

AMA Victoria Ltd
Submission to the Inquiry into Organ and Tissue Donation in Victoria

1. The operation of existing legislative, procedural and governance frameworks and policies, including in other jurisdictions.

Relative to other wealthy nations, Australia has a low rate of deceased donor organ donation. There are many people who could benefit from organ donation for whom organs are unavailable.¹

Currently, there is a lack of community discussion about organ and tissue donation and general awareness of the processes for donating. It is difficult for patients and their families to broach the question of whether or not to donate among themselves, or with their doctor, given the sensitive nature of the issue. Potential donors are not asked with enough frequency whether or not they would be willing to donate. Doctors themselves, as well as nurses, are not used to asking their patients about whether they like to donate their organs – this is especially true of doctors in rural hospitals.

Recent funding for organ donation coordinators in some hospitals and the associated awareness campaign appears to have led to increased rates of donation. Historically, however, the impact of awareness campaigns has been short-lived.² A number of studies have shown that the family's knowledge of the deceased's wishes is the primary factor in giving or refusing consent.³ Doctors' experience tells us that cultural issues are often an impediment to donation.⁴

Raising awareness however is not the complete answer. There needs to be more training for doctors in raising the issue with patients, and talking them through the processes for organ and tissue donation.

While the provisions of the legislation in other Australian jurisdictions are similar to those of the *Human Tissue Act 1982* (Vic), there may be some lessons to be learned from South Australia, where the donor rate is high by international standards, and from Queensland's recognition of organ donation as part of Advance Care Directives.⁵

2. Assessment of available national and international evidence on the effectiveness and efficacy of policies to increase donation rates, including the operation of various disclosure and consent arrangements such as presumed consent.

There is a significant lack of research into donor rates and causative factors and it is against this background that possible solutions to low rates of donation must be assessed.

The 'opt-out' register, also known as presumed consent, has attracted considerable attention in discussions around organ donation. Opt-out has been favoured seemingly because there is a view that the donor rate is higher in opt-out countries. Strong evidence to support this view however seems to be lacking – the

¹ Richards, B, Rogers, W, 'Organ Donation after cardiac death' legal and ethical justifications for ante-mortem intervention' (2007) 187(3) Medical Journal of Australia 168.

² Lawlor, M et al, 'Public Education and Organ Donation: untested assumptions and unexpected consequences' (2007) 14 Journal of Law & Medicine 360.

³ Institute of Medicine. (2006). Organ Donation: Opportunities for Action, National Academies of Sciences, Washington D.C, The National Academies Press; Siminoff, L., Mercer, M-B., Graham, G., & Burant, C. (2007). The Reasons Families Donate Organs for Transplantation: Implications for Policy and Practice, Journal of Trauma, Injury, Infection and Critical Care, 62(4).

⁴ Dobb, G, 'The ins and outs of organ donation' (2010) Medicus, Journal of AMA Western Australia, November 2010.

⁵ Powers of Attorney Act 1998 (Qld).

availability of potential donors, the underpinning infrastructure for transplantation, systems and resources, and underlying public attitudes may all have a role in determining whether some countries with presumed consent have low rates of donation and some countries have comparatively high rates.⁶ Strong evidence that an opt-out system increased organ donation rates would be necessary to justify the financial and emotional costs associated with its introduction and to justify the possible infringement of the deceased's residual ethical rights to autonomy.

In any opt-out system it would be necessary to ensure potential donors' participation (or absence of participation) in a register could be considered informed consent. Consent, arguably, would not be accepted by the community as legally or ethically valid unless it is informed. The Legal Working Group of the UK Organ Donation Taskforce ('the UK taskforce') suggested that introducing an opt-out system in the UK would require a five year public education period prior to implementation in order to fulfil valid presumption of consent.⁷ The UK Taskforce itself decided there would be no way of telling whether an education campaign had been sufficient to ensure that all wanting to opt out had indeed registered. It is arguable that even an effective education campaign may not reach each and every member of society.

An ethical concern is that the disadvantaged in society could suffer more erosion of their rights, given the greater likelihood that they would miss out on education or advice about the need to register objections.

There may be an increased risk of legal challenges in a compulsory regime. Such challenges would potentially be directed at individual health professionals as well as hospitals and the authorities. Because of the potential legal risks, as well as the risks that the organ and tissue donation system would be adversely affected or destabilised at least, a considerable amount of education would be needed before the introduction of an opt-out system. For instance, while an individual may choose to donate skin, or not, it is not made clear in the information provided that in the foreseeable future there may be partial face transplants in Australia. If such information is given out, members of the community may be reluctant to donate.

Austria's relatively 'hard' form of presumed consent law entails that organ recovery proceeds unless the deceased had registered an objection before death, and the views of relatives are not actively sought. Arguably, this sort of consent would likely conflict with Victoria's Charter of Human Rights, as the rights of the family may be overridden.⁸

The model of an opt-out system that Australians would most likely support is the 'soft' form of presumed consent law. This is currently in force in Spain whereby doctors take active measures to ascertain that the next of kin do not object to organ recovery. However, support for this form of presumed consent would be contingent on sufficient evidence to suggest that organ donation rates would increase significantly. Although some studies may suggest a correlation, there appears to be insufficient evidence to show causation.

Further, a move to opt out would entail a move from the notion of volunteerism to that of compulsion. The most important considerations here are probably whether the recipient would accept a compulsory donation and further whether the medical and nursing professionals would. It is likely that recipients and professionals would not be comfortable with a strong element of compulsion.⁹

For the community to be justified in taking the risk of overriding an unknown number of individuals' wishes in the interests of a relatively small number of

⁶ Rhitalia, A et al, 'Impact of opt-out for organ donation on donation rates: a systematic review' (2009) British Medical Journal 338, 3162.

