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Posthumous Organ Donation – why Australian jurisdictions should not move to an 'opt-out' system

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It is a recurring topic ... that some proposed legislative changes could resolve, in a radical and one might even say magical fashion, all day-to-day problems that plague those responsible for transplant programs, particularly the scarcity of organs.¹

Posthumous organ donation is a well established practice in Australia that saves many lives each year. However there is a large gap between the number of people on the waiting list for organ donation and the number of actual donors. In fact, Australia currently has one of the lowest rates of posthumous organ donation amongst westernised countries.² In recognition of this, one potential solution that is often raised due to its apparent success in other countries is whether or not Australia should shift to an 'opt-out' system of posthumous organ donation.

Australia currently operates under an 'opt-in' system of posthumous organ donation, whereby a person must demonstrate during their lifetime a willingness to be an organ donor after death, either through legally recording their decision in a donor registry or through communication with their families in relation to their wishes. Therefore, through an 'opt-in' system, it is presumed that a person is not an organ donor, unless they have informed others, formally or informally, of their preference during their lifetime.

An 'opt-out' system is the opposite of this, whereby a person is automatically considered an organ donor unless they demonstrate they are opposed to it during their lifetime.

¹ Matesanz R (1998). 'Invited Comment: Cadaveric organ donation: comparison of legislation in various countries of Europe', *Nephrology Dialysis Transplantation*, Vol 13, 7, pg1632-1635.

² National Clinical Taskforce on Organ and Tissue Donation (2008) *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally.* Commonwealth of Australia. p12-13.

This essay will explore and analyse the two models of posthumous organ donation outlined above, through taking into consideration the legal, ethical and practical factors that influence these models. Through this analysis, the most fitting model of organ donation for Australia in the current climate will be proposed.

The current legal framework for organ donation in Australia

Under the current law, when a person dies a hospital officer is authorised to determine whether the deceased person has consented to organ donation, through checking the national donor registry and/or driver's licenses in some states, and discussing it with the family.³ Australia currently has one single national register of organ and tissue donors, administered by Medicare Australia, which registers both consent and objection to organ donation.⁴ If consent has been given, either formally or informally, and not rescinded at any stage, the tissue can be taken for the purposes prescribed by the donor. Tissue cannot be taken from someone who has been known to object to it throughout his or her lifetime.⁵ However, if the person has not objected, in New South Wales, Queensland, Tasmania and Western Australia the senior available next of kin can consent on their behalf.⁶ Also, according to the law, the next of kin *cannot* override the deceased person's wishes (except in Victoria).⁷ However, in practice this law is not upheld.⁸

Contrary to the actual laws in place, the next of kin *does* have the power to override a deceased person's wishes to donate their organs. This is largely due to the recognition by clinicians of the potential trauma organ donation could have on a family.⁹ Therefore, in reality, even when a person has made an informed decision to become an organ donor, this

 ³ Stewart C, Kerridge I, & Parker M, *The Australian Medico-Legal Handbook (2008)* Elsevier Australia, p171.
⁴ National Health and Medical Research Council (NHMRC) (2007). 'Organ and tissue donation after death, for transplantation: Guidelines for ethical practice for health professionals'. Endorsed 15th March. p10.

⁵ Stewart et al, above n 2.

⁶ Ibid.

⁷ Stewart et al, above n 2, p172.

⁸ Ibid.

⁹ Ibid.

may not occur if their family is uncomfortable or opposed to their decision, or unable to comprehend the decision during their time of grief.

This conflict between current processes and the law is emphasised further through the current ethical guidelines for health professionals involved with organ donation, issued by the National Health and Medical Research Council.¹⁰ Within these guidelines there is a large focus on the importance of including next of kin in decisions regarding organ donation.¹¹ This may imply that the practice of obtaining organs for donation would not change too much from the current process, even if there was to be a change in the legislation.

Incidentally, several studies have shown that this aspect of organ donation, where families can veto a person's decision to become an organ donor, is one of the biggest causes for loss of organs.¹² Therefore improving the approval rates from families is considered to be possibly one of the most effective ways to increase organ donation.¹³

Current practice in Australia

Associated with this factor, according to recent system reviews undertaken by the Government and not-for-profit organisations such as ShareLife Australia, the biggest problem affecting organ donation rates in Australia is the fragmented and inefficient organ donation sector itself. Australia does not currently have a national body coordinating the organ donation process, which many other countries with a higher donation rate have. Instead Australia has a system which varies across states and territories and involves over

¹⁰ NHMRC, above n 3, p33-34.

