

REVIEW OF HUMAN TISSUE LAWS

Issues Paper 51

May 2025

RESPONSE TO ISSUES PAPER

Submission by Brian Myerson OAM

Director, ShareLife Australia Limited

1. Introduction

ShareLife Australia Limited

ShareLife Australia was formed in 2006 by a group of eminent Australians with the goal of finding effective solutions to reform Australia's low rates of organ donation for transplantation. Many highly capable Australians have contributed time and expertise to ShareLife on a pro-bono basis to achieve success in finding and implementing a solution.

ShareLife's website is available here: <https://ShareLife.org.au/>

In May 2010, members of ShareLife were interviewed as part of a special feature for ABC Radio National's Health Report, regarding organ donations. A copy of that special feature and its transcript are available here: <https://www.abc.net.au/listen/programs/healthreport/organ-donations/3104784>

Brian Myerson OAM

I am the co-founder of ShareLife, and an organ transplant recipient. I was diagnosed with diabetes in 1963, and succumbed to diabetic nephropathy and required dialysis between 1996-1999. In June 1999, I received a kidney and pancreas from a deceased donor. My experiences during dialysis, with people dying and others becoming depressed due to a shortage of donated organs, led me to dedicate my efforts to saving many more lives of those suffering from organ failure.

In addition to my role with ShareLife, I am a member of the NSW IAG (Implement and Advisory Group) for NSW Health and a member of the Sydney Local Health District Organ Donation for Transplantation Steering Committee.

Overview

Thank you for the opportunity to bring my own and ShareLife's views to the attention of the Australian Law Reform Commission (**ALRC**) as part of the current review. ShareLife agrees that major changes in the Australian policy and regulatory landscape are desperately needed in order to fulfil the aim of Australia being a world leader in organ donation for transplantation.¹

ShareLife submits that the ALRC inquiry ought to encompass a review of the following matters:

- (a) the powers of the Organ and Tissue Authority, including powers to audit hospitals and health departments and hold them to account;
- (b) the role of the Organ and Tissue Authority in collecting data relating to organ donation for transplantation and reporting that data to Government and the public;

¹ See Appendix 1.

- (c) legal impediments to connecting organ transplant recipients with members of the family of deceased organ donors;
- (d) legislative impediments to effective organ donation, including the role of State and Territory coroners; and
- (e) Legislative impediments to organ donation registration

We set out our submissions in relation to these matters, along with my personal experience as an organ transplant recipient and advocate in this space below.

In the interest of meeting the response deadline, we have confined our discussion to the above matters. We welcome the opportunity to engage further with the ALRC following publication of the Discussion Paper. We would also be happy to meet with you to discuss the matters raised in this response.

2. Personal experience as an organ transplant recipient

2.1 Question 1 of the Issues Paper (IP) asks: *What is your personal experience of how human tissue is obtained or used in Australia?*

2.2 After 34 years of living with diabetes, my kidneys failed and I was placed on the waiting list for a kidney/pancreas transplant while on dialysis from November 1996 to June 1999. I received a kidney and pancreas on 19 June 1999. During my years on dialysis, I observed so many patients suffering and dying while hoping that their day would come to receive a transplant. After receiving my transplant, I was consumed by the very difficult and competing emotions of guilt and appreciation.

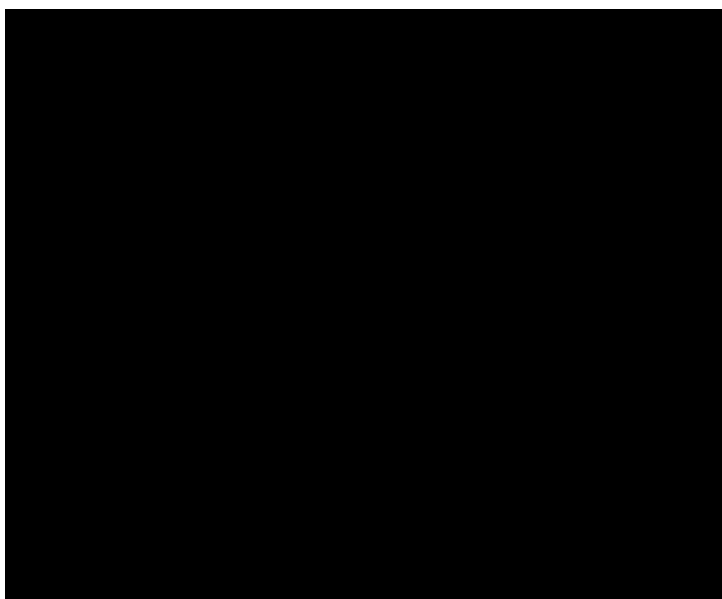
2.3 I could not rest until:

- (a) I personally thanked my donor's family.

Meeting my donor's family was one of the most wonderful and memorable experiences in my life. After an exhaustive search I met the family on 23 November 2012. I do not have the words to describe how special it has been developing a close relationship with them. I then met my donor's sister in 2015 which was recorded by the ABC.

http://mpegmedia.abc.net.au/news/730/video/201512/730s_OrganDonor_2212_1000k.mp4

Our relationship has gone from strength to strength and we have celebrated wonderful occasions together. On 19 June 2025, I celebrated my 26th transplant anniversary and I received this text message from my donor's sister:



'Hey Brian, I will always miss my brother and I'm very proud of the decision he made all those years ago. I'm so glad it was you and thrilled beyond words that you have been part of our life for all these years. You bring us lots of joy. X'

Denying donor families the opportunity to meet the recipients of their family member's organ donation, is simply cruel and heart-breaking for them. Some donor families, the heroes in this entire process, are severely hurt by the current practice of using threats of legislation to block any efforts made to connect despite a mutual desire to do so by many involved. Many countries now allow donor families and transplant recipients to meet, and it is our firm recommendation that Australia follow suit. In the UK it is a very simple process.²

- (b) I did whatever I can to increase the organ donation rate to improve and save the lives of those suffering from organ failure.

In 2003 I met Marvin Weinman and convinced him that we should work together to find a way to increase the organ donation rate. We then spent a number of years forming ShareLife and gathering a team to work on a solution for Australia's low organ donation rate. The then Governor General, Major General the Hon. Michael Jeffery AC, AO(Mil), CVO, MC and the International President of the Transplantation Society, Professor Alan Glanville were deeply committed to supporting this work amongst many others.

