

DISCUSSION PAPER

IMPROVING ORGAN DONATION

BUILDING ON ACHIEVEMENTS OF FIRST TRIENNIUM

A COMMUNITY PERSPECTIVE

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Introduction

For about 20 years, the number of Australians who became multi organ donors in any one year was stagnant at about the 200 mark¹. In 2009, a new Authority was established² to develop a nationally coordinated framework to implement world's best practice in the Australian context.

For the first time, organ donor specialists came together to build a system that worked across and within jurisdictions. The results have been modestly successful and it is evident that a national approach with national leadership is the best outcome. In 2009, there were 247 multi organ donors at a rate of 11.3 donors per million (dpm) while in 2012, 354 multi organ donors made up the rate of 15.6 dpm population³.

While it is pleasing that the results over this period are positive, nevertheless they did not reach the target for 2012, which was 375 multi organ donors or just over 16 dpm population. This was a five per cent increase on the 337 multi organ donors (14.9 dpm) in 2011.

Importantly the results did not demonstrate the potential to reach between 23 and 25 donors per million which a MidPoint Review⁴ of the reform process in 2011 had predicted was 'potentially achievable'. It is pleasing to note that, at the end of the first quarter in 2013, Australia is getting close to that number with 119 multi organ donors⁵, with a donor per million population rate of about 21.

A lot of the work in improving Australia's organ donation rate has been modelled on the strategies used in Spain. There is, however, one striking difference between the two countries and that is 'extended criteria'⁶ or 'expanded criteria' organs are used in Spain whereas they are unlikely to be used in Australia. Australia is a world leader in transplantation services and one of the key reasons for this is that transplant teams are very careful in doing no harm to patients. Thus, by and large, very few extended criteria organs are used.

¹ Australian & New Zealand Organ Donation Registry Annual Reports 1989-2012

² Australian Organ and Tissue Donation and Transplantation Authority Act 2008, No. 122, 2008

³ Australian & New Zealand Organ Donation Registry.

⁴ MidPoint Review, Executive Summary, Page 2, Australian HealthCare Associates

⁵ <http://www.anzdata.org.au/anzod/v1/summary-org-donation.html>

⁶ Extended criteria organs are those from donors who fall outside the retrieval and allocation protocols.

Significant work has also been undertaken by the Authority in advertising and media campaigns to effect attitudinal change – see, for example, the *OK* campaign⁷. Market research is regularly undertaken to assess the success of these campaigns and to measure how many families have had a conversation about organ and tissue donation status.

Another key platform in the reform agenda relates to the professional development of staff involved in the sector so that they are able to discuss organ and tissue donation appropriately, and successfully, with relatives. This work is ongoing and its fruits should be seen in 2013.

One key piece of work relates to the New South Wales driver's licence, arrangements for which were introduced on 1 December 2012. This involved closing down any relationship between organ donor status and the issuing of driver's licence in New South Wales, recognising that this registry was having a negative impact on the Authority's ability to obtain consent from next of kin. There were false *no* registrations on this register and it was difficult to access out of hours.

Next Steps

It is clear to us that there is an expectation amongst the community that more can be done. We find that people are stunned by the low number of organ donors when we report annual outcomes.

This is not to diminish in any way the great achievements that have already been made. However, if significant changes are to be made, a critical look at other strategies would seem necessary.

It is proposed that a key platform from the reform agenda in the United States of America be introduced in the Australian context. Known as *First Person Consent*, it is described in detail below. It is likely that implementation of such a system will result in many more donors while respecting the transplant teams' desires to ensure that no harm is done to patients by increasing access to extended criteria organs. Logically, the community would be supportive of such an

⁷ As outlined on Authority's website:
<http://www.donatelife.gov.au/resources/donatelife-campaign/know-their-wishes-campaign>

approach as well. This is because approximately 80% of Australians support organ donation⁸.

