Robert Little: Submission to House of Representatives *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*

Robert Little

Mr Steve Irons MP

Chair

House of Representatives Standing Committee on Health

Via Email: Health.reps@aph.gov.au

Dear Chair

Please find following my submission to the House of Representative's Standing Committee on Health's *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*.

I would welcome an opportunity to speak to the Committee in person.

In making this submission I refer mainly to chronic kidney disease and kidney transplantation. However all of my recommendations apply equally to other areas of organ donation. As I make some extra points in this cover letter I would ask that it forms part of the body of my submission. I'd also like to put on the record that I feel blessed to live in a country that spends money on dialysis and organ donation. Without my fellow Australians being happy to use their tax money to keep me alive, well, I'd be dead. More than the fact that I'm waiting for a kidney transplant the poor results, given the $240 million spent by Organ and Tissue Authority (OTA)/DonateLife, is extremely concerning. I say this mainly as member of the community who pays my taxes and expects value for money from the government. I also hasten to add that my criticism of the OTA and DonateLife does not extend to the front line staff. Clearly these are dedicated professionals who have been let down by OTA's leadership.

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For completeness I should state that I have been Chair of the DonateLife ACT Principal Advisory Committee, am a member of the DonateLife ACT Consumer and Community Advisory Committee and have accessed research from ShareLife (www.sharelife.org.au).

Interestingly, I would not have questioned anything about AOTA and DonateLife until Mr David Koch quit 'on air' from AOTA's Advisory Committee[1] and was quite critical of ShareLife. As a person waiting for an organ donation it was depressing to see someone with the media profile of Mr Koch play the man (ShareLife) rather than the ball (Australia's poor organ donation rate). Since Mr Koch's on air resignation I have engaged in a steep learning curve as to the actual process of organ donation in Australia and in the practice in countries such as Spain and Croatia.

I hasten to point out that, although I have been on DonateLife Committee's I don't and cannot have a detailed knowledge of exactly what happens in relation to organ donation in Australia. The Terms of Reference require someone to have a detailed knowledge of AOTA and hospital internal practice and documentation. As an individual I do not have such access. This points to the transparency (or lack thereof) of the process. All I can do is compare the figures from comparable western countries with Australia. This comparison shows Australia is too far behind. Because of this people are dying or having their lives severely curtailed.

I would also draw to your attention the article *Five myths about organ donation in Australia*[2] by Aric Bendorf which is available at:

http://theconversation.com/five-myths-about-organ-donation-in-australia-5008

Thank you so much for accepting my submission.

Yours sincerely

[1] See http://www.theaustralian.com.au/business/media/get-a-backbone-david-koch-quits-organ-donation-council-live-on-air/story-e6frg996-1227370977071 accessed 29 June 2015.
[2] http://theconversation.com/five-myths-about-organ-donation-in-australia-5008

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Executive Summary

- I am a 42 year old previous transplant recipient currently waiting for a kidney transplant.
- Chronic Kidney Disease (CKD) is a significant and growing public health problem, responsible for substantial burden of illness and premature mortality.
- The best treatment for kidney failure is a kidney transplant.
- Australian's promised that Australia would become a "world leader in organ donation for transplantation" this has not occurred – as follows:
    - Globally organ donation rates are measured in Donors Per Million of Population (DPMP) as this takes into account changes in population over time. Leading Performance is 35 DPMP. By the end of 2014 Australia was performing at 16.1 DPMP, only 46% of world leading practice.
    - Australia is currently ranked 20th in the world and is projected to fall even further in the next global ranking. If we had reached leading performance as intended, around 1100 more lives could be saved each year.
    - The gap between Australia's performance and leading performance has only been closed by 8.7% over six years, even though an unprecedented $240 million has been spent. This is a very poor return on investment; one that results in the needless suffering and loss of life of over 1000 Australians each year.
    - Over the period from 2008 to 2013, Australia's number of organ donors per million population only increased by 4.8 whereas other countries such as Croatia, Belarus and Malta increased by more than 10.
- There is not appropriate date for exact average waiting times for kidney/organ transplants. This data would greatly help patients.
- Australia's average wait for a kidney transplant is 3.5 years – with many people waiting much longer whilst Spain's average is 8 months. This is unacceptable.
- Clearly, in relation to organ donation, Croatia and Spain are doing something that Australia is not. We should learn from Croatia and Spain.
- Transplant Coordinators should be trained doctors who have no other task than assessing potential donors and having an appropriately empathetic discussion with relatives of potential donors.
- In recognition of the above the Sydney Health District's Royal Prince Alfred (RPA) Hospital has acknowledged problems with their transplant program and have appointed a Director of the Organ Donation for Transplant Unit at RPA.
- Ernst and Young should assess Australia's Transplant Program from the point a possible donor reaches hospital through to the discussion had with families then to the point of donation. They should ensure that there are dedicated (ie: with no other role/tasks) doctors assessing and referring patients to organ donation.

- The DonateLife website should have a clear section on organ donation rate, including in comparison with other leading nations and should have a section for those "Awaiting Transplant".

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Terms of Reference[3]

The Standing Committee on Health will inquire into and report on best practice in chronic disease prevention and management in primary health care, specifically:

1. Examples of best practice in chronic disease prevention and management, both in Australia and internationally;

2. Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management;

3. Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;

4. The role of private health insurers in chronic disease prevention and management;

5. The role of State and Territory Governments in chronic disease prevention and management;

6. Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management.

7. Best practice of Multidisciplinary teams chronic disease management in primary health care and Hospitals; and

8. Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

[3] See http://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Chronic_Disease/Terms_of_Reference accessed 23 July 2015.

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About Me

Qualifications:

> Bachelor Arts, Bachelor Arts (Asian Studies), Bachelor of Laws, Graduate Diploma in Applied Finance and Investment, Graduate Diploma in Financial Planning

My interest in the health sector stems from my personal experiences having been born with obstructive reflux nephropathy (posterior urethral valves). I first started dialysis, then known as Continuous Ambulatory Peritoneal Dialysis (CAPD) at the age of 12 — then the youngest in the Australian Capital Territory. I have been the recipient of two living related donor transplants, the first in 1987 and again in 2002. In March 2013 I again commenced haemodialysis and await my third kidney transplant.

I am an active community volunteer, having been Chair of the Donate Life Principal Advisory Committee and the transplant consumer representative on the Renal Advisory Meeting (RAM). I am a Community Member of the National Medical Board of Australia and of the ACT Board of the National Medical Board of Australia.