I was privileged to be one of the directors of ShareLife who approached the then Prime Minister, Kevin Rudd, in April 2008 with a detailed plan to set up an Australian version of the Spanish Model for organ donation.³ All our recommendations were accepted and we then spent the next few months working with the Health Minister Nicola Roxon's staff setting out the details. We were jubilant when on 2 July 2008, 'The Rudd Government today proposed a major new national reform package to establish Australia as a world leader in organ donation for transplantation.'⁴

- 2.4 Despite the establishment of the Organ and Tissue Authority and the allocation of significant funding, there has been limited improvement in organ donation rates in Australia. Data analysis in paragraph 4.5 and 4.6 along with Appendix 8 clearly shows that very little has been achieved in the years since 2008.

3. Audit and investigative powers of the Organ and Tissue Authority

- 3.1 The Organ and Tissue Authority (**OTA**) was established pursuant to *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth) (**OTA Act**).
- 3.2 The remit of the OTA is to improve organ and tissue donation and transplantation outcomes in Australia, including to implement an Australian version of the "Spanish Model" through the provision of funding to state and territory health departments, including for individuals to be employed as Donation Specialist Medical Officers (**DSMs**) and Donation Specialist Nurses (**DSN**). DSMs and DSNs work in 95 designated organ donation hospitals throughout Australia.
- 3.3 The functions of the OTA are set out in section 11(1) of the OTA Act. Notably, section 11(2) sets out Constitutional limits on the functions of the OTA.
- 3.4 Although the functions set out in section 11(1) of the OTA Act are broad in scope, the OTA has limited power to audit or investigate the state and territory health departments to ascertain precisely how the Commonwealth's funds are being spent, or to assess the performance of the DSMs and DSNs that are funded by the authority.
- 3.5 In early 2023, the Sydney Morning Herald reported on comments made by Professor Allan Fels (former chair of the National Mental Health Commission) ahead of a federal government round table discussion in relation to mental health.⁵ The SMH article stated:

...Fels warned there was little evidence about whether government funding for mental health was being used productively.

² See the email in Appendix 5.

³ An overview of the "Spanish Model" is available here: Streit, S., Johnston-Webber, C., Mah, J., Prionas, A., Wharton, G., Casanova, D., Mossialos, E., & Papalois, V. (2023). Ten Lessons From the Spanish Model of Organ Donation and Transplantation. *Transplant international : official journal of the European Society for Organ Transplantation*, 36, 11009. <https://doi.org/10.3389/ti.2023.11009>.

⁴ See Appendix 1.

⁵ Article available here: <https://www.smh.com.au/politics/federal/mental-health-commission-needs-authority-to-speak-freely-fels-20230126-p5cfmr.html>

"[The commission] should specify desirable outcomes such as measures of improved mental health, and then require the provision of information about how well those measures are being met," he said.

But he said it was failing to do so because it was not truly independent and lacked the legislated authority of entities such as the Productivity Commission or the Australian Competition and Consumer Commission, which Fels led for 14 years before chairing the mental health commission from its inception in 2012 until 2018.

"There's not a lot of confidence that the commissioners, acting as a commission, can speak freely and uninhibitedly. That is the key point," Fels said.

"The original concept [was] to set it up as an independent body that would hold the Commonwealth government to account and as a result enjoy the confidence of the community, especially the mental health community."

Fels said that had gradually changed since the mid-2010s as its independence was downplayed and it took on a more advisory function.

- 3.6 We submit that the OTA has similar problems to the National Mental Health Commission, and that in order to be effective, the OTA must:
- (a) function as an independent body, separate from the Commonwealth Department of Health, and state and territory health departments; and
 - (b) be empowered with statutory authority to hold the Department of Health and state and territory health departments to account in connection with the expenditure of Commonwealth funds, and whether measurable outcomes in relation to organ donation are being achieved in line with the Government and community's expectations.

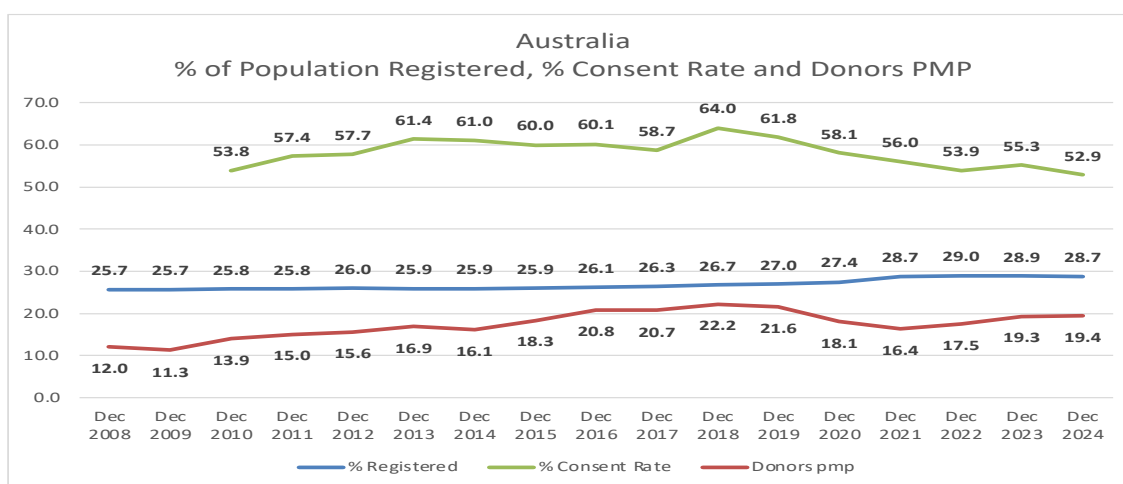
4. Data collection and reporting by the Organ and Tissue Authority

- 4.1 At every meeting that I have attended relating to organ donation held by all levels of Government, it is emphasised that the de-identified performance data from the OTA and the state based organisations is not for further distribution - the lack of transparency and accountability is deeply concerning for a publicly funded organisation. The politicians and the general public are intentionally being kept in the dark ensuring that there is no criticism of those managing the OTA and organ donation programs within hospitals and state health departments.
- 4.2 The OTA Act ought to be amended to include mandatory data collection, along with monthly and annual reporting obligations, for each of the 95 designated organ transplant hospitals in Australia, in relation to the following matters (at a minimum):
- (a) the total number of deaths per hospital;
 - (b) the total number of deaths in the emergency department per hospital;
 - (c) the total number of deaths in the intensive care unit per hospital;
 - (d) the total number of intubated deaths per hospital;
 - (e) the total number of potential organ donors per hospital;
 - (f) the total number of requests per hospital;
 - (g) the total number of consents per hospital;
 - (h) the total number of actual donors per hospital; and
 - (i) the total number of organs transplanted.
- 4.3 In my view, the collection and reporting of this data will increase transparency regarding the efficacy of organ donation transplant programs and the OTA. I note that such reforms were proposed in the *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation* released on 2 February 2016.⁶

⁶ See Appendix 7, Media Release – Minister Nash release independent organ donation and transplantation review.

