



Register and talk about it

Inquiry into increasing the number of registered organ and tissue donors

Summary booklet



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Inquiry into increasing the number of registered organ and tissue donors: Summary booklet

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Published by order, or under the authority,
of the Parliament of Victoria
March 2024

ISBN 978 1 922882 68 4 (print version)
ISBN 978 1 922882 69 1 (PDF version)

This booklet is available on the Committee’s website:
parliament.vic.gov.au/organtissuedonor-reports

Cover photo: © Victorian Institute of Forensic Medicine 2024, reproduced with permission.

Photo description: Donor Tissue Bank of Victoria’s Tree of Life mural that recognises and promotes awareness of tissue donors. Green, yellow and red leaves reflect the cycle of seasons and grief responses, and bear the first name of people who have donated tissue.

Register and talk about it

Inquiry into increasing the number of registered organ and tissue donors

The Legal and Social Issues Committee's *Inquiry into increasing the number of registered organ and tissue donors* is critical because organ and tissue donor registration on the Australian Organ Donor Register (AODR):

- is low in Victoria,
- increases the likelihood that donation will proceed, and
- has a significant influence on a family saying 'yes' to donation, saving lives and producing significant health, economic and community benefits.

The Committee heard from many expert and community stakeholders during the Inquiry who were inspiring with their compassion, dedication and strength.

“ donation is perhaps the most valuable, even sacred, gift it is possible to give. At a time of profound grief, the family of [a] donor have found the grace to recognise that they can help others.

Alfred Health, Victorian trauma hospital and transplant provider

This is a summary of the Committee's final report which makes 74 findings and 41 recommendations. It is available here: parliament.vic.gov.au/organtissuedonor-reports.

The Committee has relied on data from the Organ and Tissue Authority's 2022 activity report for the purposes of its final report and this booklet. The recommendations in this booklet are summarised from the Committee's final report.

Opportunities presented by a ‘yes’ donor registration option on Victorian driver licences

Victorians have not been able to record interest in becoming a donor on driver licences since the early 2000s.

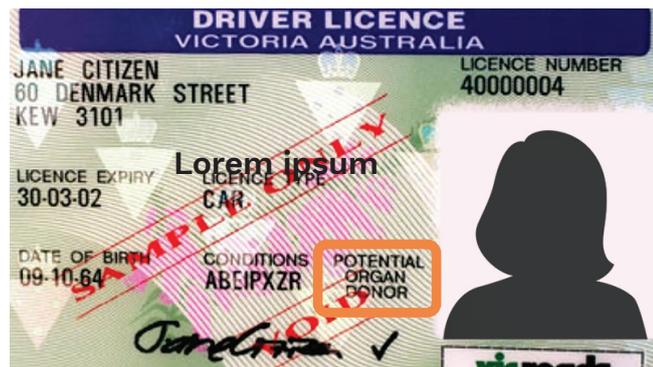
When Victoria discontinued recording donation decisions, not all state records were successfully transferred to the Australian Organ Donor Register (AODR).

There is confusion in the community about whether a previous record to become a potential donor on a driver licence is a valid registration on the AODR today.

Historic Victoria driver licence

Historically Victorians could record **potential organ donor status** by ticking a box. This was an expression of interest to register to be a donor.

This method of registration has not been available in Victoria since the early 2000s.



FACT: Past donor registration through a Victorian driver licence may not be valid, but you can check your registration status via Medicare through myGov or the Medicare app.

The Committee recommends:



given the uncertainty around historic Victorian driver licence donor registrations, the Victorian Government advise Victorians aged 42 years or older, who held a driver licence in the early 2000s, to register or check that they registered a donation decision on the AODR (recommendation 1)

The Committee’s final report sets out this recommendation in full

Only in South Australia is it possible to record a donation decision on a driver licence.

South Australia's AODR registration rate (72%) is much higher than Victoria's (23%).

“ If it is just about registrations, that is a no-brainer, in that South Australia is the only state that still has that, and it is not surprising they have the highest registration rate. It is in front of every adult who goes for a drivers licence ... and it gets renewed every 10 years. So that would be the easiest, simplest way—to get VicRoads to be able to talk to the [AODR].

Melbourne Lions Eye Donation Service, Victoria's eye bank and one of Australia's largest providers of eye tissue

Almost all eligible Victorians hold a driver licence.

99.9% of Victoria's eligible population holds a driver licence, meaning the option to register to be a donor through the driver licence system presents an opportunity to increase Victorian registrations on the AODR on a mass scale.