I work for the Department of House of Representatives Committee Office. He is the Principal Research Officer/Inquiry Secretary for the Standing Committee on Education and Employment. He has previously worked for the Parliamentary Joint Committee on Intelligence and Security (PJCIS) and the Defence sub-committee of the Joint Standing Committee on Foreign Affairs, Defence and Trade.

I have Degrees in Arts (Honours in Political Science), Asian Studies and Law from the Australian National University. He also has Graduate Diplomas in Applied Finance and Investment and Financial Planning from the Securities Institute of Australia.

Chronic Kidney Disease[4]

Chronic Kidney Disease (CKD) is a significant and growing public health problem, responsible for substantial burden of illness and premature mortality.

HOW MANY PEOPLE HAVE CKD?

- Approximately 1.7 million Australians (1 in 10) aged 18 years and over have indicators of CKD such as reduced kidney function and/or the presence of albumin in the urine[1].
- Less than 10% of the people with CKD are aware they have this condition[2].
- This means over 1.5 million Australians are unaware they have indicators of CKD.

WHO IS AT INCREASED RISK OF CKD?

- 1 in 3 Australians is at an increased risk of developing CKD[3].

- Adult Australians are at an increased risk of CKD if they:
    - have diabetes
    - have high blood pressure
    - have established heart problems (heart failure or heart attack) and/or have had a stroke
    - have a family history of kidney disease
    - are obese (Body Mass Index BMI - more than or equal to 30)
    - are a smoker
    - are 60 years or older
    - are of Aboriginal or Torres Strait Islander origin

WHAT CAUSES KIDNEY FAILURE?

Data from the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry shows that the three most common causes of kidney disease requiring renal replacement therapy (dialysis or transplant) in Australia in 2013 were diabetes (35%), other (26%), hypertension (14%) glomuleronephritis (inflammation of the kidney) is unchanged at 19%[4].

WHY WORRY ABOUT CKD?

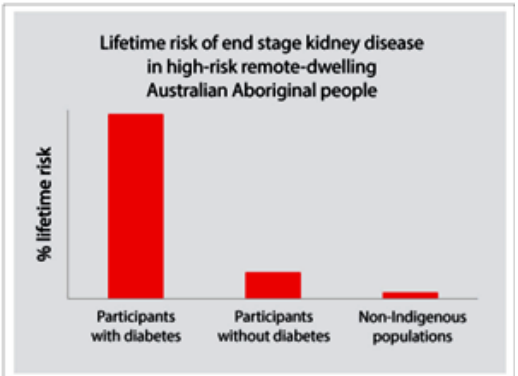
In Australia, CKD is:

- Common
    - 10% of people attending general practice have CKD, but most do not know it.

[4] The information in this section is taken from http://www.kidney.org.au/KidneyDisease/FastFactsonCKD/tabid/589/Default.aspx (footnotes omitted) accessed on 23 July 2015.

  - 42% of people over 75 years of age have an indicator of CKD.
- Harmful
  - People with CKD have a 2 to 3-fold greater risk of cardiac death than people without CKD.
  - For people with CKD, the risk of dying from cardiovascular events is 20 times greater than the risk of requiring dialysis or transplantation.
- Treatable
  - If CKD is detected early and managed appropriately, then the otherwise inevitable deterioration in kidney function can be reduced by as much as 50% and may even be reversible.

KIDNEY DISEASE AMONG ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE



- In 2012-13 almost 1 in 5 (18%) Aboriginal and Torres Strait Islander people aged >18 years had indicators of CKD.
- After adjusting for age differences, Aboriginal and Torres Strait Islander people were more than twice as likely as non-Indigenous people to have indicators of CKD. They were 3 times as likely to have indicators of Stage 1 CKD, and more than 4 times as likely as non-Indigenous people to have indicators of Stage 4-5.
- The incidence of end stage kidney disease for Indigenous peoples is especially high in remote and very remote areas of Australia, with rates almost 18 times and 20 times those of comparable non-Indigenous peoples.
- Around 9 in 10 Aboriginal and Torres Strait Islander people with signs of CKD were not aware they had it.
- Although Aboriginal and Torres Strait Islander people represent less than 2.5% of the national population, they account for approximately 9% of people commencing kidney replacement therapy each year.
- Aboriginal and Torres Strait Islander people are almost 4 times as likely to die with CKD as a cause of death than non-Indigenous Australians.

Treatment for Kidney Failure[5]

Most recent data from Australia & New Zealand Dialysis & Transplant (ANZDATA) Registry[4, 12] shows:

[5] The information in this section is taken from http://www.kidney.org.au/KidneyDisease/FastFactsonCKD/tabid/589/Default.aspx (footnotes omitted) accessed on 23 July 2015.

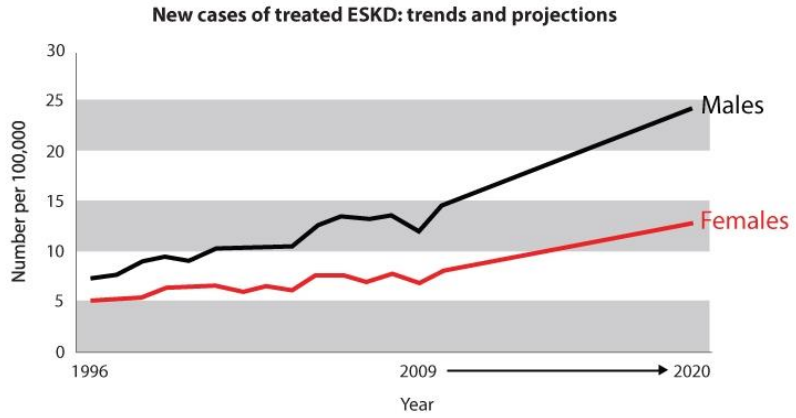
- 2,544 people started kidney replacement therapy (dialysis or transplant) in 2013.
- 21,470 people were receiving renal replacement therapy - dialysis or kidney transplantation - at the end of 2013. This represents a 4% increase from 2012.
- 21% of people who begin kidney replacement therapy are referred 'late' to a nephrologist - i.e. less than 3 months before beginning kidney replacement therapy.
- In Australia, late referral is more common among people of Pacific Islands (29%), Indigenous Australian (29%) or Maori (26%) origin, compared with the Caucasian population (22%).

Dialysis

- 11,774 people were receiving dialysis treatment at the end of 2013[4].
- This presents an increase of 3% from 2012.
- Of all people on dialysis, 29% dialyse at home.
- Dialysis treatments at the end of 2013:
  - 7% use Continuous Ambulatory Peritoneal Dialysis
  - 12% use Automated Peritoneal Dialysis
  - 9% use Home Haemodialysis
  - 71% use satellite or hospital dialysis
- In 2013, home dialysis as a percentage of all dialysis was 31% in Queensland 36% in New South Wales, 21% in the Australian Capital Territory, 25% in Victoria, 26% in Tasmania, 21% in South Australia, 13% in the Northern Territory, and 23% in Western Australia.

