



Legislative Assembly Legal and Social Issues Committee

Register and talk about it

Inquiry into increasing the number of registered organ and tissue donors

March 2024

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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.

Committee membership



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About the Committee

Functions

The Legal and Social Issues Standing Committee is established under the Legislative Assembly Standing Orders Chapter 24—Committees.

The Committee’s functions are to inquire into and report on any proposal, matter or thing connected with—

- the Department of Families Fairness and Housing
- the Department of Health
- the Department of Government Services
- the Department of Justice and Community Safety
- the Department of Premier and Cabinet and related agencies.

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Terms of reference

Inquiry into increasing the number of registered organ and tissue donors

On 9 March 2023, the Legislative Assembly agreed to the following motion:

That this House refers an inquiry into increasing the number of registered organ and tissue donors to the Legal and Social Issues Standing Committee for consideration and report no later than 31 March 2024.

Chair's foreword

I am pleased to present the Legislative Assembly Legal and Social Issues Committee's first report for the 60th Parliament, *Register and talk about it*.

Through its *Inquiry into increasing the number of registered organ and tissue donors* the Committee was inspired by the generosity and altruism of donors who gave the gift of life, and their families who bravely shared their personal stories.

Organ and tissue donation is a selfless act that has the power to save and transform lives. Transplants provide a unique opportunity for people who are very sick to improve their health and quality of life.

The reality that faces a grieving family when asked to provide consent to donation is not something anyone wants to experience. Yet many families find the strength at a time of intense sadness to recognise that they can help others and provide consent for their loved one to become a donor.

The Committee learned that donor registration and prior family discussion about donation wishes significantly influences the likelihood that a family will provide consent for a donation to proceed—as does the involvement of trained donation specialists. Firsthand evidence showed that families feel much more comfortable consenting to donation when they know they are affirming and fulfilling their family member's donation wishes. This makes increasing the number of Victorians registered to be organ and tissue donors especially important.

Victoria's organ donation rate is consistently above the national average and most people support donation (81%), but only 23% of Victorians are registered to be donors. Among young people these statistics are even lower, with just 10% of people aged 16 to 25 having registered a donation decision on the Australian Organ Donor Register (AODR). The Committee identified building awareness and discussion opportunities about donation among young Victorians as a key opportunity, and makes a series of recommendations to encourage this cohort to register to become a donor and share their donation wishes with family. This includes the delivery of a program targeted at 15- and 16-year olds ahead of them becoming eligible for driver licences and incorporating donation into primary and secondary school curriculum.

South Australia's (SA) donor registration rate (72%) is much higher than Victoria's, and the highest in Australia. SA is also the only state where it is still possible to record a donation decision on a driver licence. While Victorians were able to record interest in becoming a donor on driver licences for a short period, this has not been possible since the early 2000s.

The Committee's recommendation that the Victorian Government scope the reintroduction of the option to register to become a donor on the AODR when applying for or renewing a driver licence was guided by the proven success of the SA driver

licence registration system combined with evidence that almost all (99.9%) eligible Victorians hold a driver licence. The Committee also makes further recommendations to provide other easy, simple, accessible ways for Victorians to register a donation decision on the AODR.

Victoria's culturally diverse population and varying registration rates across different areas of the State mean education and community awareness activities about donation need to be tailored. The Committee was advised by multicultural and religious communities that even though most religions support donation, building collaborative and consultative relationships with respected leaders before promoting organ and tissue donation information is critical. The Committee makes recommendations for more targeted education awareness campaigns that include co-designed projects and provide diverse resources to engage with different groups, including to support intergenerational discussion about donation and the introduction of a First Nations donation ambassador program.

A key topic raised throughout the Inquiry was a lack of awareness and understanding about tissue donation and how it differs to organ donation. The Committee makes several recommendations to reduce this knowledge gap.

The Committee received evidence about the many benefits of living kidney donation. People who donate a kidney to family, friends or anonymously, can save and improve lives as well as help reduce dependence on dialysis.

People who register to become stem cell donors can help treat patients with certain types of blood cancers (like leukaemia and lymphoma), the incidence of which continues to grow. Interestingly, the Committee learned that Australia gets approximately 3 in 4 of its stem cell donations from overseas. This means not enough Australians are registered to become stem cell donors on the Australian Bone Marrow Donor Registry (ABMDR). With less than 1% of people aged 18 to 35 (the ideal age for donors) registered, the Committee makes a series of recommendations to improve national funding for the ABMDR and to extend the reach of stem cell donor recruitment and awareness campaigns, including for the recruitment of younger and ethnically diverse Victorians.