“ Many Victorians still associate organ donation registration with their driver licence, and the most natural place to encourage sign-ups would be to reintroduce this link ... We believe that introducing a link between the Victorian driver licence system and the AODR—along with a public awareness campaign—is the single thing that will make the most significant impact to registration, over time ... We recognise this is a long-term strategy, but believe it is worth the investment.

DonateLife Victoria (DLV), agency responsible for educating and encouraging Victorians to register on the AODR

The Committee recommends:



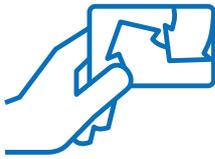
the Victorian Government scope the option to allow Victorians to register on the AODR when applying for or renewing a driver licence (recommendation 2)

The Committee's final report sets out this recommendation in full

Registration increases your chance of becoming an organ and tissue donor

Australian Organ Donor Register (AODR) facts

If you register to be an organ and tissue donor and tell your family:



9 in 10 chance
your family
will consent
to donation

If you don't:



4 in 10 chance
your family
will consent
to donation

The AODR is for recording decisions about becoming an organ and tissue donor.

Registering on the AODR provides clear direction to families and donation staff on a potential donor's wishes and substantially increases the likelihood that a family will consent to donation.

“ increasing the number of registered Victorians not only honours individual donor intent but also directly enhances the life-saving potential of organ [and tissue] transplantation within our community.

Austin Health, Victorian hospital with donation and transplantation experience



FACT: Registration on the Australian Organ Donor Register is important because it significantly increases your chances of becoming a donor.



To register on the AODR or find out more, visit: donatelife.gov.au

More Victorians need to register on the Australian Organ Donor Register

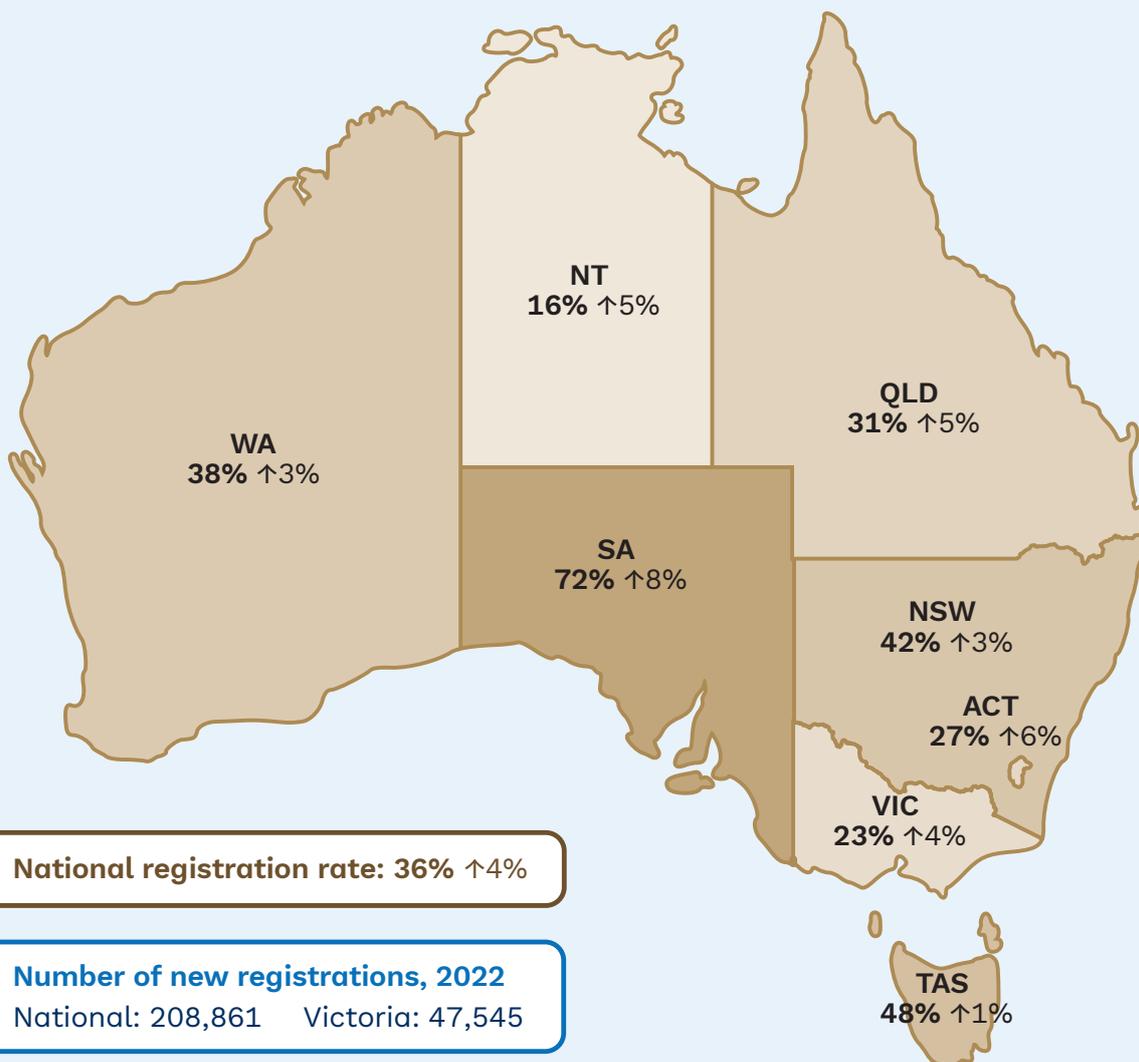
Compared to other states, Victoria has a low AODR registration rate.