⁷ UK Organ Donation Taskforce Report, The Potential Impact of an opt out system for organ donation in the UK, (2008), 20.

⁸ Ibid, 27.

⁹ Ibid.

potential transplant recipients, a case must be made that opt-out registers make a substantial difference to donor rates.

The ethical considerations around opt-out systems are yet to be debated fully at AMA Victoria, and we hope a further submission may be possible later in the year once a position has been established.

3. Identification and assessment of various possible mechanisms to increase organ donation in Victoria.

Mandated choice, whereby patients must make a choice as to whether or not to donate, is a possible option. However a study in NSW found that mandated choice may lead to more people refusing to donate their organs as well as more registering consent. In a NSW 'mandated choice' exercise, where drivers were asked to nominate on their driver's licence their willingness or not to donate, the rate of positive responses rose higher than under the previous voluntary registration system but the rate of negative responses rose at a much greater rate.¹⁰

A system of mandated request by health professionals could be advantageous, however evidence that it increases the rate of organ donation is lacking.¹¹

At a fundamental level, measures must be taken to heighten awareness of organ donation issues among both the nursing and medical professions – a more hands on approach, incorporating organ donation discussions into day to day practice and procedures. Measures would include improved training opportunities and time allocation for intensivists and health professionals to speak with potential donors and their families. The prime example of a high donation rate country is Spain. The rate increase occurred more than a decade after the introduction of an opt-out system, and is attributed to changes in the procurement system, including the location of specially trained intensivists in each hospital. South Australian donor rates have been comparable to those of Spain since they introduced a similar system.¹²

Public education is also crucial in raising the awareness of organ and tissue donation. There must be greater literature on organ donation made available to potential donors and the greater public. Educational campaigns would perform a vital role in improving community awareness of organ donation. Potential donors and family members should be targeted. Education targeting family members is particularly important given knowledge of a family member's wishes is the key factor in a family giving or withholding consent.

4. An appropriate ethical framework for decision making, procedures and safeguards regarding organ donation, including the rights of the prospective donors and family members.

The ethical issues that arise in relation to organ and tissue donation include the rights of donors, the families of donors and of potential recipients.

Patients and their families may not fully understand the subtleties of the dying process when agreeing to organ donation. Material produced by the Australian Organ Donor Registry, while it notes two types of death, does not explain them in detail. Further, the donor form, when asking which kinds of organ and tissue are to be donated, does not explain which may be donated only after brain death and

¹⁰ Lawlor, M et al, 'Public Education and Organ Donation: untested assumptions and unexpected consequences' (2007) 14 Journal of Law and Medicine 360, 365.

¹¹ McLean, S, *Autonomy, Consent and the Law*, (2010), 189.

¹² Australia and New Zealand Organ Donation registry (ANZOD) Annual Report (2010) Summary and Appendix 1. Informal advice from South Australian intensive care physicians suggests that the higher rate is attributable to the Spanish model procurement system, but no research has been done.

which may be donated after cardiac death. Arguably this sort of detailed information is necessary in an opt-in registry system, but it would be even more crucial in an opt-out system.

Ethical and professional guidelines highlight the need to care for the family of the deceased and respect their wishes. These reflect a strong societal ethic relating to respect not only for the dead, but for the grieving family.

There are also ethical, rather than legal issues around the rights of the deceased (the dead have few legal 'rights', and no proprietary rights over their bodies), but legal challenges would emanate from families. Individual health professionals may be at risk at this point.

Current Australian ethical guidelines emphasise the need to consider family feelings, and preclude overriding their wishes.¹³ From the perspective of the deceased's autonomy, however, giving greater weight to the family's objections over a donor's informed, explicit consent, is ethically questionable.

The rights of the recipient, in a health ethics context, include that they be treated with beneficence. It is submitted that the potential recipient does not have any overriding right which could dislodge the rights of the other participants in the situation. However they retain the right to be treated for their conditions in the most effective, practicable way.

5. Any other matters that should be considered in relation to mechanisms to increase organ donation in Victoria.

Despite efforts to increase the number of donors, there will still be a high proportion of potential recipients who miss out. Currently, only 1% of deaths entail conditions suitable for organ donation.

It is submitted that smaller hospitals could be provided with sufficient resources to enable them to deal with and facilitate organ donation. This might include the establishment of regional centres to procure and preserve organs. Extensive consideration of geographical issues would be necessary before the implementation of such a plan.

Advance Care Directives could well include instructions as to a patient's wishes regarding organ and tissue donation. Legislative provisions modelled along the lines of those in Queensland's *Guardianship and Administration Act 2000* could be useful. Comments included in Advance Care Directives would indicate properly informed intention in a clear, unambiguous way. Further, discussions around the development of Advance Care Directives would necessarily involve the family and encourage the conversation to occur. Advance Care Directives, inclusive of a patient's wishes as to organ and tissue donation, could be included as part of the hospital admission process and the forms required to be completed at the time.

Within the primary care setting, the addition of a dedicated Medicare item number allowing adequate time and remuneration for Advance Care Planning would allow General Practitioners to include Advance Care Planning in patient records. General Practitioners are ideally placed to conduct these specific consultations outside of crisis situations and in the presence of other family members.

¹³ Australian & New Zealand Intensive Care Society, Statement on Death and Organ Donation Edition 3.1, (2010); NHMRC, Organ and Tissue Donation, after Death for Transplantation: Guidelines for Ethical Practice for Professionals (2007).