The Committee is grateful for the contribution of expert and community stakeholders who shared learnings about barriers to registering to become an organ and tissue donor, and ideas to create a more accessible registration system. Relevant Australian, Victorian and South Australian government departments also provided valuable evidence to the Inquiry. This input guided the Committee to reach its conclusions and make informed recommendations.

Evidence provided by family members of their own experience of a loved one's donation enriched this report and its recommendations. The Committee is exceptionally grateful to all who shared their personal stories.

I wish to thank my fellow Committee Members, Deputy Chair, Annabelle Cleeland MP, Christine Couzens MP, Chris Crewther MP, Meng Heang Tak MP, Cindy McLeish MP, Jackson Taylor MP and former member, Gary Maas MP, for their contribution and dedication to the Inquiry.

On behalf of the Committee, I also extend our gratitude to the Committee Secretariat, Jessica Strout, Katherine Murtagh and Danielle Broadhurst as well as the Graphic Design and Publishing team for their invaluable work and support.

A handwritten signature in black ink that reads "Ella George". The script is fluid and cursive, with the first letters of "Ella" and "George" being capitalized and prominent.

Ella George MP
Chair

Executive summary

Why is registration and organ and tissue donation important?

Encouraging Victorians to register to become an organ and tissue donor on the Australian Organ Donor Register (AODR) is important because it increases the likelihood that a donation will proceed. This both honours an individual's donation wishes and helps someone in need of a transplant.

Victoria has a low percentage of its population registered on the AODR and there are opportunities available to improve this and facilitate more donations.

Donation and transplantation have significant health and economic benefits for individuals and the healthcare system. People can donate both organs and tissues. Unlike organ donation which can only occur when a person dies in hospital, tissue donation can occur up to 24 hours after death. People can also donate some organs and tissues while living, such as kidneys or stem cells.

There is a need to increase deceased organ and tissue donations, and living kidney and stem cell donations. While more deceased organ donations have taken place over the past ten years, most organ waitlists continue to rise, with the majority of patients being waitlisted for a kidney. Victoria also needs more deceased tissue donations to meet demand and more living stem cell donations to treat the growing number of patients with blood cancer.

Who is responsible for organ and tissue donation in Victoria?

AODR registration and promotion, and donation and transplantation service provision, is shared by federal and state government bodies and donation organisations.

The Australian Department of Health and Aged Care has policy responsibility for the AODR and Services Australia manages the register. The Organ and Tissue Authority (OTA) is a federal independent statutory authority leading Australia's national approach to improve donation rates, including by promoting the AODR and encouraging registrations across the country.

DonateLife Victoria (DLV) is responsible for raising Victorians' awareness of organ and tissue donation—encouraging them to register on the AODR and to share their donation wishes with their family. OTA provides funding to the Victorian Department of Health (DH) who provides this to various Victorian hospitals who deliver donation and transplantation services and employ donation specialists.

The Donor Tissue Bank of Victoria (DTBV) is a not-for-profit multi-tissue bank that screens donors for tissue donation, and retrieves, processes, stores, tests and distributes tissue. The Melbourne Lions Eye Donation Service is a not-for-profit collaboration providing eye tissue for transplantation and research.

What can be done to get more Victorians registered on the Australian Organ Donor Register?

One of the biggest opportunities to increase donations to save and improve lives is to lift AODR registration rates. There are several ways to register on the AODR, including an online form, Medicare through myGov or the Medicare app, or by post or phone. OTA aims to boost Victorian registrations from 23% of the population to 50% by 2027.

There were difficulties transferring historic data from the state-based means of recording donor decisions to the AODR in the early 2000s. One way to increase registrations is to make this issue more well-known and encourage Victorians to check their registration status, as some Victorians may think they are registered, but their data was not transferred to the AODR.

Victorians have not been able to record donor preferences on a driver licence since the early 2000s, although many people think this is still possible. Reintroducing driver licence registrations is a pivotal opportunity to amplify AODR registrations on a mass scale, noting nearly all eligible Victorians have a driver licence.

More Victorians will register on the AODR if it is easy to find, access and use. The Victorian Government can do more to promote the AODR and seamlessly integrate it into government touchpoints and websites. Incorporating a prominent 'Register online' call to action button on online services like the Service Victoria app and website is a key opportunity to increase registrations.

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.

Why is family discussion about donation important and how does this impact family consent rates?

Family consent to donation is always sought when a person dies and their organs and tissues are suitable for donation. But Australian family consent rates have decreased over the past approximately ten years, a trend accelerated by the COVID-19 pandemic.

While the factors influencing the decline in family consent rates in Australia are not well understood, there is compelling evidence that speaks to why families are more likely to provide consent for organ and tissue donation:

- if a person is registered on the AODR and discussed donation with their family, then family consent is much more likely

- if a donation specialist is involved in conversations about the potential for donation, then family consent is also more likely.