Victoria has a lower percentage (23%) of its population registered on the AODR compared to other states (36% national average).

“ With 23% of eligible Victorians registered (1.24 million), and 81% of the community supporting donation, based on 2021 ABS Census data there is a gap of around 3.3 million Victorians who are comfortable with donation but have not taken the time to register.

DonateLife Victoria (DLV)

Australian Organ Donor Register (AODR) registration rates, 2022 and the percentage increase in registration rates, 2015–2022



Note: Darker colours indicate states/territories with higher Australian Organ Donor Register registration rates.

There are many ways to increase the promotion of the AODR in Victoria.

More people will register if the process is easy and accessible.

This was demonstrated by a spike in registrations when people accessed vaccination certificates during the COVID-19 pandemic through the Medicare app, where people can also register on the AODR.

“encouraging people to find the time to log onto a government website ... is challenging. Mass registration is an opportunistic trigger that easily facilitates the registration process.

“making the registration process quick, easy and direct—like ticking a box—will encourage more people to take action. This was demonstrated by the 87% increase in new registrations in 2021 (from 2020), largely due to people registering on the AODR while downloading their COVID-19 vaccination certificates on the Medicare app.

Organ and Tissue Authority, federal organisation leading Australia's program to improve donation rates

The Committee recommends that to promote the AODR, the Victorian Government:



introduce a prominent ‘Register online’ call to action button on the Service Victoria website and app, as well as other touchpoints like proof of age card applications (recommendation 3)

incorporate links to securely register on the AODR when accessing Victorian Government online services (recommendation 4)

enhance collaboration with DLV to increase the presence of promotional and educational material about donation through TV, radio, social media and online platforms as well as posters, billboards and pamphlets in public spaces (recommendation 25)



assist DLV to collaborate and partner with Victorian businesses (including farming and health insurers), charities, not-for-profits, professional and sporting associations, and unions (recommendation 26)

support DLV and Lifeblood to work together to increase the promotion of organ and tissue donation through Lifeblood's network (recommendation 27)

The Committee's final report sets out these recommendations in full

Australia operates an opt-in registration model as opposed to opt-out. The Committee received varied evidence on the benefits and detriments of both models. Overall evidence suggested that improvements to the donation, transplantation and donor identification system, investment in professional training and clinical staff, and better community awareness about donation—rather than the introduction of an opt-out system—will help Australia achieve higher organ donation rates.

Sharing donation wishes with family increases your chance of becoming a donor

Family consent in the donation process is critical.

Families are always asked for consent when organ and tissue donation is considered.

Registration on the AODR changes the nature of donation conversations by making it easier for families to honour and respect their deceased loved ones' wishes.

“ I have had quite a few families say to me, ‘Oh, that makes me feel so much better that they have registered, because I know that is the right decision.’

Laura Fleckner, Donation Specialist Nursing Coordinator at Alfred Health

Discussing organ and tissue donation and sharing donation wishes with family reduces the burden of decision making for a potential donor's family at a time of intense grief, and substantially increases the likelihood that a family will consent to donation.

“ It is important to note here that it was from all the conversations that we had as a family that we were fully aware of his wishes, which made it easier to fulfil when his time was here. It is crucial for a person's loved ones and next of kin to be aware of their wishes. If not, the additional shock at a time of such grief and sadness is almost overwhelming for families to take in, and the decision, with such a small window, is sometimes lost.

Cynthia Caruana, donor parent

The rate of family consent to donation has decreased over the past ten years.



FACT: It's important to talk to your family once you register to become a donor, because they will be asked to consent to donation.