¹¹ Ibid.

¹² Abadie A, Gay S (2006). 'The Impact of Presumed Consent Legislation on Cadeveric Organ Donation: A Cross Country Study', *Journal of Health Economics*, Vol 24, 4, p602; Siegal G, Bonnie R (2006). 'Closing the Organ Gap: A Reciprocity-Based Social Contract Approach', *DNA Fingerprints and Civil Liberties*, Summer 2006, p415.

¹³ Abadie et al, above n 10.

70 different organisations which work at varying levels using differing processes.¹⁴ In addition, the majority of hospitals do not have a specialist donor coordinating position to manage the organ donation process and it is usually left up to doctors working in the intensive care unit to take on the process themselves.¹⁵

The 'opt-out' model is considered to be one solution to this systematic problem, as proponents of the system argue that it will promote systematic change through changing the way clinicians and the public regard organ donation.

The 'Opt-out' Model

The 'opt-out' model is currently favoured by many stakeholders over the alternative 'optin' model, as it is considered to be a model that naturally promotes higher rates of organ donation. This is based on the assumption that there would be fewer people to object to donation under an 'opt-out' system than there would be people failing to register support under an 'opt-in' system.¹⁶ In addition, advocates of this system argue that through an 'opt-out' system there would be fewer objections from families regarding organ donation.¹⁷ This is thought to be due to the fact that consent to donation by families becomes implicit, as it is seen as the social 'norm' to donate, meaning that consent is gained under the pretext of 'do you have any objections?' rather than 'would you like to donate?' ¹⁸ This assumption has been supported by several studies, including a mathematical model produced by Abadie and Gay, which demonstrates that the 'opt-out'

¹⁴ National Clinical Taskforce on Organ and Tissue Donation (NCTOTD) (2008) *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally.* Commonwealth of Australia. p 16-19; Sharelife Australia, 'Australia's Transplant Outrage' - Fact Sheet (2007),

http://www.sharelifeaustralia.com.au/public/public.aspx accessed 17 May 2008.

¹⁵ Cameron, S & Forsythe J (2001). How can we improve organ donation rates? Research into the identification of factors which may influence the variation, *Nefrologia*, Vol 21, 5 p73-74.

¹⁶ Coppen R, Fiele R, Marquet R, Gevers S (2005). 'Opting-out systems: no guarantee for higher donation rates', *Transplant International*, Vol 18, p1275-1279.

¹⁷ Abadie et al, above n 10.

¹⁸ Healy, K (2006) Do Presumed Consent Laws Raise Organ Procurement Rates? *DePaul Law Review*, vol 55, p1028-1029.

model of organ donation is likely to produce higher rates of family consent to organ donation, and therefore higher levels of organ availability.¹⁹

The 'opt-out' model has largely gained its credibility through the success of Spain, Italy and other European countries, which enjoy the highest rates of organ donation in the world.²⁰ However there are several studies that dispute the link between the 'opt-out' legislation and an increased organ donation rate that is often implied.²¹ The key reason given for this is the sheer number of factors that can influence the organ donation process, including factors such as rates of road accidents, and the overall wealth of a country. In contrast, one widely quoted cross-country comparison study, also undertaken by Abadie and Gay, attempts to take some of these confounding factors into account, and successfully demonstrates that posthumous donation rates are still 25% to 35% higher on average in countries with 'opt-out' legislation.²²

The Spanish Model and the importance of a strong organisational structure

However, one factor that is not accounted for in this study and others like it²³ is the fact that in most of the countries studied, the change in legislation to an 'opt-out' model also instigated an overhaul of the organ donation sector within that country, with increased investment in areas such as infrastructure, staffing levels and training, and donation coordinators for hospitals.²⁴

One such example is the case of Spain, which has one of the highest rates of organ donation in the world. In Spain the legislation change to an 'opt-out' model occurred in 1979, however rates of organ donation did not start improving until 10 years later when in

¹⁹ Abadie et al, above n 10, p609-612.

²⁰ Cameron et al, above n 13; Healy, above n 16, p1038-1043; NCTOTD, above n 12, p38-40.

²¹ Coppen et al, above n 14, p1275-1276; Healy, above n 16, p1023;

²² Abadie et al, above n 10, p12-20.

²³ Healy, above n 16, p1023.