- 4.4 I have conducted my own analysis of the limited publicly available data from the following sources:
- (a) Donatelife web site: <https://www.donatelife.gov.au>;
 - (b) Australian and New Zealand Organ Donation registry (ANZOD): <https://www.anzdata.org.au>;
 - (c) Australian Bureau of Statistics (ABS): <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0>;
 - (d) Services Australia: <https://www.servicesaustralia.gov.au/australian-organ-donor-register-statistics?context=22>
- 4.5 Based on my review of this data, it is reasonable to conclude that the OTA has had a negligible impact on the rate of organ transplantation in Australia.

Figure 1: Organ donors in Australia (percentage, per million population)



- 4.6 Figure 1 focuses on the three key measures that OTA is accountable for:
- (a) Donors per million population (**dpmp**).
This is the internationally accepted measure for organ donation comparison of countries' performance. Apart from the increase in Donation from Circulatory Death as shown in Appendix 8, there has been minimal increase in the organ donation rate per million population and the organ donation rate dpmp is currently less than it was in 2016.
 - (b) Percent of the Australian population registered as organ donors.
Apart from the large increase from June 2021 to February 2022 (which was a result that occurred independent of OTA), the increase in registered organ donors has been minimal. In 15 years, the proportion of individuals registering as organ donors has only increased from 25.7% to 28.7%, with almost half of that increase in 2021/2.⁷
 - (c) Percent consent rate for organ donation by families of potential organ donors.
The deceased donor consent rate is now lower than when OTA was established. For the last 6 years there has been a declining consent rate in Australia (54% in 2010, 64% in 2018 and 53% in 2024). This is despite a small increase in the registration rate, the increased number of staff, the training of staff and the funding of promotions for organ donation.

5. Connecting recipients with donor families

- 5.1 As discussed in section 2 above, the relationship that I have developed with the family of the person from whom I received the organ donation is one that has been extremely rewarding for me and them. However, transplant recipients are often actively discouraged from connecting with their donors' families, and individuals are denied the opportunity to develop these relationships.

⁷ See Appendix 2 for discussion regarding the impact of the COVID-19 Pandemic.

- 5.2 In my view, a clear and consistent approach that permits consenting transplant recipients and donor families to be put in contact with each other ought to be formally brought within the remit of the OTA.⁸ Such a process ought to include a process through which consent may be sought and obtained at a future point in time.
- 5.3 Creating and funding a formal process to seek and obtain consent of the individuals most affected by organ transplantation would take the pressure off healthcare practitioners and hospitals who are prohibited under privacy laws and the state and territory human tissue legislation from disclosing personal information about transplant recipients, organ donors and the organ donor's next of kin (without the consent of the transplant recipient or organ donor's next of kin).⁹
- 6. Removing legislative impediments to organ donation**
- 6.1 There are a number of legal impediments that can potentially prevent transplantation occurring. For example, section 25 of the *Human Tissue Act 1983* (NSW) provides:
- (1) If a coroner has jurisdiction to hold an inquest under the Coroners Act 2009 in respect of the death of a person, a designated officer for a hospital, a senior available next of kin or the principal care officer must not authorise the removal of tissue from the person's body unless a coroner has given consent to the removal of the tissue.*
- Maximum penalty—40 penalty units or imprisonment for 6 months, or both.*
- (2) A consent by a coroner under this section may be given before a person's death if the coroner reasonably believes the coroner will have jurisdiction to hold an inquest under the Coroners Act 2009 in respect of the person's death.*
- (2A) A consent by a coroner under this section may be withdrawn by the coroner at any time.*
- (3) If a coroner has jurisdiction to hold an inquest under the Coroners Act 2009 in respect of the death of a person to whom section 24(1) applies, the removal of tissue from the body of the person is not authorised unless a coroner has given consent to the removal of the tissue.*
- (4) A consent by a coroner under this section may be expressed to be subject to such conditions as are specified in the consent.*
- (5) A consent by a coroner under this section may be given orally and, if so given, is to be confirmed in writing as soon as practicable.*
- (6) A coroner shall, in determining the conditions (if any) to which a consent shall be subject, have regard only to the effect which the removal of tissue from the body of the person to whom the consent relates may have in relation to the conduct of any inquest which a coroner has jurisdiction to hold in respect of that person's death.*
- 6.2 If there is a delay in seeking or obtaining consent from the coroner, then the proposed organ or tissue recovery and transplant may not ultimately be able to proceed. While the jurisdiction of the coroner ought not to be usurped by the desire to make organs available for transplant, in my view additional mechanisms, including timing provisions ought to be built into the legislation. In Spain, for example, although similar provisions exist, there is a legislated requirement for the coroner to respond within 30 minutes of a request for consent. Without legislated intervention this ongoing problem will continue in Australia. The link to the two articles clearly shows why, without legislation, the loss of life saving organs for transplantation will continue.
<https://www.sciencedirect.com/science/article/abs/pii/S1752928X20300469?via%3Dihub> and
<https://www.sciencedirect.com/science/article/abs/pii/S1752928X20300469>

⁸ See Appendix 4 Letter to Andrew Bragg (Showing my request for support from my local Senator), Appendix 5 Email from Donor Family Care NHS UK (Showing how easy the process is for donor families and transplant recipients to meet) and Appendix 6 Senator Linda Reynolds' remarks during the debate on the Bill (Showing political support).

⁹ See, for example section 37 of the *Human Tissue Act 1983* (NSW).