The Committee recommends:



automatically contacting people after they register on the AODR, to encourage them to share their donation wishes with family, and to provide information on starting family discussion and an option to share donation decisions with family members via email (recommendation 8)

The Committee's final report sets out this recommendation in full

Donating organs and tissues can save and improve lives

A deceased donor can help up to seven people through organ donation and 200 people through tissue donations.

Many Victorians know they can be an organ donor but are unaware they can also become a tissue donor.

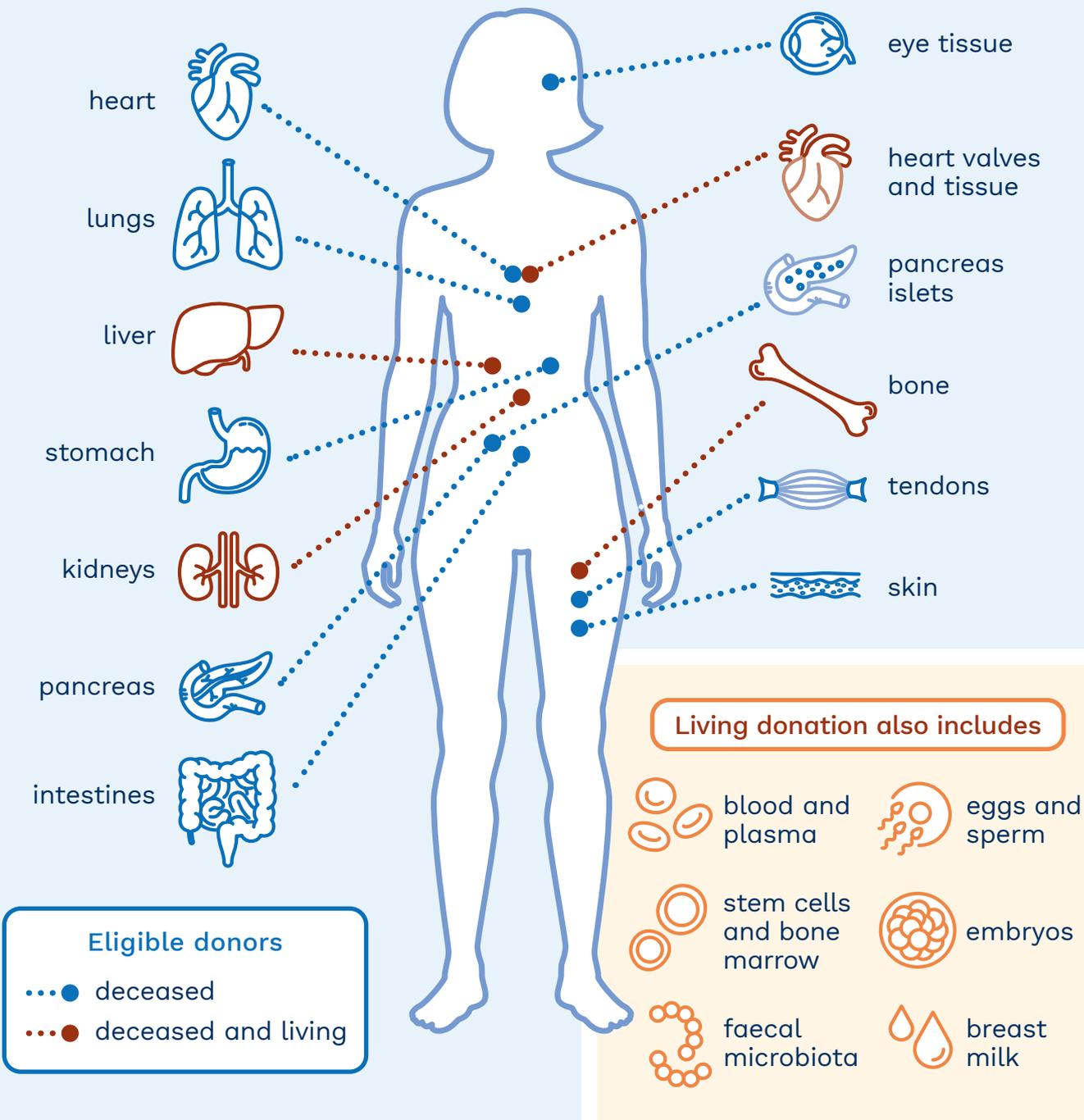
“ Organ donation was not an option because they still had to go through a process of investigation, but he was a prime candidate for tissue donation. We thought, ‘This is what Rhys would want.’ You know, [Rhys was always] sharing and giving [during his life], so it was kind of perfect for that. So the machine kicked in, the process went through. Later on we found out that he donated corneas and skin, and over time we found out that all of his donations were successfully—I do not know what the word is—not transplanted but gifted, and it gave us a lot of comfort knowing that he had helped other people.