²⁴ Healy, above n 16, p1030-1043.

the early 1990s a centralised organ donation system was established - the National Transplantation Organisation (ONT).²⁵ Indeed, reviewers of the success of the 'Spanish model' have directly attributed the increased rate of organ donation over the last decade to the improvements in the logistics of organ donation systems, rather than to the change in legislation.²⁶

This point is especially promoted by Rafael Matesanz who was the former inaugural Director of the ONT. In a presentation given to the Institute of Medicine in the United States, Matesanz states that in Spain the 42 hospitals with organ transplant teams account for 62% of the donors for the country, while the remaining 38% of donors come from the 92 hospitals without organ transplant teams.²⁷ This statistic alone provides a stark example of the effect that increased investment in hospital donation systems can have, despite having the exact same underlying legislative background. Furthermore, Matesanz suggests that classic approaches to improving organ donation rates, such as making changes to legislation, implementing donor registries and undertaking publicity campaigns have little benefit.²⁸ He believes the biggest improvements can be made through:

a proactive donor detection program performed by well trained transplant coordinators, the introduction of systematic death audits in hospitals, and the combination of a positive social atmosphere with adequate economic reimbursement for the hospitals.²⁹

However, for argument's sake, even if conclusive evidence were provided that demonstrated that the 'opt-out' model did have a direct positive effect on donation rates, there would still be problems with implementing the legislation in Australia, due to concerns in relation to the underlying ethics of the model.

²⁵ Ibid.

²⁶ Ibid.

²⁷ Matesanz R 'The Spanish Model'. (Presentation presented at the 'Workshop on Increasing Rates of Organ Donation', Washington, 20th June 2005.)

²⁸ Ibid.

²⁹ Matesanz, R (2001) 'A Decade of Continuous Improvement in Cadaveric Organ Donation: The Spanish model, Nefrologia, Vol 21, as cited by Healy, above n 18, p1040.

Ethical problems with the 'opt-out' model

One of the biggest criticisms of 'opt-out' systems is that they are unethical. This is based on the argument that such models inhibit altruism, and do not appropriately recognise the autonomy of the individual.³⁰

Under the 'opt-in' model, the choice to donate organs posthumously in Australia is currently considered as an altruistic act in that 'it is an intentional, voluntary, unrewarded action that seeks to increase the welfare of others'.³¹ In other words it confers on the donor the ability to give the 'gift' of organ donation.³² Converting to an 'opt-out' model removes this element from the picture and places a greater importance on the body organs themselves and how they can be used to benefit the 'greater good.'³³ This could potentially deny relatives of the deceased person the sense of feeling that a good deed was done through donating organs. Opponents of the 'opt-out' system also suggest that the removal of altruism from the system could open the door for incentive-based organ donation schemes.

According to Beauchamp et al, in order to respect a person's autonomy, one must 'acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs' and, this extends to obtaining consent for intervention with patients. ³⁴ In addition to this Beauchamp et al add that consent should refer to an individual's actual choices, not to presumptions about the choices the individual would or

³⁰ Kerridge I, Lowe M, McPhee J, Ethics and law for health professionals (2nd ed, 2005), Federation Press, Sydney, p411.

³¹ Healy, K (2004). Altruism as an Organisational Problem: The Case of Organ Procurement. *American Sociological Review*, Vol 69, p393.

³² Pierscionek B, (2008). 'What is presumed when we presume consent?' *BMC Medical Ethics*, Vol 9, 8, p1-5. ³³ Ibid.

³⁴ Beauchamp T, Childress J (2001). *Principles of Biomedical Ethics 5th Ed*, Oxford University Press, New York, p63-67.

should make'.³⁵ Proponents of the 'opt-out' system generally believe that this value is upheld in their system, as persons still have the right and opportunity to 'opt-out' of the system, and are granted adequate time and given appropriate levels of information to ensure that they are equipped to make an informed decision on whether or not to 'optout'.³⁶

However, even with the most comprehensive education policies in place, under an 'optout' system there will always be an inherent risk that some people in society will be unaware of the policy and the need to 'opt-out', or will not have understood the policy correctly.³⁷ In some cases this situation may arise in respect to some of the most vulnerable and marginalised people in our society. As put by Piersionek, if Australia was to implement an 'opt-out' system, measures would need to be taken to ensure the more vulnerable members of society are not exploited or used as 'reservoirs of body organs'.³⁸

In refute of this assertion, several authors have produced strong ethical arguments that suggest autonomous decision-making is compromised equally under both systems of organ donation, as there is always scope to make mistakes regarding the actual choice the deceased person would have made in instances where no preference is recorded either way.³⁹ Moreover, that these circumstances apply to both autonomous adults and more vulnerable adults equally.⁴⁰

One such case is put forward by Gill in which he argues that the mistake of not removing organs where there may have been consent is morally as bad as the mistake of removing

³⁵ Ibid. p66.