Transplantation

- 905 kidney transplant operations were performed in Australia in 2014[13].
- A total of 9,696 Australians were alive as a result of a functioning kidney transplant at the end of 2013 - this represents a 4% increase from 2012.
- As at April 2015 - 1,142 people were waiting for a kidney transplant in Australia[13].
- 73% of people on the waiting list are aged less than 60 years, and 79% are waiting for their first transplant.
- The average waiting time for a transplant is about $3^{1/2}$ years, but waits of up to 7 years are not uncommon[14].
- The survival rate following a kidney transplant is high - 98% of recipients are alive at 1 year and 89% are alive at 5 years.
- In 2014 there were 378 deceased organ donors in Australia, who saved or improved the lives of 1,117 people.
- The number of deceased organs in 2014 was 3% lower than that achieved in 2013.
- There were 268 live kidney donations in 2014, a 7% increase on 2013[16].



Graphic of existing (and projections for 2009 to 2020) for End Stage Kidney Disease in Australia

THE COST TO THE AUSTRALIAN HEALTH SYSTEM

- The best available evidence[17] we have on cost per person per year on dialysis is:
  - Hospital or unit-based haemodialysis - $79,072
  - Satellite Haemodialysis - $65,315
  - Home haemodialysis - $49,137
  - Peritoneal Dialysis - $53,112
- The costs of treating end-stage kidney disease from 2009 to 2020 is estimated to be around $12 billion to the Australian Government.
- Increasing the use of Home Dialysis over the next 10 years is estimated to lead to net savings of between $378 and $430 million for the health system.
- Kidney disease contributes to approximately 15% of all hospitalisations in Australia.

HOW MANY PEOPLE DIE FROM KIDNEY FAILURE?

The most recent data available from the Australian Bureau of Statistics[18] show:

- Around 56 people die every day with kidney related disease.
- Kidney-related disease kills more people each year than breast cancer, prostate cancer or even road traffic accidents.
- In 2013, diseases of the kidney and urinary system were the 11th leading cause of death in Australia with 2,987 deaths.
- Diseases of the kidney and urinary tract contributed to approximately 14% of all Australian deaths.
- Globally, the number of deaths where CKD is the underlying cause of death increased by 82% from 1990 to 2010. This is likely to be an underestimate as the cause of death data does not reliably capture death due to earlier stages of CKD[19].

For individuals with kidney failure, palliative care can provide support with symptom management, advance care planning, psychological support and education for both patients and their families

In Australia:

- Kidney failure (as a principal or additional diagnosis) is the 3rd most common cause of palliative care-related hospital separations (behind secondary cancer and lung cancer).
- Kidney failure as the principal diagnosis accounts for 36% of all palliative care patient deaths.

Kidney Transplantation is the best treatment for Chronic Kidney Disease – but it is still a treatment not a cure

Having been on dialysis and having had a kidney tranmsplant I can attest to the fact that Kidney transplantation is the best treatment for chronic kidney disease. But it is still a treatment not a cure. The article *Kidney Transplantation as Primary Therapy for End-Stage Renal Disease: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDOQI™) Conference* states that:

> Kidney transplantation is the most desired and cost-effective modality of renal replacement therapy for patients with irreversible chronic kidney failure (end-stage renal disease, stage 5 chronic kidney disease).[6]

Australian's were promised that Australia would become a "world leader in organ donation for transplantation"

On 2 July 2008 in a Joint Media Release between Prime Minister Rudd and Health Minister Roxon the following statement was made:

> The Rudd Government today proposed a major new national reform package to establish Australia as a world leader in organ donation for transplantation.[7]

Section 12 (b) of the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth)* states that the CEO must have regard to:

> International best practice;[8]

[6] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2390948/ accessed on 23 July 2015.
[7] See http://pandora.nla.gov.au/pan/79983/20080812-0001/www.pm.gov.au/media/Release/2008/media_release_0340.html accessed 29 June 2015.
[8] *Australian Organ and Tissue Donation and Transplantation Authority Act 2008 (Cth)*, s 12(b) http://www5.austlii.edu.au/au/legis/cth/consol_act/aoatdataa2008687/s12.html accessed 29 June 2015.

The Organ and Tissue Authority are not even aiming for world's best practice!

Donors per million of population are barely moving. The figures, from the International Registry in Organ Donation and Transplantation International[9] are as follows:

- 2008: 12.10;
- 2009: 11.40;
- 2010: 14.0;
- 2011: 15.10;
- 2012: 15.60;
- 2013: 16.90; and,
- 2014: 16.10.

Remember, being a world leader would mean a donation rate of 35 donors per million. We are currently achieving less than half of the original goal, at 16.10. Fair enough you might say, but what standard does the OTA hold itself to?

The June 2015 communiqué of the Advisory Council states that:

> Members agreed that the 2014-18 Strategic Plan, focussing on increasing the number of potential donors and increasing the consent rate, provides the appropriate direction for the OTA, in partnership with state and territory governments and other key stakeholders, to achieve the agreed indicative donation target of 25 donors per million population by 2018.

So the Authority set up to drive a leading practice reform program doesn't hold itself to being a world leader. Even if we accept 25 donors per million as an appropriate target, after more than six years and $250 million spent, the rate has improved by only four donors per million. Even the reduced targets require an improvement of nine donors per million in 3 years when the figures show that, using the current management and implementation practices, our donation rate has actually declined over the past year.

[9] See http://www.irodat.org/?p=database&c=AU%20-%20data accessed 23 July 2015.

International data – shows that after 6 years and a quarter of a billion dollars spent Australia is not a world leader

The following pages' data is taken from ANZOD Registry, 2014 Annual Report, Chapter 2: International Data. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2014. Available at: http://www.anzdata.org.au

As the data shows, in relation to kidney donation, Australia lags behind its international counterparts Croatia, Spain, Austria, Norway etc. The following analysis of all organ donation – including graphs - from ShareLife is instructive:

- Globally organ donation rates are measured in Donors Per Million of Population (DPMP) as this takes into account changes in population over time. Leading Performance is 35 DPMP. By the end of 2014 Australia was performing at 16.1 DPMP, only 46% of world leading practice.
- Australia is currently ranked 20th in the world and is projected to fall even further in the next global ranking. If we had reached leading performance as intended, around 1100 more lives could be saved each year.
- The gap between Australia's performance and leading performance has only been closed by 8.7% over six years, even though an unprecedented $240 million has been spent. This is a very poor return on investment; one that results in the needless suffering and loss of life of over 1000 Australians each year.
- Over the period from 2008 to 2013, Australia's number of organ donors per million population only increased by 4.8 whereas other countries such as Croatia, Belarus and Malta increased by more than 10.[10]

[10] See http://www.sharelife.org.au/australian-organ-donation-comparison accessed 29 June 2015.