David Gillard, donor parent

What can be donated?

Organ donation includes

Tissue donation includes



A person who becomes a **deceased organ donor** can also become a **tissue donor**

More education and awareness about donation can help increase registrations

People have a strong desire to make an informed decision about registering on the AODR and to understand the donation process.

There are a range of ways to increase education and awareness about organ and tissue donation, how to register on the AODR and the donation process.

“ ... we believe, in summary, that the best approach is (1) a drivers licence system of registration and (2) a mass communications and education campaign for the conversation, because it is also very important to have the conversation along with the registration to convey what your wishes are to your family.

DonateLife Victoria

Personal stories play a key role in educating people and raising awareness of organ and tissue donation.

Personal stories from donor recipients and donor families, as well as content to dispel myths and misconceptions about donation are important to include in education and awareness campaigns.

“ In fact the stories that we are able to tell—those personal stories about donation and about that life-saving gift of transplantation—are the stuff that resonates well. It does not matter how old you are or where you are from, if you see someone that looks like you or is in a similar circumstance in life that has gone through this experience, there is nothing more powerful in terms of being able to convince people to register or to talk about donation.

Organ and Tissue Authority

Some people have misconceptions about eligibility to become a donor. But you don't have to be in perfect health to be a donor—if you would like to become a donor you should register and let the experts decide.



FACT: Older people can become organ and tissue donors.

FACT: Unhealthy habits or medical conditions don't necessarily exclude people from becoming donors.

Some people have misconceptions about what a body will look like after organs and tissues have been removed for donation—but deceased organ and tissue donors are treated with care and respect.



FACT: Organ and tissue donation does not disfigure a donor's body: the family can still have an open casket funeral, even for eye tissue donations.

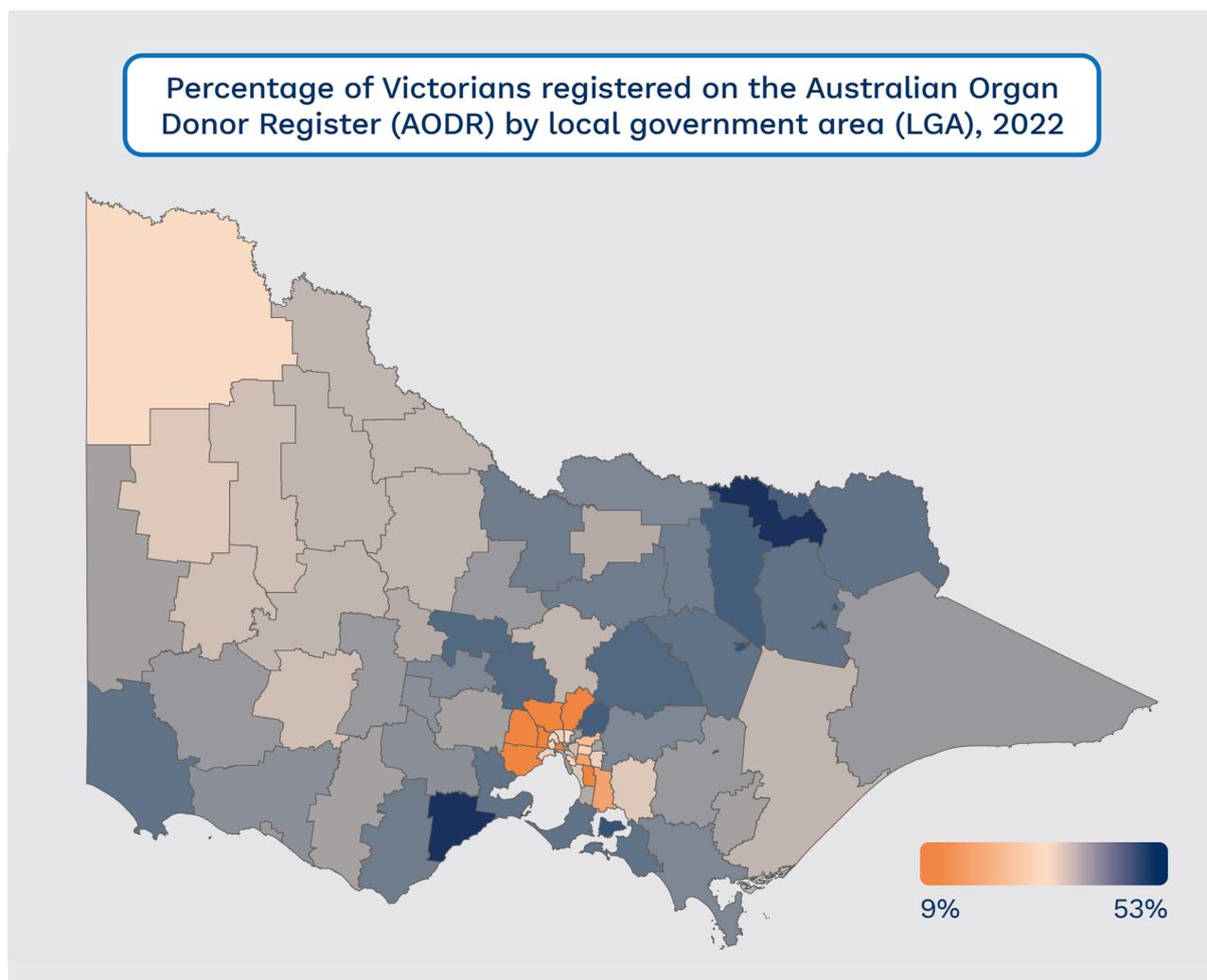
Tailoring education and awareness to different communities

