

# Bodies, organs and saving lives: the alternatives

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**ABSTRACT** – In a paper in the last issue of *Clinical Medicine*,<sup>1</sup> some of the background to attitudes to newly dead bodies, the current context of an urgent need for organs for transplant and the objections to calling a proposal to address this ‘presumed consent’ were outlined. Here further concerns are explored.

**KEY WORDS:** mandated choice, opt-in, opt-out, organ donation, presumed consent

## Presumed lack of objection as policy

Even accepting that ‘presumed consent’ is really presumed lack of objection (PLO), would such a change in policy work? There is no consensus. Certain countries with policies of PLO, such as Luxembourg, Sweden and Greece, have lower transplant rates than the UK; others such as Austria and Spain have higher ones.<sup>2</sup> Countries such as the USA and Ireland are among those with the highest donation rates, yet have opt-in policies. Comparisons are complicated further by the differences in PLO policies: whether family members have a veto even without hard evidence of prior refusal by the proposed subject of organ removal. Austria, for example, has a ‘hard’ form of PLO requiring such evidence, whereas the British Medical Association (BMA) advocates ‘soft’ policy with family objection retained. One meta-analysis suggests that PLO policies might increase organ supply by 25–30%.<sup>3</sup> However, current UK practice initiates the approach to relatives with inquiry as to whether the patient was known to have objections to organ removal. Although a legally backed policy of PLO would make retrieval clearer where there are no next of kin available, it is uncertain whether the level of improvement suggested would be achieved by a ‘soft’ proposal. While retaining the advantages of a continuing dialogue with the family, the legal change seems to offer relatively little: perhaps some change in ethos and expectation over the longer term. Given the negative effects that could result from debate over such legal change, there is legitimate anxiety that the situation could even worsen. Whereas opinion polls and focus groups are necessary, essential and responsible tools before such a legal change should occur, this is an area (rather like research in children) where intentions in polls and actions in real life may not concur.

Presumed lack of objection also has difficulty in addressing the concerns of the Organ Donation Taskforce about the quality of understanding. For if PLO bases itself on the registration of objection to donation of any organ (and not all potential donors are willing to donate any organ, the eye being a

common exception), then the public understanding of its need to register such objection must involve a campaign of education. How often would such a campaign be needed, as the need to register objection will continue indefinitely? The American Medical Association’s (AMA) Council on Ethical and Judicial Affairs pointed out that PLO is likely to trade either on the ignorance of, or on a failure by, the decedent to have overcome inertia and confront the decision squarely, not because the decedent’s failure to opt out actually indicated a willingness to opt in.<sup>4</sup> Against this, it will be asserted that up to 90% of citizens say they support organ donation, (even if only 60% support PLO).<sup>5</sup> The majority 60% or 90% (depending on how one views these data) would have their wishes realised under PLO, even in the absence of next of kin or an appointed attorney for healthcare. The problem here is obvious enough: probable wishes are misinterpreted for a lot of people, higher in an ethnic minority population.

If there is no realistic alternative, many might still believe that PLO could be justified, when it is balanced against the preventable harms accruing from their disease to those awaiting transplantation if, and only if, the alternative(s) has been judged inferior. Better transplant without consent than give organs to the worms or the crematorium. At the time of writing, the latest Task Force Report has rejected the proposal for a system of PLO (opt out).<sup>6</sup> Its conclusions were summarised by one of its members and the report itself provides an update on current policies elsewhere.<sup>7</sup> An independent Welsh report reached a similar conclusion.<sup>8</sup>

The least controversial alternative is an intensification of present policy. Spain changed the law to introduce its opt-out scheme in 1979. However, it had no impact until the Spanish government appointed donor transplant coordinators in every intensive care unit in 1989. The coordinators’ job was to negotiate with relatives when a patient died to gain consent for removal of their organs, and it was this that led to the rapid increase in donor rates.

As Rafael Matesanz, director of the Spanish National Organisation for Transplants, wrote last year, ‘the increase in organ donation during the 1990s cannot be attributed to any change in Spanish law’.<sup>9</sup> Moreover, there are other actions that could improve the organ supply that are less controversial than changing the Human Tissue Act. These include widening the donor pool eg consideration of use of ‘marginal’ donors (eg older, diabetic, Creutzfeldt-Jakob disease risk, hepatitis B and C positive in certain groups, etc) or encouraging an increase in living donations for certain organs.