Families feel more comfortable when they know they are affirming and fulfilling their family members' donation wishes. Families should feel support and trust before, during and after donation to make the process easier for them at a time of grief. Ensuring donation specialists are appropriately trained and able to build rapport with families is critical.

Another way to better support families after donation is for the Victorian Government to implement legislative change to allow donors to be recognised on death certificates.

Prior knowledge of donation and health literacy about donation processes can also increase the likelihood that families provide consent. This is why expanding education and knowledge about registration, family discussion and donation is important.

Cultural, social and religious beliefs or perspectives can influence donation conversations and family consent. It is important for clinicians and donation specialists to have sufficient cultural knowledge to sensitively raise donation with diverse families, involving spiritual leaders and incorporating cultural requirements wherever possible.

How can more Victorians be informed about organ and tissue donation and registration?

OTA and DLV share responsibility for promoting the AODR and donation. There are several valuable awareness and education campaigns and events run throughout Australia, including DonateLife Week and DTBV's Tree of Life recognition, as well as others run by community organisations. Events like this honour and celebrate donors and can encourage registrations at scale. However, OTA has not made any big investments in mass media over the last ten years.

DLV undertakes grassroots community campaigns, but current Victorian legislation requires the Victorian Minister for Health to approve DLV's advertising, restricting DLV's ability to undertake awareness campaigns. This requirement should be removed or modified.

The Committee's analysis of local government area AODR registration data revealed some of the inner metropolitan suburbs with the lowest registration rates are also some of the most culturally diverse and fastest growing. Data like this can be used to inform mass community awareness and education campaigns, that:

- use personal stories from donor recipients and donor families
- address myths and misconceptions, including for diverse communities
- provide detailed and clear information about the donation process so people can make informed registration decisions and be supported to start family discussion about donation
- increase awareness of tissue donation, which is not well understood.

The Victorian Government and DLV should work together to promote donation and registration through online platforms, traditional media and in public spaces; and collaborate with Victorian businesses, not-for-profits, professional associations and Lifeblood.

Tailored and co-designed community engagement strategies can help spread the word about donation and the AODR and address misconceptions. This includes engaging across generations in multicultural families to have effective discussions about donation, involving multicultural community leaders and organisations to share information and producing easy-read and translated resources. Building collaborative and consultative relationships with Victorian First Nations communities and Elders to ensure initiatives to increase awareness about donation and registration are culturally appropriate is especially important.

Encouraging younger Victorians to register on the AODR is essential to create familiarity with donation and registration from an early age. Developing a donation and registration awareness-building, education and discussion program for younger Victorians will help them to make an informed decision about donation and share this with their family. This could be further enhanced by incorporating information about organ and tissue donation into formal education channels.

What can be done to get more Victorians to register to become stem cell donors?

People can become stem cell donors by joining the Australian Bone Marrow Donor Registry (ABMDR) through Lifeblood or Strength to Give. ABMDR, Lifeblood and state governments have responsibility for recruiting stem cell donors. Stem cell donations are important because they are used to treat blood cancers, the incidence of which has increased by 47% over the past ten years.

Not enough Australians are registered on the ABMDR, which means Australia imports 3 in 4 stem cell donations from overseas. In particular, Australia needs more male and ethnically diverse stem cell donors aged 18 to 35.

Awareness of the need for stem cell donors and how to register is low, and misconceptions about the process can deter people from registering. Expanding modern cheek swab recruitment campaigns (through Strength to Give) can help encourage registrations and donations, particularly in target communities. The intermittent and delayed release of Australian Government funding for stem cell donor recruitment is currently a roadblock to achieving this.

Why is living kidney donation important?

Living organ donation involves donating a kidney or part of a liver. Living donor liver transplants are rare. Living kidney donations—both anonymous or to a relative or friend—are particularly important because the number of living donors is decreasing

but the kidney waitlist is increasing. More living kidney donors can save more lives and provide better early and long-term care for patients, and reduce dependence on kidney dialysis.

Additional support for living kidney donors, including by expanding the Australian Government's *Supporting Living Organ Donors Program*, can reduce some financial barriers to living donation.

What are some other opportunities to increase donation rates?

While the Committee's Inquiry focused on increasing Victorian registrations on the AODR, stakeholders also provided evidence about other ways to improve donation rates. This can help fulfill the wishes of people who registered on the AODR and wanted to be a donor.

There is room to maximise opportunities for deceased tissue donation in Victoria, including by:

- facilitating better collaboration and information-sharing between key stakeholders to identify and refer potential tissue donors
- increasing awareness of tissue donation in the medical community.