AODR registration rates vary across Victoria.

Education and awareness initiatives about the AODR and donation can be tailored for different communities.

Local government areas across Victoria have varying AODR registration rates. Every locality has different demographics, for example, some are more culturally diverse than others or expect to see a large increase in population.

Improved data collection and reporting at a national level would help identify what motivates people to register and assist in creating targeted community awareness campaigns.



For an interactive version of this map, visit: parliament.vic.gov.au/organissuedonor-reports

Ten Victorian LGAs with the lowest percentage of people registered on the AODR in 2022, population increase from 2021 to 2036 and number of language communities with low English proficiency in 2022

LGA	Percentage of people registered on AODR, 2022	Percentage increase in population, 2021 to 2036	Number of language communities with low English proficiency, 2022
Greater Dandenong	9%	19%	77
Brimbank	10%	13%	74
Wyndham	12%	59%	87
Hume	13%	44%	66
Melbourne	13%	58%	55
Melton	13%	93%	70
Whittlesea	13%	45%	62
Casey	16%	43%	86
Monash	16%	21%	59
Manningham	19%	15%	39
State average	23%	29%	50^a

a. 50 is the metro average and the lowest throughout Victoria is 20 in Nillumbik and Warrnambool.

There are many differences between Victoria’s multicultural and religious communities.

One approach to raising education and awareness about donation and how to register on the AODR will not fit all communities.

“ But it is still a sensitive topic, so the message and the education and the awareness really need to come through trusted sources within the Muslim community ... if you have imams and religious leaders—the ICV—saying, ‘Look, this is something that is important. You need to understand what’s involved and you need to understand the positives by doing this, but by the same token we understand you’ll have concerns. This is some information that hopefully will address your concerns, and if you have any more concerns, please raise them and we can discuss them very openly and sensitively.’ I think that is really the approach that needs to be taken.

Adel Salman, President of the Islamic Council of Victoria (ICV), the State’s peak body representing Muslims



FACT: Most religions support organ and tissue donation.

It is important to build relationships with communities when developing education and awareness campaigns.

Tailored and co-designed community engagement strategies can help spread the word about donation and the AODR in culturally diverse communities.

“ [To engage with culturally diverse communities] invest in reciprocal relationships in multicultural communities, by spending time, being genuine, having a presence and building personal connection. Community leaders are a good starting point to building these relationships [and can help co-design resources].

Ethnic Communities' Council of Victoria (ECCV) Policy Advisory Committee on Health and Wellbeing, ECCV is the State's peak body for migrant and refugee communities

Building collaborative and consultative relationships with Victorian First Nations communities and Elders about donation is essential to ensure that community awareness about the AODR and donation processes increase in a culturally appropriate way.

“ It came down to education, education, education, and it has to be at community level so that [First Nations] peoples have heard of the concept of organ donation well before that terminal or pre-terminal admission to hospital ... the strengths of our study are that it truly inserts an Aboriginal voice into the process of improving health care. I think it is a framework that can be lifted from central Australia and reimplemented or re-used almost anywhere else if the right people are there.