7 Organ Donation Registration - Opt in vs Opt out

The current legislation is the worst of both as it combines Opt-in and Opt-out allowing individuals to opt-in or to opt-out. The analysis in Appendix 3 clearly shows that to date the net benefit of the current registration system is not clear and that there must be other more important factors influencing the consent rate and subsequent organ donation rate than the registration rate. We believe that a simple Opt-in should be legislated to appear on application forms for drivers licence. A simple question asking whether one wants to be registered as a donor on the register. If yes, one is registered and if no, one is not registered. South Australia driver's licence application form does exactly that:

“7. ORGAN DONATION – OPTIONAL QUESTION

ARE YOU PREPARED TO BECOME AN ORGAN DONOR? YES NO

If yes, an organ donor indicator will be shown on any photo learner's permit, P1 or P2 provisional licence or driver's licence issued and recorded on the department's database. Your details will be provided to the “Australian Organ Donor Register” who may contact you for further details.”



PRIME MINISTER

MINISTER FOR HEALTH AND AGEING

**PARLIAMENTARY SECRETARY TO THE
MINISTER FOR HEALTH AGEING**

\$136.4 million national plan to boost organ donation and save lives

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

Despite more than 90% of Australians supporting the idea of organ donation, Australia has a longstanding shortage of organs for transplantation.

To address this, the Government proposes a total Commonwealth funding package of \$151.1 million, including new funding of \$136.4 million over four years to boost the number of life-saving organ transplants for Australians.

This is an important development for the 1,800 Australians on transplant waiting lists.

The key features of the reform package include:

- **\$67 million** to fund dedicated organ donation specialist doctors and other staff in public and private hospitals;
- **\$46 million** to establish a new independent national authority to coordinate national organ donation initiatives.
- **\$17 million** in new funding for hospitals to meet additional staffing, bed and infrastructure costs associated with organ donation.
- **\$13.4 million** to continue national public awareness and education;
- **\$1.9 million** for counselling for potential donor families; and
- Other significant measures including enhanced professional education programs, consistent clinical protocols, 'clinical trigger' checklists and data collection for organ transplants in hospitals.

A new national organ donation and transplantation authority would be set up by 1 January 2009 to drive and oversee a comprehensive set of reforms outlined in the attached fact sheets.

The reform package will be proposed to the States and Territories at tomorrow's Council of Australian Governments' meeting.

The Rudd Government is confident that in the spirit of cooperation all states and territories will sign up to the new National Plan to Boost Organ Donation.

Transplantation is a highly successful treatment that transforms the lives of individuals and the families who care for them.

Australian families deserve the best organ donation and transplantation system in the world, but our current system falls short.

As a consequence of long waiting lists, Australians spend years with more costly treatments such as dialysis. This costs our hospitals \$83,000 per person per year, compared to the cost of a kidney transplant - \$65,000 per recipient for the first year and \$11,000 a year thereafter.

As Australia's population ages and more Australians are affected by lifestyle diseases such as obesity and diabetes, the demand for transplants will continue to grow.

The package developed has drawn together the best international evidence and practice, as well as the expertise of stakeholders such as the Transplantation Society of Australia and New Zealand, the Cognate Committee on Organ and Tissue Donation, and [ShareLife](#).

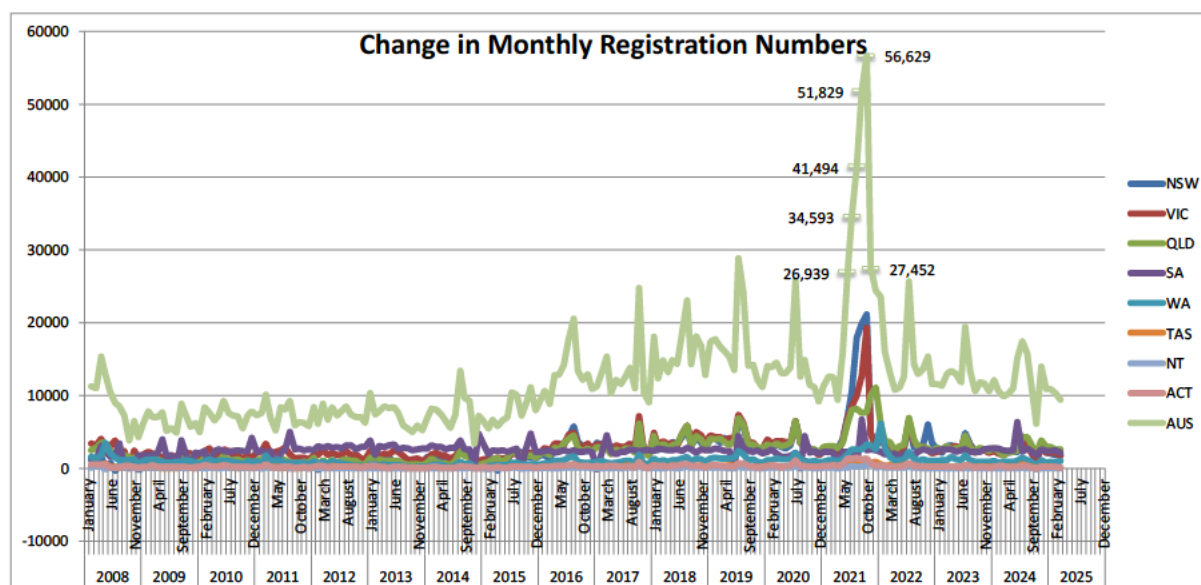
The package does not change the framework of legal consent for donation. The families of all potential donors will be supported to make the choice of whether to donate at what is a very difficult time.

The package continues the Rudd Government's commitment to making our hospital system work for Australian families.

The Government will undertake detailed consultation on implementation of the package with relevant groups including the states and territories.

SYDNEY
2 JULY 2008
PRESS OFFICE (02) 6277 7744
OFFICE OF MINISTER FOR HEALTH (02) 6277 7220

Appendix 2



The massive increase in monthly registration shown on the above graph, commenced in June 2021 through to February 2022 occurred completely independent of the promotions by OTA.

TRANSCRIPT LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—19 May 2023

DonateLife Victoria submission to Victorian Parliamentary Enquiry

'In 2021, many Victorians were required to download the myGov or Medicare app for the first time to link their COVID-19 vaccination certificate. The button directly below 'Proof of vaccination' is 'Organ donation', where users can join the register in just three taps. Between June and October 2021, more than 60,000 Victorians registered on the AODR through the myGov or Medicare apps, which is more than has ever been recorded in a full calendar year (the highest number of registrations in a full calendar year outside of 2021 was 54,806 in 2019).'