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International comparisons

International Kidney Transplantation from Deceased Donors (Per Million Population)

Figure 2.6

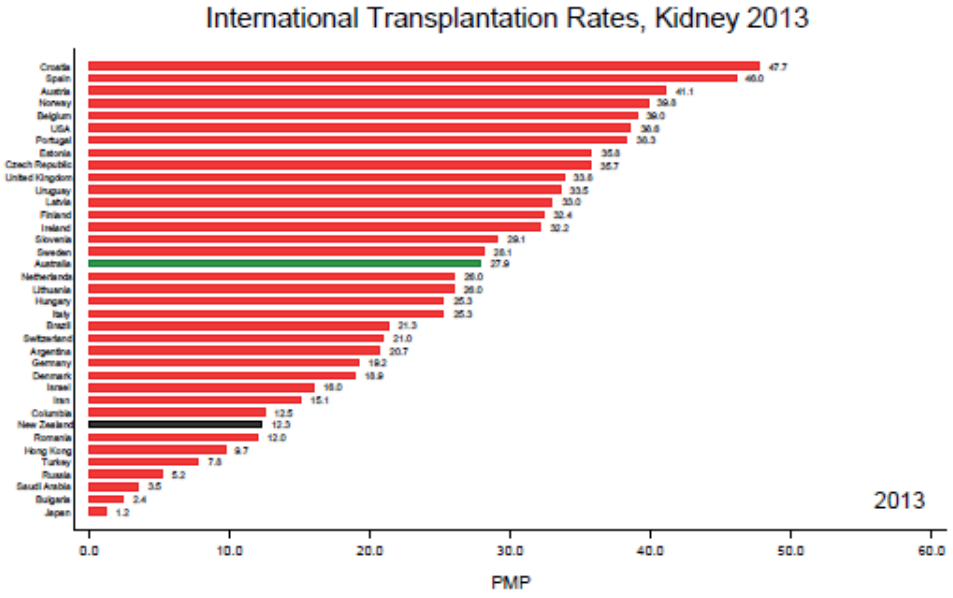
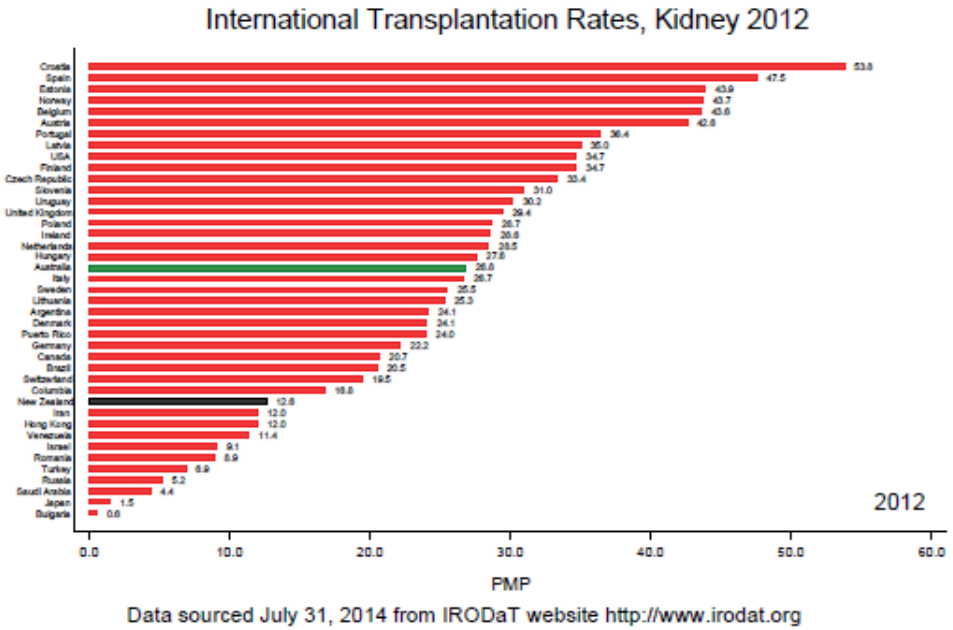


Figure 2.7



Data sourced July 31, 2014 from IRODaT website http://www.irodat.org

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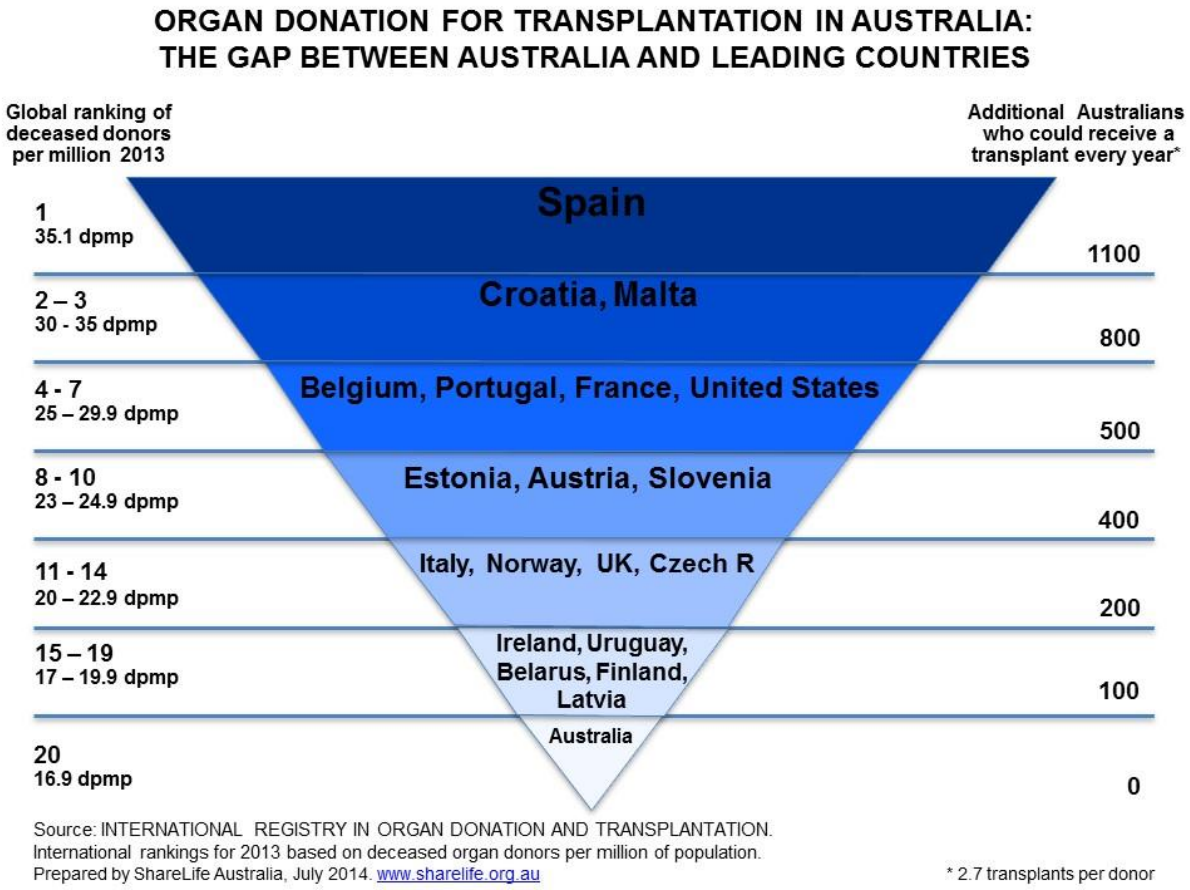