Dr Paul Secombe, Senior Specialist Clinician with the Central Australia Health Service who recently studied First Nations people's attitudes to donation in Central Australia

The Committee recommends:



more targeted education and awareness campaigns about donation, using Victorian registration and demographic data (recommendations 17 and 18)



the Victorian Government consult with community leaders, Elders and organisations to co-design and tailor engagement projects, including:

- mail drops, easy-read and translated resources to engage with digitally disadvantaged Victorians
- resources promoting registration and family discussion when Victorians engage with government touchpoints
- programs to support intergenerational discussion in families from multicultural and faith-based communities
- a First Nations organ and tissue donation ambassador program (recommendation 21)

The Committee's final report sets out these recommendations in full

Increasing registration rates among young people

Young people have a low registration rate on the AODR despite many supporting donation.

Many young people support the idea of donation but across Australia only 10% of people aged 16 to 25 have registered on the AODR.

“ there was a significant lack of awareness and understanding of organ and tissue donation among young people. Many young people were also not aware of the importance of having conversations about this or that they needed to join the register. Young people did express a strong desire to make informed decisions but felt there was a significant lack of information available to them. This was the main barrier in them signing up ...

Dr Brooke Huuskes, La Trobe University researcher who recently studied young people’s knowledge, attitudes and perceptions of donation

More donation-related awareness-building, education and discussion opportunities for younger Victorians will help them make an informed decision about donation and discuss this with their family.

“ we often think of children in school education as change makers within their families. They go home and talk to their parents, and even more than their parents they might talk to their grandparents, who actually are the age where people may become ... donors.

Dr Dale Gardiner, Associate Medical Director of Deceased Organ Donation at the United Kingdom’s organ and tissue donation body

The Committee recommends the Victorian Government and relevant departments:



develop and deliver a program targeted to 15- and 16-year-olds to increase knowledge about donation to enable informed decision making and promote effective family discussions ahead of becoming eligible for driver licences (recommendation 22)



include information about donation in the primary and secondary school curriculum (recommendation 23)

promote awareness and family discussion about donation to Victorian schools during DonateLife Week (recommendation 24)

The Committee’s final report sets out these recommendations in full

Improving knowledge about tissue donation

Awareness about tissue donation is low in the general and medical community and can be improved.

There are some key differences between organ and tissue donation, including that tissue donations can be recovered up to 24 hours after death.

Improved collaboration between key stakeholders can help with identifying and referring potential deceased tissue donors to increase tissue donation opportunities.

“ In my past role as a medical executive and Responsible Officer for organ donation at a major public hospital in Melbourne, I wasn’t aware of the key differences in the process of organ and tissue donation. It has probably led to unintended oversight of opportunities for tissue donation. A much stronger medical professional and community awareness and better notification system will be critical in ensuring this precious resource does not go to waste.

Dr Kean Kuan, Chief Medical Officer and Deputy Director at the Victorian Institute of Forensic Medicine (VIFM), Donor Tissue Bank of Victoria (DTBV) is part of VIFM



FACT: Tissue donations have many positive health impacts and can be accepted from a diverse range of donors up to 24 hours after death.

The Committee recommends the Victorian Government and relevant departments:



support DLV and DTBV to work together to increase understanding about tissue donation in the general and medical community (recommendations 20 and 36)



explore options to more easily notify donation organisations about deaths involving organ and tissue and tissue-only donations and share hospital records with DTBV (recommendation 37)

The Committee’s final report sets out these recommendations in full

Legislative reform for donation acknowledgement on death certificates

Current legislation means donation cannot be recognised on death certificates.

Legislation in Victoria does not allow donation to be acknowledged in the death register and on a donor's death certificate because health professionals and hospital staff are prevented from verifying that a deceased donation occurred.

“ I think [recognising donation on a death certificate] is a really important thing. It is their last official document. If they were the one that did it, I think in 50 years how wonderful it would be when the death certificates are finally released and someone will go, ‘Oh, look, my family member was an organ donor.’

Leanne Campbell, donor parent

Legislation has been amended in the Australian Capital Territory and introduced in South Australia to address these issues.

The Committee recommends:



the Victorian Government seek to amend legislation to ensure a deceased donor (including a past donor) can be recognised and acknowledged as a donor in the death register and on a death certificate (recommendations 12 and 13)

The Committee's final report sets out this recommendation in full

More Australians need to register to become stem cell donors

Australian stem cell donor facts

The Australian Bone Marrow Donor Registry:



is the **only source** of volunteer donors



gets **3 in 4 donations** from overseas



needs more donors that are young, male and ethnically diverse

The Australian Bone Marrow Donor Registry (ABMDR) is for people to register to donate stem cells.

Stem cell transplants are used to treat blood cancers like leukaemia and lymphoma.

There are not enough Australians registered to be stem cell donors, meaning Australia gets approximately 3 in 4 of its donations from overseas.