By adopting the American approach, Australians would be given the opportunity to support decisions of the person who has died, while respecting the views of relatives and more detail is provided below.

In the first triennium of reform, Australia has devoted considerable time to the family discussion and knowing loved one's wishes. However, it is incredibly difficult to objectively measure this outcome. And we cannot manage what we cannot measure.

At the same time the Authority's own research reveals that while 80% of Australians support donation, awareness of how to register for donation remained at 33% of those surveyed.

A move to First Person Consent would appear to be the next logical step. It builds on the existing Australian Organ Donor Register (AODR) while avoiding the temptation of considering an opt out system which we do not believe would be in the best interests of donation in Australia.

Importantly a first consent system goes that further step of knowing *and respecting* loved one's decision.

First Person Consent

This policy was enacted in the US in 2002 and revised in 2006. The underlying assumption was that families would accept donation decisions of their loved ones if they knew about that decision. The principle is that hospitals are given the legal authority to retrieve organs from a deceased person if that person has registered to be a donor on an official donor registry. Legally, hospitals do not need to seek approval from families, but in reality they do seek endorsement. Importantly, however, families of such donors are not legally asked for their consent but are taken through a different process based on supporting the original 'first consentor' decision. Organ donor coordinators monitor for any potential adverse reactions, manage the families through the process and in the event of any residual adverse response, lead the family to a logical and acceptable outcome.

⁸ Australian Organ & Tissue Authority *DonateLife Website* (www.donatelife.gov.au) *Facts and Statistics*.

During 2012, DonateLife arranged a forum which was addressed by Professor Laura Siminoff of Virginia Commonwealth University. She explained how First Person Consent works and her slides are available through the Australian Organ & Tissue Authority. The key issues were that⁹:

- In a study of general public attitudes in 2000, 71% believed that family members should not override the potential donor's wishes¹⁰.
- As already identified by the Authority, knowledge of the potential donor's wishes is an important factor.
- The most frequent reason for refusing donation was not knowing potential donor's wishes.
- An outcome of 97% consent rate was achieved with first person consent.

These are influential findings and could lead to a significant increase in organ donation without moving to a fraught system of presumed consent. In the US, only about 30% agree with presumed concept. The concept of presumed consent is that a person will be deemed to be an organ donor unless there is any explicit direction to the contrary¹¹. Other terms used include opt out and opt in. Opt out is the same as presumed consent while opt in is the system that operates in countries including Australia. However, relatives are able to override the decision of the potential donor in the Australian context.

According to the Organ & Tissue Authority's performance report for 2012¹², an audit identified 790 potential donors of the more than 150,000 estimated deaths for the year. The following data are significant:

- Of the 790 potential donors, 710 requests for organ donation were made.
- Of the 710 requests, 410 families agreed to organ donation.
- Of those 410 consents, there were 354 multi organ donors.

There is no mention in that report of how many of those were on the Australian Organ Donor Register, the NSW driver's licence or any other legal instrument indicating a decision to be an organ donor. It would appear that this is a significant gap in the sector's research.

⁹ Siminoff, LA, (2012), *US Strategies to Improve Consent*. Paper delivered at DonateLife Forum, Brisbane, March 2012 (available from DonateLife)

¹⁰ May, T., Aulisio, P., and DeVita, MA., (2000), *Patients, families and organ donation: who should decide?* **Milbank Quarterly**, 78: 323-36, 52

¹¹ Abadie, A., and Gay, S. (2006), *The impact of presumed consent legislation on cadaveric organ donation: A cross country study.* **Journal of Health Economics**, 25 (2006) 599-620.

¹² Australian Organ & Tissue Authority (2013), *Performance Report 2012*.

We do know that in 2011 there were a total of 77 donors in NSW while an additional seven donors¹³ who had formally consented to donation did not proceed because of family objection. While this is just under 10%, it needs to be acknowledged that these seven donors could have provided organs for an additional 21 to 25 people. That is an opportunity missed to save an additional 21 to 25 lives while not forgetting that those people who died had expected their decision to be honoured.