Source: http://www.sharelife.org.au/graphs/donation-triangle-2014b2.jpg

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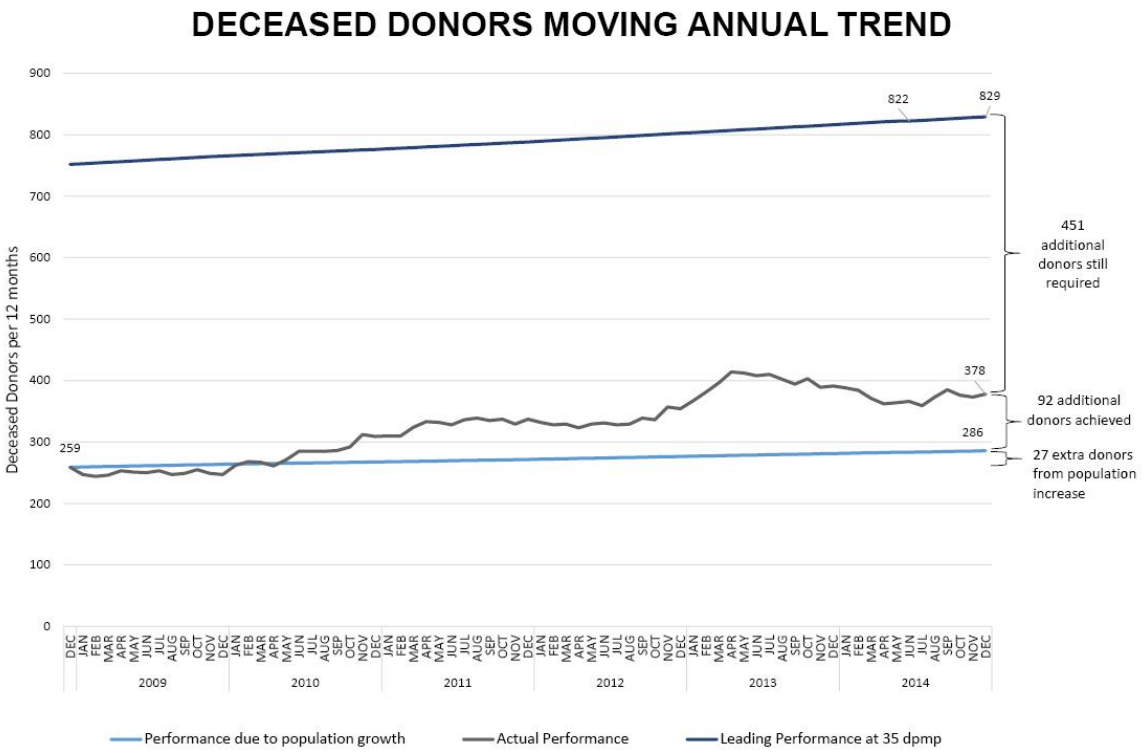
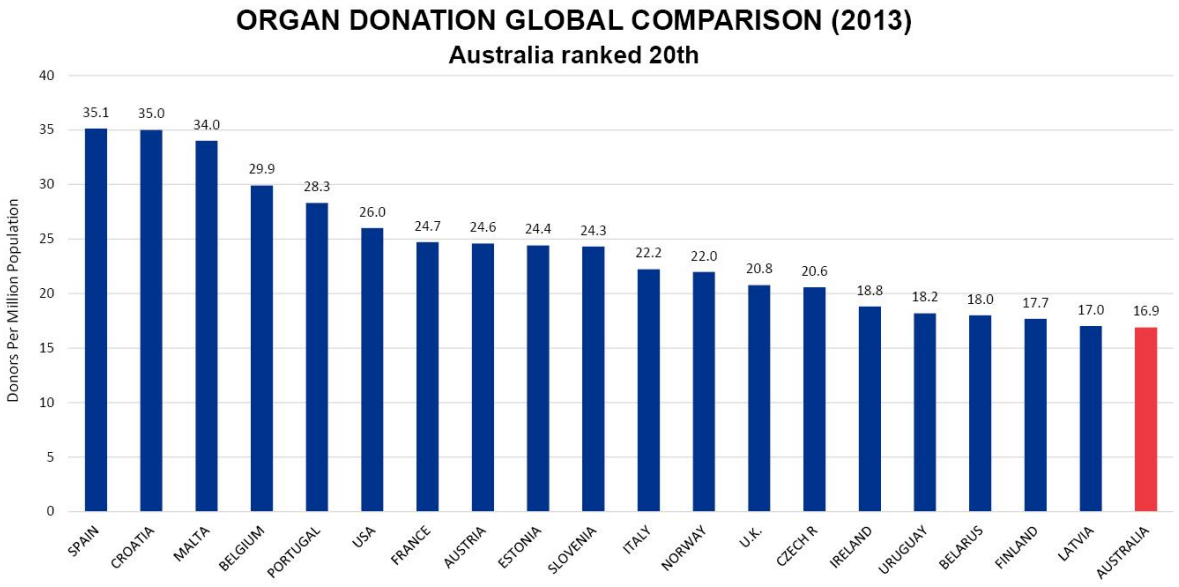