“depending on the rest of the world to donate to our patients means that some of our patients have little hope of ever finding their match. We live in a very multicultural country, and your chances of finding a match increase when there are a lot of donors on the registry with the same ethnicity as you.”

Lisa Smith, CEO of ABMDR, Australia's only source of unrelated volunteer stem cell donors



FACT: It's easy to register to be a living stem cell donor on the Australian Bone Marrow Donor Registry.



To register on the ABMDR or find out more, visit: strengthtogive.org.au

Increasing the diversity of stem cell donors would benefit more patients.

More domestic registered ideal donors would produce more equitable outcomes for diverse patients, in particular those from First Nations, Pacific Islander and Southeast Asian communities.

“ many people are simply not aware that others may require stem cell transplants, and hence that stem cell donors are needed. There is also little awareness of the bone marrow registry and variable knowledge about how to become a donor ... This inadequate donation or donor pool disproportionately and adversely affects minority groups and First Nations people.

Chris Tanti, CEO of the Leukaemia Foundation, a national charity supporting people with blood cancer and ABMDR recruitment partner

Home-delivered cheek swabs are an evidence-based and modern recruitment method to increase the number of registered stem cell donors. Expanding Strength to Give—which focuses on recruiting donors through cheek swabs—can help increase awareness of stem cell donations and encourage people to register to donate.

Facilitated cheek swab collection at targeted community events with experienced and trusted partners would assist in increasing the number of registered stem cell donors.



FACT: Stem cell donations are drawn from blood and there is minimal pain or side effects—it is similar to donating blood or plasma.

The Committee recommends the Victorian Government and relevant departments:



routinely use multiple government channels to promote awareness of stem cell donations and registration on the ABMDR (recommendation 30)

support Lifeblood, ABMDR and stem cell donor recruitment organisations to extend the reach of stem cell donor awareness and recruitment campaigns, including by targeting the recruitment of younger and ethnically diverse Victorians (recommendations 31 and 33)



advocate at a national level for the immediate release of the \$1 million in stem cell donor recruitment funds agreed to in 2023, and for a commitment to establish a permanent and ongoing funding mechanism for stem cell donor recruitment (recommendation 34)

The Committee’s final report sets out these recommendations in full

Living kidney donation saves and improves lives

The number of Victorian and Australian living kidney donors has decreased over the past ten years.

People can become living kidney donors by donating to friends or family if they are a match, or anonymously through an exchange program.

“ There isn't very much awareness of the opportunity to be a live kidney donor. Knowing what I know now that there is virtually no impact on life expectancy or health for a live donor, I would definitely consider donating to someone else and change their life.

Jeff Ryall, living kidney donor

Increasing living kidney donor rates can save lives and provide better early and long-term outcomes for patients who receive a transplant. They can also reduce the time spent waiting for a kidney transplant and kidney transplant waitlists, leading to cost savings by reducing dependence on kidney dialysis.



To find out more about living kidney donation, visit:
donatelifegov.au/all-about-donation/understanding-living-donation

Registering to become an organ and tissue donor significantly increases the likelihood that a donation will proceed

“ Registering to be a donor will save and improve the lives of others. We strongly encourage Victorians to register to become organ, tissue and stem cell donors, and to discuss this with family and friends.

Legislative Assembly Legal and Social Issues Committee

Adopted by the Legislative Assembly Legal and Social Issues Committee
Parliament of Victoria, East Melbourne
4 March 2024

Acknowledgements

The Committee heard from a range of stakeholders who shared learnings and experiences about barriers to registering to become a donor, and ideas to create a more accessible registration system.

Australian and international donation, health and community organisations and people with personal experiences of donation impressed and inspired the Committee with their compassion, dedication and strength. A special thank you to those who generously shared their family stories.

The Committee thanks all those who participated in the Inquiry for their time, interest and contribution.

The Committee acknowledges that Australia's organ and tissue donation and transplantation sector relies on extensive collaboration and goodwill. As many responsibilities are shared or split between state and federal governments and bodies, ongoing cooperation and dedication is required to increase donor registration rates in Victoria.

The Committee encourages all Victorians who want to become a donor to register and talk about it

Register to become an organ and tissue donor

To register on the Australian Organ Donor Register or find out more, visit: donatelife.gov.au

To find out more about talking to your family about donation, visit: donatelife.gov.au/all-about-donation/talk-your-family-about-donation



scan code to register

Register to become a stem cell donor

To register on the Australian Bone Marrow Donor Registry or find out more, visit: strengthtogive.org.au



scan code to register

Find out more

For more information about the Committee's Inquiry and to read the full report, visit: parliament.vic.gov.au/organissuedonor-reports