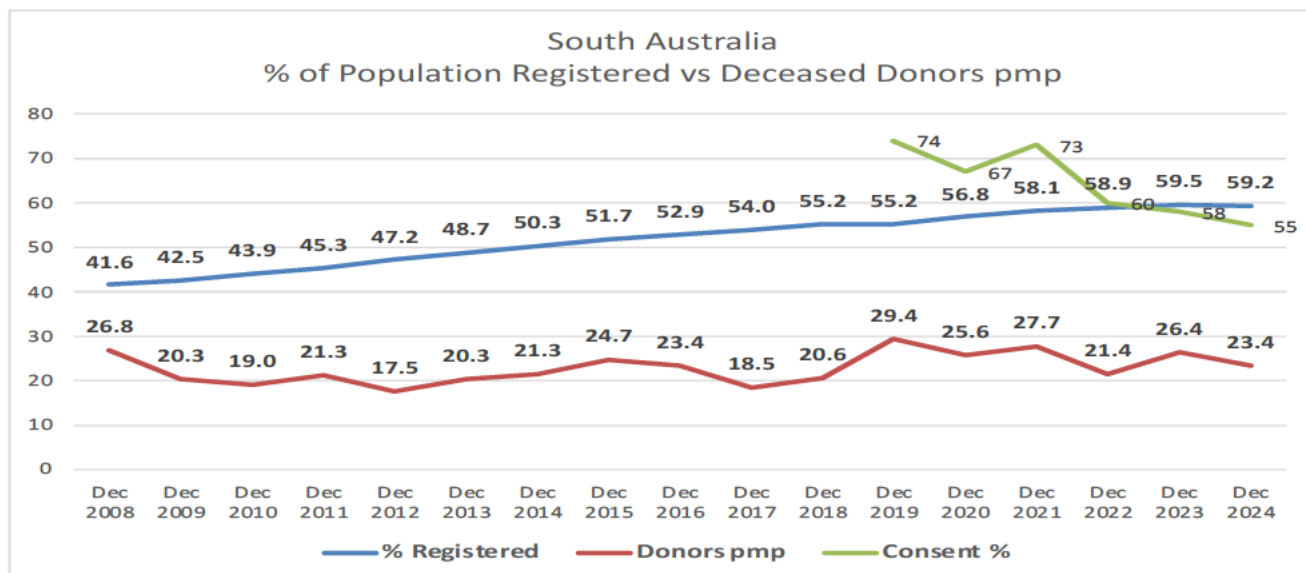
Appendix 3

How important is Registration?

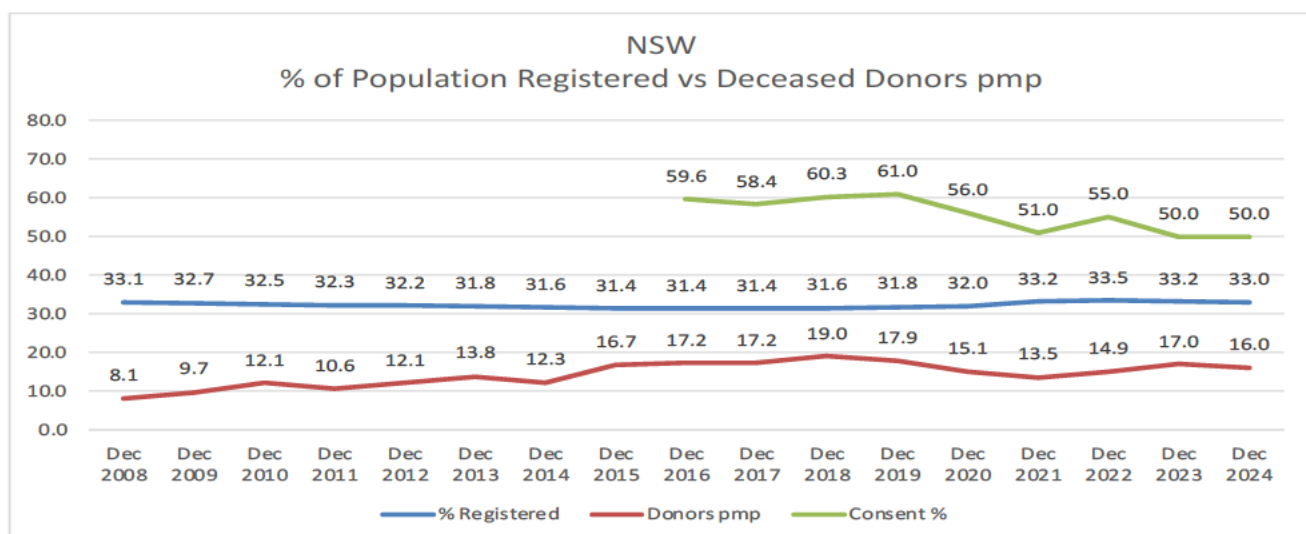
At the outset let me state quite clearly that I support the system allowing each and every Australian to register their desire to be an organ donor when they die. It also makes the Family Donation Conversation (FDC) easier on both the loved ones of the dying patient and on the staff in the hospital who leads the FDC.

At December 2024, almost 60% of the entire population in South Australia were registered, 33% in NSW and 18.6% in Victoria. Despite this very large discrepancy, the consent rates were more closely aligned with South Australia at 55%, Victoria at 53% and NSW at 50%.