³⁶ Gill M (2004) 'Presumed consent, autonomy and organ donation', *Journal of Medicine and Philosophy*, Vol 29, 1, p37-38.

³⁷ Price D (2000). *Legal and Ethical Aspects of Organ Transplantation*, Cambridge University Press, United Kingdom, p113-118; Kerridge et al, above n 30.

³⁸ Pierscionek B, above n 32.

³⁹ Gill, above n 36, p37-58; Jacob M (2006). 'Another look at the presumed-versus-informed consent dichotomy in post-mortem organ procurement', *Bioethics*, Vol 20, 6, p293-300; Price, above n 36, p109-111.

⁴⁰ Pierscionek, above n 32, p4.

organs when there may not have been consent. ⁴¹ Gill goes on to show that most general population surveys suggest that a much larger proportion of people are in favour of organ donation. ⁴² Therefore, the conclusion he draws from this is that the 'opt-out' system is the more preferable system, as less mistakes would be made under an 'opt-out' system than there would be under an 'opt-in' system.⁴³

A similar argument to Gill's is that of Jacob, she suggests that mistakes made under both systems are as morally bad as each other.⁴⁴ However, Jacob goes on to propose a new way of determining the best model, despite the shortcomings of both, using contract theory.

According to policy-oriented legal theory, legislatures should purposely provide default rules that are contradictory to the stronger parties' preference.⁴⁵ The reasoning behind this is that it gives the impetus to the stronger party to avoid the default rule through providing the more vulnerable party the opportunity to discuss and express their own interests and become more informed about the 'contract'.⁴⁶ This would not happen if the contract were structured the other way around, as the more vulnerable party would not be aware of their more vulnerable position. In terms of organ donation, this means that the impetus should be on the government and organ donation organisations to provide a greater level of support and education to encourage informed decisions around organ donation.⁴⁷

Jacob's argument is more appealing than Gill's as it recognises the limitations of both models, but gives a greater focus to one of the main underlying ethical problem associated with the 'opt-out' model – namely the needs of marginalised people in society. It also

⁴¹ Gill, above n 35, p37-39.

⁴² Gill, above n 35, pg 39-40. Gill shows the rate of approval for organ donation to be around 70% in the United States. This argument is thus applicable for Australia as general surveys have shown the approval rate in Australia to be as high as 90%. (

⁴³ Gill, above n 35, pg 40-55.

⁴⁴ Jacob, above n 35, pg 296-297.

⁴⁵ Jacob, above n 35, pg 299-300.

⁴⁶ Ibid.

⁴⁷ Ibid.

provides a logical framework for understanding why Australia's society may be more inclined to stay with an 'opt-in' system of organ donation.⁴⁸

However, although these ethical issues have been raised in other settings, if Australia were to consider moving to an 'opt-out' system of organ donation, a focused debate would need to take place around these issues within the specific cultural context of the country.

Conclusion

Although in theory the 'opt-out' system of organ donation may induce an increase in the number of available organ donors in Australia, there are several ethical issues that would need to be addressed before such a system could be implemented. Due to the fact that some aspects of the current system of organ procurement in Australia operate independently from the law, it is possible that introducing new legislation would not affect the way organ donation systems actually operate in practice.

Furthermore, if the success of the 'Spanish Model' is anything to go by, it seems that there is currently too much emphasis placed on determining which legal framework is most conducive to organ donation. As was eloquently stated by Matesanz:

I am profoundly skeptical whether any change in legislation in and by itself could modify a social reality which is supported by the majority. The sequence of events goes the other way round. Laws are good laws when they conform with that which has been accepted by society and do not try to modify society by coercion.⁴⁹

Therefore it would appear that a more effective approach to increasing the number of organ donors in Australia would be to maintain the current 'opt-in' system of posthumous organ donation, and instead undertake an overhaul of the sector. Using the lessons learnt

⁴⁸ Kerridge et al, above n 30, pg 411.

⁴⁹ Matesanz, above n 1.

from the 'Spanish model', Australia should concentrate efforts on developing a centralised system for organ donation that focuses on improving efficiency and coordination across the sector whilst also fostering an increased awareness of organ donation issues in the community through education.

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