## Mandated choice: the third way

The third option is mandated choice (MC). It has barely been considered in the UK. This may reflect a lack of political courage

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or will. Yet it warrants detailed study: not least because it has significant ethical advantages over PLO. Like PLO, rejected in 1999, it may take time to be accepted, although it may be preferred to PLO even without strong public advocacy.<sup>10</sup>

Mandated choice is a legally mandated decision. That, in a jurisdiction sensitive to any perceived infringement on civil liberties, even when lives are at stake, is what is difficult. No doubt opponents will prefer the terms ‘forced’ or ‘coerced’ choice. However, before dismissing the idea of a legally mandated decision, both the choices to be offered and the advantages should be considered. To the former question, a working group would need to explore what public preferences might be. Asking whether one wishes to donate one’s organs or not is simple enough. This would need to be followed by a second request to identify which organs could be taken or left. However, choices should not stop there. It must include an option to delegate the decision to someone else such as a family member or even not to choose at all. The key feature of the proposal is that the current figure of 24% on the donor register with 76% unknown would be increased to almost 100% with known wishes. If you want to know what someone wants, ask them, and make sure that you get a reply. MC offers muscle and speed.

There would need to be special provision for those with mental incapacity (an equal problem for PLO) and the present system of parental decision making would need to continue for children.

The nearest precedent lies in Australia where MC occurs in parliamentary elections: voting is compulsory. However much we recoil from the idea of a financial penalty, compulsory voting in Australia is accepted and works. (It has its advocates for the UK too.) In the case of MC, penalties could either be optional or a symbolic minor fine or depend on the method used to ascertain the choice. For example, if registration for the electoral roll was deemed a suitable vehicle, the penalty could be non-registration. The (crucial) details require exploration but I would urge concentration on the principle at this stage. In a survey of young adults in the USA, an overwhelming 90% indicated that they would support MC, while only 60% approved of ‘presumed consent’.<sup>11</sup> It surely is reprehensible that we have no data on UK opinion and, seemingly, no willingness at present to explore this option.

The second advantage of MC is that it addresses the concern of the Organ Donation Taskforce with regard to information provision. Regular collection of electoral roll registration, as one possibility, would offer an economical and standardised route to regular provision of information; or it could be added to the Quality Outcomes Framework in primary care with a fee paid for completion. It would be easier to address the gaps in public education or changes in choice than sporadic campaigns about rights to opt out under a PLO policy.

### **An evidenced-based and ethical policy?**

Advance registration of donation wishes implies that maintaining the dying patient’s organs in the best possible state is

promoting that patient’s best interests. If I have stated that my interests are to save another’s life by organ donation, then to maintain my organs is something done for me, not merely for a third party. Under PLO this objection, identified in the Organ Donation Taskforce report, cannot be addressed. An additional benefit might lie in realising the ‘Exeter protocol’. In this protocol, potential donors were moved to the intensive treatment unit explicitly to maintain the patient in a condition to enable organ donation (and it would now be donation and not merely retrieval).<sup>12</sup> Data showed roughly a doubling in organ retrieval rates under that protocol until it was banned. So there are actually UK data, not just speculation, that donation rates could improve from a source currently untapped.

A recent ‘personal view’ described the experience of deciding on organ donation in the state of confusion, exhaustion and bereavement that follows a death, when the author was ‘in no state to make a decision about anything’.<sup>13</sup> MC avoids all this. The decision has already been made with the comfort that it is a genuine choice. MC would relieve the uncomfortable action of refusal that would occur under ‘soft’ PLO. It would also relieve the accusation that patient wishes are being thwarted. Under any system where relatives have concerns about the patient’s wishes and where inquiry is made (such as the BMA’s ‘soft’ PLO), the assertion of objection is more likely than agreement. Moreover, if opinion polls correctly suggest that at least 10% do not wish to donate organs, these wishes will be thwarted in the absence of articulate family members or if none are available. These numbers are not trivial (and they are proportionately even greater in black and ethnic minority groups). Under MC, family members would not have to live with the anxiety that what was done was not wanted.

Having choice increases the probability of satisfying our wants.<sup>14</sup> By an advance expression of our wishes, we increase the probability of our wishes being realised. Our autonomy is enhanced: an active decision as opposed to an implied assumption of willingness that has actually never been expressed. MC may coerce a choice whereas PLO may coerce an action to us that we would not have wanted. Both may involve coercion. MC is autonomy enhancing, PLO is autonomy denying.