Role of the Australian Organ Donor Register

The Australian Organ Donor Register (AODR) was established in 2000 to record the legal wishes of potential organ donors. In 2009, a strategic decision was taken by the Department of Health and Ageing and the Australian Organ & Tissue Authority to downplay the importance of the AODR. This was on the basis that Spain does not have a register and world's best practice therefore did not rely on such a register. The AODR was not abolished; however, advertising did not include reference to the AODR.

This was a puzzle to many in the community as the common thought was that signing up to the Register was the final piece in the family discussion. It was the 'call to action' and the last piece of activity required if one wished to be an organ donor. At that time, there were 1.3 million Australians formally on the register (as at 31 December 2009) as having given their consent. At the end of 2012 (as at 30 November 2012) there were 1.6 million Australians signed up to the register. Of those, some 17,000 had registered their objection to become an organ donor.

It should also be noted that there are an additional 4.2 million Australians who have registered their consent to donation through driver's licence registries and that information has subsequently been uploaded to the national register. In these instances because the Register was not the primary source of information the consent is treated as an 'intent' to register. Effectively it is treated in the same manner.

¹³ New South Wales. Ministry of Health and NSW Health (2012). *Increasing Organ Donation in NSW: Government Plan 2012*. NSW Ministry of Health, North Sydney, NSW. p. 9

Our Hypothesis

Using data from the Australian Bureau of Statistics¹⁴, Australia's population was 22.6m. in 2012. The percentage of those having consented to donation via the AODR is approximately 7%. If we apply those data to the number of requests for organ donation in 2012 (710), we could have started with 49 donors without too much of an effort.

If 80% of Australians signed onto the register and we applied the same formula to the 2012 data, the result would have been 568 multi organ donors, a significant increase on the 354 multi organ donors achieved. Remember, 80% is the number of Australians supporting organ donation, according to the Authority. Such a move would have Australia recording a rate of about 26 dpm. The following table summarises this information:

	CURRENT SYSTEM	FIRST PERSON CONSENT SYSTEM
No. of Requests for Organ Donation	710	710
No. multi organ donors	354	568
Donations per million population (approx.)	15.6	26

It is the collective experience of those who meet regularly with the community through events that Australians are keen to have a card or some demonstration that they have decided to be an organ donor. In the past this was the driver's licence but the only valid register in Australia is now the AODR. The register is accessible by organ donor specialists in all jurisdictions and does not require any special access, which was previously required by the NSW driver's licence.

It is proposed that the AODR should again become the primary call to action, as previously intended. It would finish off or complement the family discussion, but give an opportunity to measure objectively the success of any marketing campaigns.

¹⁴ Australian Bureau of Statistics (2012), *Australian Demographic Statistics*, June 2012, 3101.0

Importantly, it is recognised that greater targeting of the donation message must occur with Culturally and Linguistically Diverse (CALD) audiences in Australia.

In the five years to and including 2011 there were 1,350 donors in Australia. A total of 1,270 (94%) were from Caucasoid (Anglo) backgrounds. Just 14 donors were identified as Indigenous, 12 with a Vietnamese background, 11 with a Chinese background, nine with an Indian background and the same with a Malay background.

The challenge faced when presenting to audiences from CALD backgrounds is the additional complexity of the family unit. Often CALD families have multi-layered decision-making processes while different CALD audiences have significantly different family hierarchies.

Any communication campaign about donation which focuses on the primary message or call to action of family discussion could potentially be misinterpreted in the CALD setting.

Recent research undertaken for Transplant Australia in the Chinese and Vietnamese communities in Western Sydney shows that the 'talk to your family' message has not penetrated these communities.

In a survey of 320 Australians of Chinese heritage, only one respondent mentioned the importance of talking to family when asked 'do you know how to indicate your decision to become a donor?' A total of 200 did not know, 80 mentioned the NSW driver's licence while just 18 mentioned the AODR.

