being on those who refuse to justify this—and still allow people to choose freely. For the solution to this problem, we have borrowed an idea from the so called Spanish model. In Spain, transplant coordinators are not just charged with gaining the consent of relatives for organ donation, they are explicitly required to attempt to persuade relatives to donate. This is done by stressing the generosity of the gift, the benefits to recipients of donation, and the importance of social solidarity. What we propose is a system of mandated choice where the accompanying public education and information is similarly prodonation. For instance, all the available literature on cadaveric donation would be far more directive than it currently is, with the legitimate intention of inclining in favour of donation all but those with the strongest objections.

To protect those who still do not wish to donate, however, the modified system would continue to guarantee confidentiality and no privileges would accrue whatever decision was made. The sense in which individuals will have to justify their decision not to donate would not require public investigation. Rather, the process of actively deciding against donation in the face of literature etc attempting to persuade one to do the opposite, is an active expression of autonomy and therefore worthy of respect without need for further investigations into the reasons, which we will presume to be at least strongly held.

Thus, the system we propose accepts the force of the utilitarian argument in favour of obligatory and, therefore, compulsory donation: this is achieved by the strong presumption in favour of donation. It also accepts the Kantian value that is placed on autonomy, but seeks to ensure that an autonomous decision is actually made by both requiring people to reach a decision and by ensuring that a “bad” decision, in utilitarian terms, is at least one that is reached in the face of arguments to the contrary. In this sense it has the value of being an active decision, the reasoning behind which is likely to bring it closer to that which one might expect when upholding the ideal of the autonomous agent.

CONCLUSION

We have addressed the main objections to mandated choice, namely that it undermines autonomy and that mandated donation is preferable. In the process of addressing these objections, we have argued that mandated choice enhances autonomy by ensuring that individuals’ preferences are respected after their deaths. We have also suggested a modification to the accepted system of mandated choice that gives a response to the objections raised by those supporting mandated donation. This modification concedes that it is reasonable to argue that individuals may make choices for the wrong reasons, and as a counterbalance all public information and educational material that accompanies a move to mandated choice should be biased in favour of donation. Given that the objections to mandated choice have been met, public policy makers are obliged to revisit mandated choice as the best way out of the current impasse on organ donation because they still have an obligation to increase the number of cadaveric organs that are made available for transplantation. We recommend our modified version of mandated choice because it recognises the force of the arguments for mandated donation but still ultimately relies on an individual’s explicit consent before any organs are removed.

REFERENCES AND NOTES

1 Figures from UK Transplant’s web site, for instance, state that in 2000, although a total of 1823 (cadaveric and live) kidney donations were performed the waiting list at the close of the year had 6284 patients. 709 live transplants were performed but 175 patients remained on the waiting list. 250 heart or heart/lung transplants were performed but 289 patients were still waiting for a transplant, and 98 lung transplants were performed but 203 patients were still awaiting transplant.


3 For instance, UK Transplant reported on its web site that the number of live kidney donations had risen from 89 in 1991 to 336 in 2000.

4 For example, for kidney donors, major complications for the donor are rare, and the mortality rate is about 0.03%. See: British Medical Association (BMA) Medical Ethics Committee (MEC). Organ donation in the 21st century: time for a consolidated approach. London: BMA, 2000: 10.

5 For example, although liver segments may regenerate, lung segments do not, and donors may suffer from respiratory problems. See: UNOS. Living donation—an overview on the UNOS website www.unos.org.

6 For instance, the Unrelated Live Transplantation Regulatory Authority (ULTRA) is at the time of writing considering the possibility of permitting paired donation and altruistic donation by strangers, and this consideration has been incorporated into the recently announced public consultation on the role of reviewing human tissue transplantation in the UK.

7 See reference 4: 5 where, for instance, it is pointed out that very few of those who die are actually suitable organ donors.


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We agree, however, with Tom Farsides that there are significant psychological barriers to donation that have to be addressed and that without addressing these barriers, requiring people to choose might be counterproductive. See his excellent paper: Farsides T. Winning hearts and minds: using psychology to promote voluntary organ donation. Health Care Anal 2000:8:101–21.

For a full account of the Spanish system see reference 4: 22, or the web site of the Organizacion Nacional de Trasplantes (ONT) on wiltsp.org.uk. We stress that there is much more to the Spanish system than the idea we have borrowed from it and modified.

We accept that this runs counter to the emerging tradition of impartial information giving and counselling. Our point is that this approach is justified by appeals to the greater good.

Reciprocity: compulsory treatment/testing must be matched by a social willingness to help shoulder some of the burdens faced by those who contract the virus.