Source: http://www.sharelife.org.au/graphs/deceased-donors-trend-2014.jpg



Source: http://www.sharelife.org.au/graphs/global-comparison-2013.jpg

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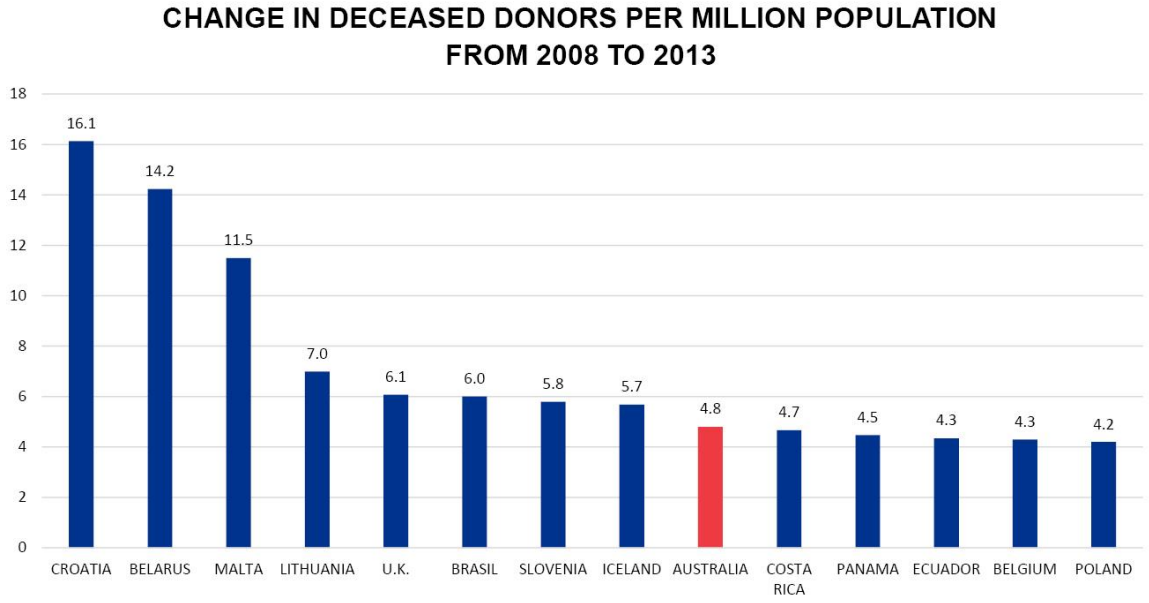

Source: http://www.sharelife.org.au/graphs/change-in-deceased-donors-2013.jpg

The wait for a kidney transplant in Australia

Kidney Health Australia state that:

> The average waiting time for a transplant is about $3^{1/2}$ years, but waits of up to 7 years are not uncommon.[11]

AOTA's website, referring to all organs, states:

> Waiting times depend on the availability of suitable donated organs and the allocation of organs through the transplant waiting lists. While this is usually between six months and four years, it can be even longer.[12]

BetterHealth Victoria (last reviewed January 2015), in relation to kidney transplants, states:

> The average wait for a kidney from a deceased donor is three and a half years.[13]

HealthDirect.gov.au states that:

> The national average waiting time for a kidney transplant is three and a half years – meaning many Australians have to rely on regular dialysis to survive, which can have a dramatic impact on their ability to work, care for their families and travel.[14]

The above quote is in the context of an article that is headed 'Kidney donation rates rise across Australia'.

Having done quite a bit of research to find the waiting times for an organ, particularly a kidney, I have found little data on this topic. Indeed, a search of AOTA's Annual Report for 2013-2014[15] shows many instances of discussion of 'waiting list(s)' but no discussion of *waiting times*. Obviously any waiting time would be an average but it should be easily captured data taking the time from a person being put onto the waiting list to when they received their organ. Although globally organ donation rates are measured in Donors Per Million of Population (DPMP) as this takes into account changes in population over time patients are more interested in the time it would take for them to actually receive their organ – although this would, necessarily, be an average time it would be useful.

[11] See http://www.kidney.org.au/kidneydisease/fastfactsonckd/tabid/589/default.aspx accessed 25 June 2015.
[12] See http://www.donatelife.gov.au/discover/about-transplantation accessed 25 June 2015.
[13] See http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Kidneys_-_dialysis_and_transplant accessed 26 June 2015.
[14] See http://www.healthdirect.gov.au/news/kidney-donation-rates-rise-across-australia accessed 26 June 2015.
[15] See http://www.donatelife.gov.au/sites/default/files/2013-%202014%20OTA%20Annual%20Report.pdf accessed 26 June 2015.

Finding: Although globally organ donation rates are measured in Donors Per Million of Population (DPMP) as this takes into account changes in population over time patients are more interested in the time it would take for them to actually receive their organ – although this would, necessarily, be an average time it would be useful.

Recommendation 1 – That the Australian Organ and Tissue Authority, or appropriate data collection agency(ies) collect and publicly report data on exact waiting times between being placed on an organ waiting list and receipt of the needed organ.

The wait for a kidney transplant in Spain

As with Australia I could find little actual data on the waiting times for a kidney transplant in Spain. Though, as we know, it is much less than in Australia.

In an article in a Canada online paper 'thestar' Spanish Kidney Specialist Dr Rafael Matesanz discussed Spain organ donation regime. The article, published on September 30 2013, went on to state:

> Spain now has a donor rate approaching 35 per million, and performs 2,600 kidney transplants a year. Many Ontarians wait up to 10 years for a kidney; in Spain the average wait is less than eight months.[16]

The website 'txmultilisting' states as follows:

> Spain: world transplant leader
>
> Spain improved its transplantation system in 1992 after Spanish protested long waiting queues. Today, Spain continues to hold its position as leading country for providing organ donations despite cuts to healthcare spending and the economic crisis, which makes this achievement even more commendable.
>
> - Transplant coordinators in each hospital
> - Proactive approach with trained hospital coordination team
> - **Cadaveric Transplant Wait Time - under 8 months**
> - Very few living donors used
> - Highest donation rate
> - Presumed consent ('opt-out' system)[17]

[16] See http://www.thestar.com/life/health_wellness/2013/09/30/what_spain_can_teach_us_about_the_gift_of_life.html accessed 26 June 2015.
[17] See http://www.txmultilisting.com/waiting-times-worldwide.htm accessed 26 June 2015. Emphasis is mine.

It is very clear that Spain has a much lower waiting time for people wishing to receive a kidney transplant.

Finding: Australia's average wait for a kidney transplant is 3.5 years – with many people waiting much longer whilst Spain's average is 8 months. This is unacceptable.