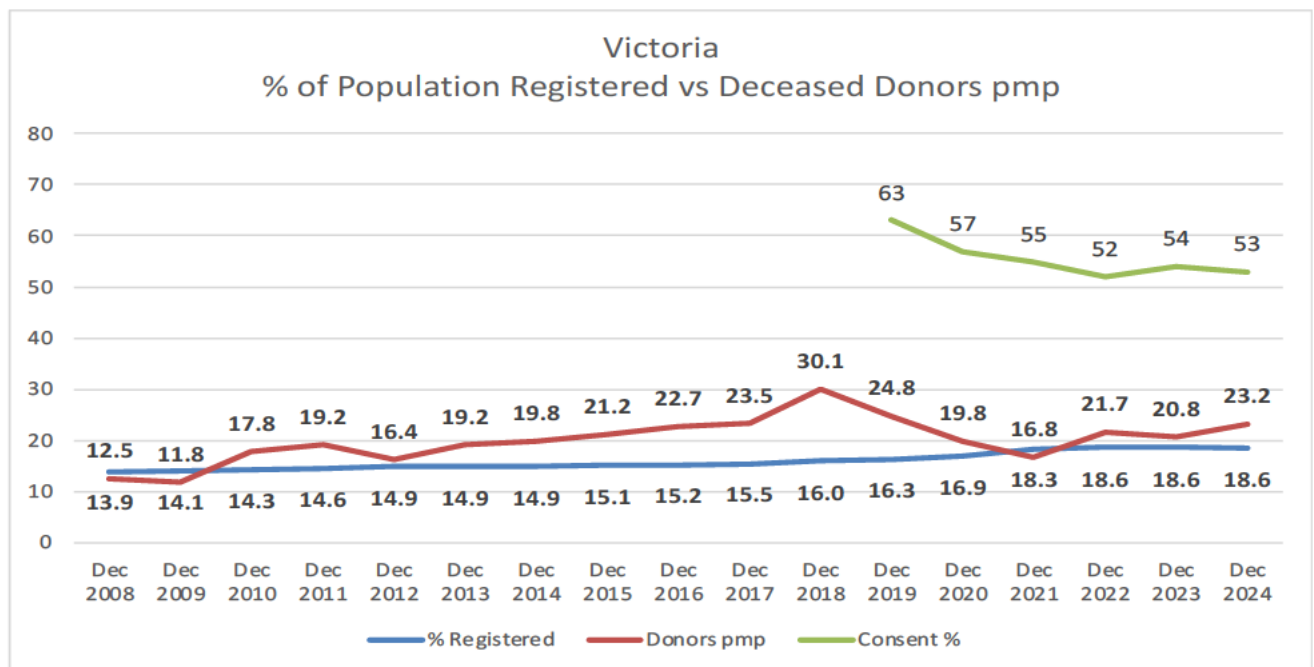
In recent years, many supposedly 'in the know' are claiming that South Australia's impressive organ donation rate is due to its increasingly high organ donation registration rate and that other States should follow SA's lead. But the FACTS are that the massive increase in the registration rate, has hardly increased the organ donors pmp. SA has been the leading Organ Donation State ever since Professor Geoffrey Dahlenburg effectively introduced a 'mini-Spanish Model' into the major SA hospitals in the 1990's. The decline in the consent rate since 2019 is a major concern given the large increase in the registration rate.



On the other hand, NSW has had one of the highest registration rates while at the same time being the worst performing organ donation State over the last 14 years.



And then Victoria has had one of the lowest registration rates while at the same time being the second-best performing organ donation State over the last 14 years.



What the above three graphs clearly demonstrate is that there must be other more important factors influencing the consent rate and subsequent organ donation rate than the registration rate. This is never explored by the politicians or bureaucrats in any public media release. Perhaps it is because neither the politicians nor the bureaucrats wish to accept any responsibility for the low organ donation rates. They would rather blame the public for not registering than acknowledge that the systems in place in the hospitals are not working to increase the number of organ donors. All the politicians and the public are told is that the organ donation rate is low because of Australia's low organ donation registration rate

Appendix 4

Senator Andrew Bragg
Liberal Senator for New South Wales
senator.bragg@aph.gov.au
andrew@andrewbragg.com

Dear Andrew,

Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023

I hope you remember me as I met you prior to you becoming a senator in the Edgecliff Centre coffee shop with Marvin Weinman and subsequently had drinks at Parliament House after listening to your inaugural speech to the Senate.

I am approaching you for your assistance particularly as you are an advocate of true Liberal values that promotes individual rights, civil liberties, democracy, and free enterprise.

The Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 will be presented to the Senate soon and I am extremely disappointed that the Minister is, following the advice of her staff and the Department, prepared to continue to deny the rights and liberties of Donor Families and Organ Transplant Recipients.

These two groups have endured incredible hardships and suffering through sickness and death and are being denied the opportunity to divulge information about themselves and their loved ones as and when they wish. No liberal democracy should discriminate against these groups and should protect their basic rights such as freedom of assembly and free speech.

This Bill gives the Minister the opportunity outlaw the long-standing discrimination these groups have endured to speak and meet freely.

I am asking you to meet with me as soon as possible so that you will be able to represent the liberal views of these two groups.

I look forward to your response at your earliest convenience.

Best regards,

Brian Myerson OAM

[Redacted signature block]

Appendix 5

On 19 Jul 2023, at 8:53 pm, Donor Family Care donor.familycare@nhsbt.nhs.uk wrote:

Good Morning Brian

Thank you for your email.

Yes, it possible for donor families and recipients to meet in person. We would always advise on corresponding via ourselves for some time first to establish a relationship. When both sides are ready and have expressed an interest in meeting the local specialist nurse team will help facilitate this.

I hope this information helps, I have also copied the link to our website below which contains more information.

<https://www.nhsbt.nhs.uk/how-we-help/donor-family-care-service/>

Best wishes

[REDACTED]

Donor Family Care Services Supervisor
Organ Donation & Transplantation
NHS Blood & Transplant

[REDACTED]
[REDACTED]
[REDACTED]

Visit organdonation.nhs.uk

Care, Compassion, Support

Appendix 6

Chamber

Senate on 10/08/2023

Item

BILLS - Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023 - Second Reading

Speaker:

Reynolds, Sen Linda

In conclusion, we know on this side of the chamber that the topic of organ donation is an emotional one and an important one. I would like to very much thank the families of organ donors and recipients for their submissions. I'd like to finish with the words of somebody else who made a submission to this inquiry. It was Mr Brian Myerson, OAM. He expressed frustration with this bill's apparent disregard for donor recipients and their families—the other side of the coin. He said the bill continues to 'deny the rights and liberties of donor families and organ transplant recipients' and continues:

These two groups have endured incredible hardships and suffering through sickness and death and are being denied the opportunity to divulge information about themselves and their loved ones as and when they wish. No liberal democracy should discriminate against these groups and should protect their basic rights such as freedom of assembly and free speech.