### **Public policy and advance decision making**

The precedent of advance decision making is well established in English law in the Mental Capacity Act 2005. MC extends that by establishing an advance directive for this particular issue. The American Council on Ethical and Judicial Affairs, in its stated preference for MC, comments that it avoids the widespread reluctance to consider one’s own death and the prospect of body mutilation that organ harvesting might entail by ensuring that it is confronted.<sup>4</sup>

The major objection to MC is the enforcement of choice. What we choose would, of course, be free and confidential. But it will be argued that it is not acceptable to coerce making a choice (Australian elections notwithstanding) in a free society – even a choice not to make a choice.

A more or less decent society requires some compulsion. Freedom is not licence and we cannot do as we please. Where the benefits to others are great and obvious, we compel: most obviously in taxation. There is no opt out from tax, no matter how much we would like to pay less or none. Voluntarism would be incapable of delivering the benefits – rather less so than the voluntarism of current organ donation policy. We cannot get something for nothing. The objection of compulsion is not itself compelling.

Both Thomas Aquinas and John Stuart Mill argued that liberty may be restricted when harm to others may accrue from an individual's choice.<sup>15</sup> To quote Mill's formulation:

*The only purpose for which power can be rightfully exercised over any member of a civilised community against his will is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.*

In this case the harm to others is of dying without an organ. The burden of rescue is small: answering a question rather than avoiding it, as most do at present. We are not morally obligated to be good Samaritans, only to be what Thompson calls a minimally decent Samaritan.<sup>16</sup> As observed 20 years ago, 'the principle of justice (here towards renal recipients) would suggest a moral obligation at least to indicate our wishes, ante mortem.'<sup>17</sup> Hume commented that all our obligations to do good to society seem to imply something reciprocal. I receive the benefits of society and ought to promote its interests.<sup>18</sup> At present, we avoid doing good from a reluctance to face our mortality. Nearly a quarter of us do opt in (sometimes referred to as 'less than a quarter' or 'only 24%'), but this could be increased dramatically under MC.

The Code of Practice under the Human Tissue Act currently states that where a potential donor has indicated willingness to donate, the family 'do not have the legal right to veto or overrule those wishes' (para 40), but adds the weasel words 'there may nevertheless be cases in which donation is inappropriate and each case should be considered individually'. This arrangement would be no different under MC than under the current system of a potential donor on the organ donation register.

The most recent Organ Donation Taskforce report commented (para 6.9) that there was considerable support for MC in the deliberative events, while acknowledging that it would present practical problems and be a 'significant departure from UK norms'.<sup>6</sup> It 'was likely to mean greater involvement by families...and would help provide greater clarity about the wishes of the deceased, removing the need to make assumptions'. The Ethics Working Group of the Taskforce spent some time on the proposal and found that 'support grew as the discussion advanced' (annex D). It 'could offer a viable alternative to the current system, albeit with practical and political implications which would need to be carefully considered'. As annex K of the report commented, it 'might ultimately result in a clearer legal directive if implemented'.

## A threat to altruism?

Any legal change creates a risk. Both PLO and MC could threaten the altruism that characterises the current policy and some may feel that risk is too great. Popular opinion can change, suspicion of government 'interference' can be whipped up, outrage can be generated, as it was after the revelations at Alder Hey Children's Hospital and Bristol Royal Infirmary, and practicalities may negate the best theoretical proposals. For this reason we should explore the alternatives carefully. In particular the choices on offer should include not merely, the alternatives of donation or refusing donation, but also one of 'I wish my family to be consulted'. It was probably the absence of such a choice that led to the short-lived introduction of MC in Texas.<sup>19</sup> If an enhanced status quo fails, perhaps PLO will be the best way forward? I do not advocate the immediate adoption of MC, but it would be irresponsible to ignore it. An exploration of a policy based on real consent, its costs, benefits and likely acceptability is the least that we can offer to those whose lives are blighted by the knowledge that life-saving therapy could be made available if the political will could be brought to address the problem. Our changing and varied attitudes to our deaths are part of our humanity: we should design a policy that is sensitive to this and presumes as little as possible.

## Declaration of interest

JS is chairman of the Committee for Ethical Issues in Medicine, Royal College of Physicians. The views expressed in this paper are personal and do not represent those of the College.

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