Croatia

The article *Development of the Croatian model of organ donation and transplantation*[18] states that:

> During the past ten years, the efforts to improve and organize the national transplantation system in Croatia have resulted in a steadily growing donor rate, which reached its highest level in 2011, with 33.6 utilized donors per million population (p.m.p.). Nowadays, Croatia is one of the leading countries in the world according to deceased donation and transplantation rates. Between 2008 and 2011, the waiting list for kidney transplantation decreased by 37.2% (from 430 to 270 persons waiting for a transplant) and the median waiting time decreased from 46 to 24 months.[19]

The authors go on to state:

> Remarkably, only one decade ago, Croatia was lagging far behind other European countries with a low donation rate (2.7 donors per million population [p.m.p.] in 2000). The continuous improvement of the organization of the Croatian transplant program resulted in a steadily growing donor rate, which reached the highest level in 2011, with 33.6 utilized donors p.m.p[20]

The article points out that a:

> crucial step in the Croatian transplant program was the appointment of hospital transplant coordinators in 1999 and the national transplant coordinator in 2000 (located at the Ministry of Health). In the following years, the national coordinator formed a coordination team at the Ministry to attend the 24-hour duty desk, supporting the hospital coordinators and procurement teams. The hospital coordinator network consists of 30 in-house coordinators, intensive care specialists working in university and general hospitals all over the country. Hospital coordinators are under the direct supervision of the hospital medical

[18] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf accessed on 29 June 2015
[19] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf p. 1, accessed on 29 June 2015.
[20] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf p. 1, accessed on 29 June 2015.

> director, but maintain their independence within the hospital. The hospital transplant coordinator reports potential organ donors to the national coordination office, which facilitates and coordinates the donation process and international cooperation. This has eliminated many obstacles and made the process more efficient compared to the time when the local transplant team was in charge of procurement management and organ allocation.[21]

The article goes on to conclude that:

> The key factors that have contributed to the development of a "successful model for organ donation and transplantation" in Croatia in the past decade are the appointment of hospital and national transplant coordinators, the establishment of a 24 hour duty desk at the Ministry of Health, and the implementation of a new financial model with donor hospital reimbursement.[22]

And:

> The Croatian transplant program has resulted in a steep increase in organ donation and transplantation rates. These extraordinary results are primarily a consequence of a **successful organizational model for organ donation and transplantation**, the diligent work of devoted and enthusiastic healthcare professionals, respect for bioethical principles, and public solidarity and awareness of the benefits of organ transplantation.[23]

Something is clearly not being done in Australia

If we take the beginning of the reform agenda in Australia as being from 2009 we are now 5 years (heading into our 6th year) of the reform agenda – clearly, given the gap between Spain, Croatia and Australia (as one example), there must be something that Australia is not doing that is being done in Croatia and Spain.

Finding: Clearly, in relation to organ donation, Croatia and Spain are doing something that Australia is not. We should learn from Croatia and Spain.

[21] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf p. 2, accessed on 29 June 2015.
[22] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf p. 5-6, accessed on 29 June 2015.
[23] See http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3610255/pdf/CroatMedJ_54_0065.pdf p. 6, accessed on 29 June 2015. (emphasis is mine)

Why are Croatia and Spain so much better?

This, of course is the big question. One suggestion is as follows:

> In Spain, there are dedicated transplant co-ordinators in every hospital. Amid the chaos and bewilderment of sudden loss, this co-ordinator is in place to give relatives the opportunity to consider whether organ donation would offer them comfort or spiritual solace in the face of overwhelming grief. A moment to consider the values, the legacy, of the deceased.[24]

This is echoed by AOTA's document 'International approaches to donation reform':

> The role of a Transplant Coordinator in Spain is unique in that it was conceived to facilitate early identification and referral of possible donors. Transplant Coordinators are professional staff members of a specific procurement hospital and are appointed by, and report to, the medical executive of the hospital, rather than the transplantation team. The majority of Transplant Coordinators in Spain are critical care physicians (intensivists), so their daily work is carried out in units where a large number of potential donors are realised. The transplant coordinators are supported in their role by nurses.[25]

The Sydney Local Health District *Organ Donation for Transplantation Plan 2014-2017* points out that in Spain:

> Within each hospital, specific organ transplant units operate on-call under the direction of designated organ transplant coordinators, all hospitals in Spain have intensivists full/part-time **dedicated to organ donation**.[26]

Indeed the National Reform Programme states:

> Evidence from comparable countries demonstrates that a coordinated national approach, focused on clinical practice reform, improves organ donation and transplantation rates.[27]

And sets out as one of its key elements as:

> Establish specialist hospital staff and systems dedicated to organ donation;[28]

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[24] See http://www.theguardian.com/society/2009/sep/13/organ-donation-transplant-waiting-list accessed on 26 June 2015.
[25] http://www.donatelife.gov.au/sites/default/files/files/OTA_Fact_Sheets_-_International_approaches_to_organ_donation_reform_November_2013.pdf accessed 26 June 2015.
[26] See http://www.slhd.nsw.gov.au/planning/pdf/OrganDonationPlan2014_2017.pdf p. 2 accessed 29 June 2015 (emphasis is mine).
[27] See http://www.health.gov.au/internet/main/publishing.nsf/Content/review-of-organ-and-tissue-donation accessed 29 June 2015.

Advertising is not the best use of money

DonateLife spends a lot of time and money on 'generating media attention'[29]

As early as July 9 2008 Dr Rafael Matesanz, director of Spain's National Transplant Organisation was quoted as follows:

> To make publicity campaigns and to spend a lot of money on campaigns, I cannot say that that's not good, but maybe it's not the best way to spend money[30]

Indeed a formal study *Decrease in refusals to donate in Spain despite no substantial change in the population's attitude towards donation* echoes the above remarks by Dr Matesanz:

> Decreasing refusals to donate has been addressed through expensive promotional campaigns with little, if any, demonstrated impact on the attitude of the population or the rate of refusals.[31]

One article addresses this 'blaming' of the population in relation to organ donation and point out that this is not done in Spain:

> The skill and knowledge required by the health care team in identifying, requesting and responding to offers of donation is vitally important to increasing organ donation rates. As the head of Spain's world-leading organ donation organisation recently said:
>
> > *We never blame the population. If people donate less, it must be something we have done wrong.*[32]

Dedicated transplant coordinators who are doctors is key

From the above it is submitted that dedicated transplant coordinators, with no other task than assessing potential donors and having an appropriately empathetic discussion with relatives is the key to increasing Australia's organ donation rate. This was known as far back as 2007 as the article *Strategies to optimize deceased organ donation* concludes:

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[28] See http://www.health.gov.au/internet/main/publishing.nsf/Content/review-of-organ-and-tissue-donation accessed 29 June 2015.
[29] See http://www.anao.gov.au/~/media/Files/Audit%20Reports/2014%202015/Report%2033/AuditReport_2014-2015_33.pdf p. 22 [29] accessed 29 June 2015
[30] See http://www.theaustralian.com.au/archive/news/ads-not-the-answer-for-organ-donor-scheme/story-e6frg8gf-1111116861246 accessed 29 June 2015.
[31] See http://www.ont.es/publicaciones/Documents/Articulos/2010/Organtissuesandcells2010.pdf accessed 29 June 2015.
[32] See http://theconversation.com/dont-blame-families-for-low-organ-donation-rates-fix-the-system-42476 quoting http://www.newsweek.com/2015/02/20/spain-has-become-world-leader-organ-donations-305841.html accessed 29 June 2015.