Senator the Hon. Fiona Nash

Minister for Rural Health
Deputy Leader of The Nationals in the Senate
MEDIA RELEASE
2 February 2016

Minister Nash releases independent organ donation and transplantation review

The Coalition Government today welcomed the independent review into the organ donation and transplantation sector.

Work is already underway to implement some recommendations and the Federal Government will continue to work with all stakeholders to save more lives through organ donation and transplantation.

Releasing the review today, Minister responsible for organ donation Fiona Nash said the Review by Ernst and Young found the existing strategy to increase organ donations was "sound; however there is still significant room for improvement of donation rates" which requires "effective implementation and monitoring of the strategy nationally".

The review makes recommendations around governance, transparency and accountability.

The review recommended:

- New governance arrangements - a new Board of Governance to provide stronger oversight and support for the work of the Organ and Tissue Authority
- The publication of the breakdown of State and Territory funding on the OTA website
- Organ and tissue donation data to be made public on a hospital by hospital and a state by state basis
- Minimum standards for the auditing of organ donation practices to be defined
- The Donate Life Network to monitor the proportion of ICU specialists, staff and trainees in each hospital who have been trained in having the donation conversation with families
- States and Territories to clearly define who is responsible for organ donation rates in their jurisdiction
- Proceeding with a one-step online donor registration process (which the government has been working on, expected to launch in May), supported by a social media awareness campaign.

Minister Nash called for cultural change around organ donation and transplantation.

"In Australia, we worship our sporting stars and we rightly honour our war heroes, with memorials bearing their names.

"Organ donors are real heroes who save lives. Let's admire organ donors with the same passion we admire stars in sport or music or whatever our particular interest is.

"Donor families, who consent to the donation going ahead, need to be recognised for the amazing gift they give. Intensive care clinicians who retrieve and implant organs need to be recognised for the life changing work they do day in and day out. Donor nurses should also be acknowledged for the life-saving work they do.

"Hospitals need to see organ donation as a key priority. I look forward to fostering a friendly competitive rivalry between the states and territories and individual hospitals as to who has the better organ donation rate through publicising their results.

"Almost all Australians would like to be able to receive a donated organ themselves to save their life, or for their child or parent, if it was required to save their life. Yet the vast majority of Australians are not registered as organ donors. Every Australian can help improve Australia's organ donation and transplantation rate – they can register as an organ donor. If we increase the number of registered organ donors, we will save more lives.

"As of May, registering to become an organ donor will be a one-step, online process able to be completed in less than 10 minutes. The government will run an awareness campaign but government can't increase the number of organ donors on its own – it's up to Australians to register as organ donors.

"Further, the report notes 'defensiveness' in the sector and calls for 'open and transparent dialogue'," Minister Nash said.

"I hope more transparency helps foster open dialogue. However, let me be clear: I'm not interested in personalities. I'm interested in saving lives through organ donation. I ask all parties to join with me as we try to achieve the goal we all share – increasing organ donation and transplantation in Australia."

Donor Families Australia Chairman Bruce McDowell congratulated Minister Nash for her commitment to increase organ donation and transplantation.

"With the combined efforts of all involved hopefully more recipients will be the beneficiaries of an increase in organ and tissue donation rates," Mr McDowell said.

Transplant Australia Chairman, Jason Ryan, said the review should give those on the transplant waiting list confidence that the Federal Government was doing everything possible to ensure Australia maximised its donation rate.

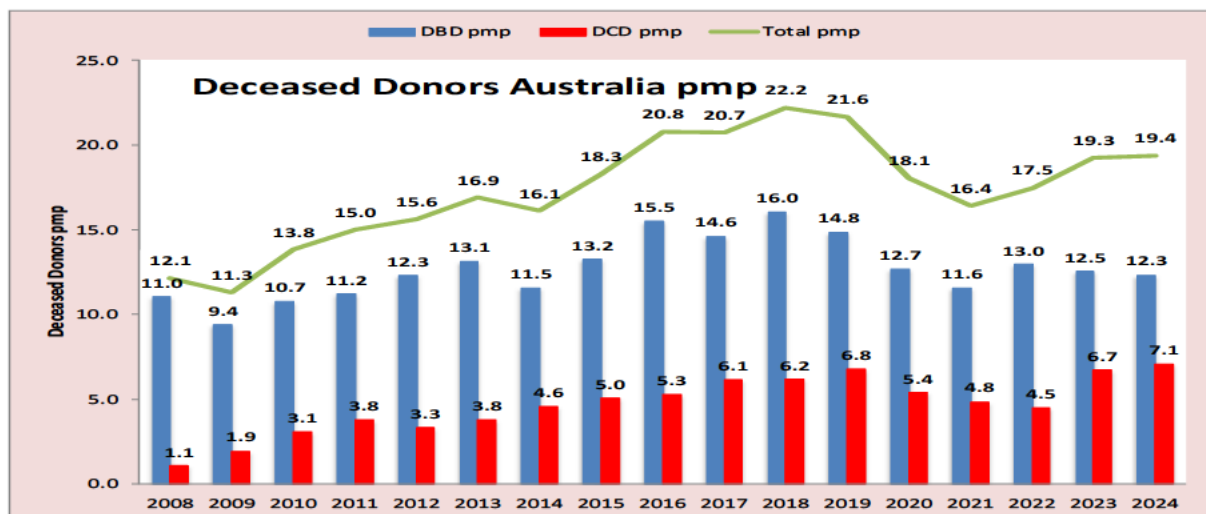
"Transplant Australia welcomes the release and recommendations of an independent review into the performance of the organ and tissue donation

sector in Australia. We are committed to working with Federal and State governments to implement all necessary changes.”