The numbers were slightly improved in the Vietnamese cohort with 67 out of 300 mentioning 'telling your family', 123 mentioning the driver's licence and 47 mentioning registering on the AODR.

A simple solution, which can also be understood by CALD audiences, is to register their decision about organ donation on the AODR.

This registration message needs to be clear and simple and provided in their own language. It should not be used in place of the family discussion message but rather in a complementary fashion.

Advice from the NSW Multi-Cultural Health Communications Unit confirms an approach that is simple and easily understood is preferred. As already suggested registration is also easily measured amongst these audiences.

We recognise that the Authority has recently adopted a specific CALD strategy and believe this would be enhanced by our proposal.

Proposal

It is proposed that the AODR be used as the source for implementing a First Person Consent process. While any such process should still include a general escape clause, nevertheless if families were aware at the outset that the intent is to honour the potential donor's decision, it would be expected that Australia would see an improvement in donor rates as occurred in the US. Our aim should be to ensure that honouring a loved one's decision becomes the community norm.

While the US and other countries do not include the option to register a decision not to be an organ donor, this would be considered a bridge too far in Australia. Citizens should be given the opportunity to record a decision one way or the other. What this proposal is about, however, is ensuring that those who have decided to be organ donors if the circumstances of their death allow, shall have their decisions honoured. If people are not on the register, clinical staff would have the opportunity to ask families for consent. And if they have registered a decision not to be an organ donor, then that decision should also be honoured.

We would also take the opportunity to modernise the process for registering on the AODR through the use of a mobile phone app or SMS-based service to better meet the technological expectations of today's generation. This was recently recommended in the NSW Organ Donation Plan¹⁵. Further details are also available from Transplant Australia.

World's Best Practice

Spain does not rely on an organ donor register. It leads the developed world in organ donation. As mentioned previously, however, it does rely on extended criteria organs, a practice that is unlikely to be accepted in Australia in the short to medium term – by either clinicians or community, although on this latter group, their opinion has not yet been sought.

It would therefore seem appropriate to look at what other world leaders do to improve their organ donor rates. America is in the top 10 and there are many similarities between Australia and the US. While aiming to improve organ donor rates, the US has implemented a First Person Consent process that enables the

¹⁵ New South Wales. Ministry of Health and NSW Health (2012). *op. cit.*

decisions of the potential donor to be honoured while still observing family members for potential adverse reactions and in those cases managing through to the most logical outcome.

While some stakeholders might argue that, because Spain is identified as world's best practice for organ donation and it does not rely on an organ donation register, Australia should not march down this route. It is our contention that Spain is culturally different from Australia. To date, it has been extremely difficult to get Australians to make firm arrangements with their loved ones about their death. We must also remember that Australia has significant ground to make up in reaching the Spanish target which has been identified as world's best practice, because Australia does not use extended criteria organs.

Cost

There is little or no cost involved in adopting First Person Consent. Indeed, moving to this process would make use of all the tools available to the sector, including the AODR. The only change we would recommend is in relation to the advertising, which would focus on the issue of respecting loved one's *decisions*. We would also contest that this move would be warmly welcomed by the community which has been incensed that family members can potentially overrule a person's previously made legal decision.

Ask and honour your loved one's decisions.

Conclusion

It is our contention that many in the community want their decisions upheld and it is puzzling that their families are able to reverse these decisions. We also contend that a commitment to the AODR will enable the Authority and the public more generally to objectively assess the success of Australia's program. Finally, if a move to First Person Consent is made, it precludes the need at this stage to consider extended criteria organs for donation and transplantation or to contemplate opt-out consent

It should be noted that the language used in this paper has been about individuals making decisions to donate their organs. It is noted that the theme for DonateLife week 2013 was about wishes (and indeed the word 'wish' has been used in a number of marketing a promotional activities). The aim should be to honour a potential donor's **decision** rather than a vague wish or hope.



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