> An adequate organization seems to be the clue to increase deceased donation activity in a sustained way. Organization is in fact the whole philosophy of what it has been internationally known as the Spanish Model of Organ Donation, a model that has led Spain in an outstanding position when referring to deceased donation. The figure of the transplant coordinator, the central office in support of all the process of organ donation, great effort in training and education, close attention to the media, and reimbursement to the hospitals are the measures that, altogether and appropriately integrated, constitute this model. If some basic conditions exist, the Spanish Model of Organ Donation can be successfully reproduced in other countries or regions in the world.[33]

The Sydney Local Health District's Royal Prince Alfred Hospital (RPA) has appointed:

> a **Director of the Organ Donation for Transplantation Unit at RPA** who will report to the Chief Executive of SLHD through the Executive Clinical Director of RPA. This new position, in partnership with the University of Sydney, will be a clinical academic who will provide leadership in the development of best practice organ donation within RPA.[34]

A review of AOTA Annual Report for 2013-14 shows very little mention, beyond mention of 'The Australian Transplant Coordinators Association' of what is being done to put in place the dedicated coordinators as described above. It is clear that these coordinators should be trained doctors who have no other task other than that described above.

The Australian National Audit Office, Report No.33, 2014–15, *Performance Audit Organ and Tissue Donation: Community Awareness, Professional Education and Family Support, Australian Organ and Tissue Donation and Transplantation Authority*, April 2015 stated that:

> OTA acknowledged that it needed to reinforce its expectation that relevant staff undertake the FDC training and adopt the FDC model when seeking consent from families. While the FDC Workshops promote the collaborative requesting model14, it was only used in 16 per cent of cases where consent was sought from families for donation in 2013.[35]

Recommendation 2: Transplant Coordinators should be trained doctors who have no other task than assessing potential donors and having an appropriately empathetic discussion with relatives of potential donors.

It seems clear that Australian Transplant Coordinators cannot be working in the same cultural context (as in organisational culture) as their counterparts in Spain. This should be investigated at a

[33] See http://www.ont.es/publicaciones/Documents/Articulos/2007/RM-TX%20REVIEWS-STRATEGIES%20OPTIM.pdf accessed 29 June 2015.
[34] See http://www.slhd.nsw.gov.au/planning/pdf/OrganDonationPlan2014_2017.pdf p. 10, (emphasis in orginal).
[35] See http://www.anao.gov.au/~/media/Files/Audit%20Reports/2014%202015/Report%2033/AuditReport_2014-2015_33.pdf p. 19 accessed 29 June 2015 – FDC is 'Family Donation Conversation'.

granular level. Ernst and Young, the Australian National Audit Office or other appropriate body should assess Australia's Transplant Program from the point a possible donor reaches hospital through to the discussion had with families then to the point of donation. They should ensure that there are dedicated (ie: with no other role/tasks) doctors assessing and referring patients to organ donation.

Recommendation 3: Ernst and Young, the Australian National Audit Office or other appropriate body should assess Australia's Transplant Program from the point a possible donor reaches hospital through to the discussion had with families then to the point of donation. They should ensure that there are dedicated (ie: with no other role/tasks) doctors assessing and referring patients to organ donation.

Robert Little: Submission to House of Representatives *Inquiry into Chronic Disease Prevention and Management in Primary Health Care*

Possible changes to the National Healthcare Agreement: Intergovernmental agreement on Federal Financial Relations[36]

The National Healthcare Agreement: Intergovernmental agreement on Federal Financial Relations:

> encompasses the collective aspirations of Commonwealth, State and Territory governments on prevention, primary and community care, hospital and related care and aged care.[37]

The Agreement has a list of *outcomes* and *performance indicators* and lists the national minimum data sets (NMDS) that the Parties agree will continue to be collected under this Agreement and which will contribute to the reports listed below.

Organ donation is not listed as an outcome or a data set within the Agreement.

Suggested changes (in **bold**) to the Agreement, to be tabled by the Australian Government, would be as follows:

Outcome	**Performance Indicator**
Better Health Services	
3. Australians receive appropriate high quality and affordable hospital and hospital related care	Waiting times for elective surgery Waiting times for emergency hospital care Healthcare associated infections Unplanned hospital readmission rates Survival of people diagnosed with notifiable cancers Rate of community follow up within first seven days of discharge from a psychiatric admission **Organ donation (donors per million)**

Section 18 of the Agreement states:

> Improvements in performance will be demonstrated by progress against the following performance benchmarks, which were agreed by COAG in November 2008:

Under the heading 'Better Health Services' following (g) insert as follows:

> (h) Organ donation rates to be over 30 donors per million by 2018-19.

[36] NB: I have shared this section with ShareLife – it may also be in their submission.
[37] http://www.federalfinancialrelations.gov.au/content/npa/healthcare/national-agreement.pdf p. A - 3 [10]

The DonateLife website contains no data on donation rates

In looking at the DonateLife website I notice that it contains no data on organ donation rates. It has links to ANZDATA and ANZOD, which are hard to find – they are buried in the site. One would have thought that an organisation 'dedicated' to increasing the organ donation rate would have a section on their performance.

The DonateLife has no section for those waiting for an organ

The DonateLife website has the following section:

- About Us
- For Donor Families
- For Health Professionals
- News & Events
- Publications
- For the Community

What is immediately apparent is that there is no section for those waiting for a transplant which could be called "Awaiting a Transplant". I think this shows that AOTA/DonateLife is so bureaucratic that they have lost sight of the people they have been set up to help.

Recommendation 4: The DonateLife website should have a clear section on organ donation rate, including in comparison with other leading nations and should have a section for those "Awaiting Transplant".