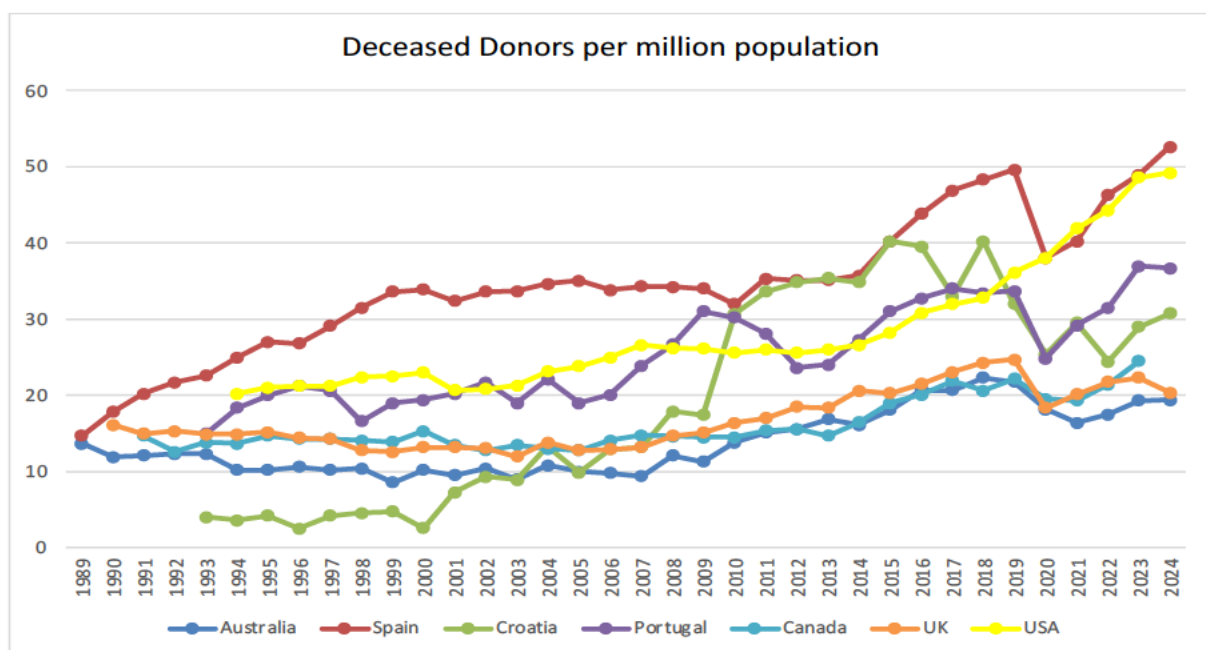
The review also confirmed the extra \$10.2 million over two years in the 2015-16 Budget was well targeted.

The Review of the Implementation of the National Reform Agenda on organ and tissue donation and transplantation, is available at the [Department of Health's website](#).

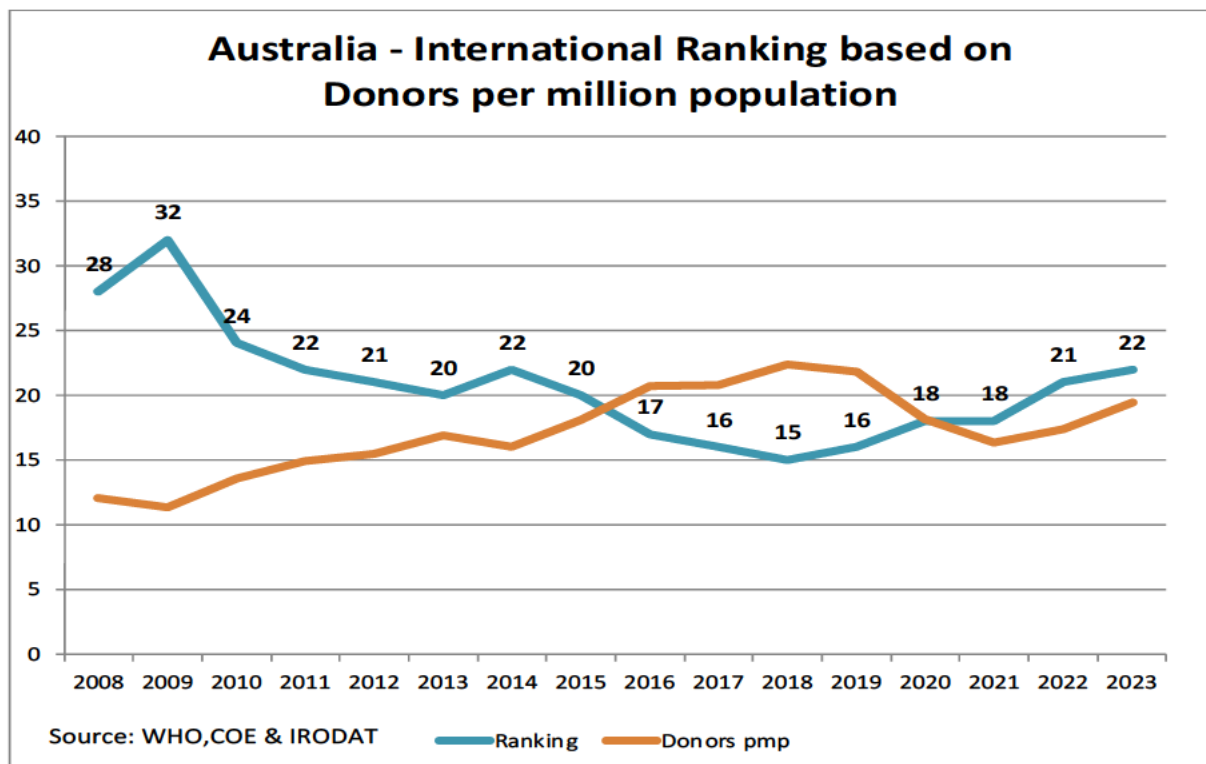
Appendix 8



After 15 years the Donation from Brain Death (DBD) has only increased from 11.0 pmp to 12.5 pmp. Of great concern is the decline since 2018. Virtually the entire increase in the donation rate that OTA boasts about comes from the introduction of the Donation after Circulatory Death (DCD) Protocols introduced in 2007 completely independent of OTA. What this graph very clearly shows is that there has been virtually no change in the practices in the hospitals to increase the organ donation rate apart from DCD. Again, the Review needs to investigate whether there is any legislation that may be having a negative impact on the above practices.



Sadly, for those desperately waiting for a transplant, Australia's increase in organ donation pmp is dismal compared to the socially comparable countries. I have chosen to compare Australia's performance with the 2 leading countries, Spain and USA, 2 countries that have successfully implemented most aspects of the "Spanish Model", Portugal and Croatia and 3 Anglo-Saxon countries, Canada, UK and Australia. The start date of 1989 was chosen as The Organización Nacional de Trasplantes (ONT) was established in that year.



Based on the latest published international data, Australia's ranking has been declining for the last 7 years since 2018. 21 countries achieve higher organ donation rates than Australia.