Most organ and tissue donation occurs in the Melbourne metropolitan area and DLV is appropriately staffed to facilitate donation for identified donors across Victoria. A donation culture may be better embedded in regional hospitals by employing specialists part-time or in a dual role. Eye and tissue retrieval from rural and regional areas can also face logistical challenges. Some initiatives are being implemented to address these challenges, and the feasibility of employing mobile tissue retrieval teams should be explored.

Routinely referring patients at end of life to DLV and embedding donation into hospital procedures ensures that a person who wanted to be a donor can be. Expanding the existing potential donor pool, for example by accepting a wider range of donors like older or less healthy people, is another opportunity to increase donations.

The Committee learned about the role of a Victorian coroner in relation to organ and tissue donation, and how a coroner makes consent decisions while investigating a death. Relevant stakeholders are already working together to promote understanding of each other's roles and responsibilities and to explore opportunities to streamline donation processes.

Advance care planning, wills and voluntary assisted dying processes are also opportunities for Victorians to make their donation wishes known, and for these to be fulfilled.

Findings and recommendations

Chapter 3 Registering to be an organ and tissue donor

FINDING 1: Victorians have not been able to record interest in becoming an organ and tissue donor on driver licences since the early 2000s. This is only possible in South Australia, where the driver licence donor registration system was continued. 52

FINDING 2: Not all Victorians who recorded their organ and tissue donation decision through a past state-based mechanism had this decision transferred to the Australian Organ Donor Register. 54

FINDING 3: Victoria has a lower percentage (23%) of its population registered on the Australian Organ Donor Register (AODR) compared to other states (36% national average). This is partly attributable to the incomplete data transfer of Victorian records to the AODR in the early 2000s. 54

FINDING 4: There is confusion in the Victorian community about whether a previous record to become a potential organ and tissue donor on a driver licence is a valid registration on the Australian Organ Donor Register today. 55

RECOMMENDATION 1: Given uncertainty around historic Victorian driver licence donor registrations, the Victorian Government advise people 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 Australian Organ Donor Register using their MyGov Medicare account or the Medicare app. 55

FINDING 5: In practice there is no difference between intent and consent registrations on the Australian Organ Donor Register: families are always asked for consent when organ and tissue donation is considered. Family consent in the donation process is critical. 57

FINDING 6: Lowering the age to register on the Australian Organ Donor Register to include children under the age of 16 may encourage family discussion about, and normalise, organ and tissue donation. 57

FINDING 7: Evidence from international jurisdictions suggests that higher organ donation rates can be better achieved through: improvements to organ and tissue donation hospital systems and donor identification; investment in professional training and clinical staff who talk to families to obtain family consent; and better community awareness about donation—rather than by introducing an opt-out system. **63**

FINDING 8: An average of 58,000 Victorians register on the Australian Organ Donor Register each year. However, this does not equate to a large percentage increase in Victoria’s population registered due to population growth. **64**

FINDING 9: Many Victorians associate registering to become an organ and tissue donor with driver licences, even though they have not been able to register to be a donor when applying for a driver licence since the early 2000s. **65**

FINDING 10: 99.9% of Victoria’s eligible population holds a driver licence, meaning the option to register to be an organ and tissue donor through the State’s driver licence system presents an opportunity to increase Victorian registrations on the Australian Organ Donor Register on a mass scale. **66**

FINDING 11: Historical experiences of registering to be an organ and tissue donor through driver licences indicate that including the option to object to donation may have unintended consequences and result in missed donation opportunities. For example, where a person selects ‘no’ to donation because they are unsure of the implication even though they support donation. **68**

FINDING 12: Registering to be an organ and tissue donor on the Australian Organ Donor Register using a Medicare number increases the likelihood that a unique match is found and a person’s donation preferences are accurately recorded. **70**

RECOMMENDATION 2: The Victorian Government scope the capability of the State’s driver licence system to allow Victorians to register on the Australian Organ Donor Register (AODR) when applying for or renewing a driver licence. This should include a ‘yes’ registration option only and ways to maximise the finding of a unique record match on the AODR. **70**

FINDING 13: There are multiple ways for the Victorian Government to increase the promotion of the Australian Organ Donor Register through government channels, including the Service Victoria website and app, proof of age card applications, Victorian Electoral Commission enrolments and Ambulance Victoria memberships. **74**

FINDING 14: Using a prominent ‘Register online’ call to action button on Victorian Government websites and apps that provide an easily accessible and simple link to register on the Australian Organ Donor Register is an opportunity to increase registrations.

75

RECOMMENDATION 3: The Victorian Government increase its promotion of the Australian Organ Donor Register through the creation and use of a prominent ‘Register online’ call to action button on the Service Victoria website and app, as well as multiple other government channels, for example, proof of age card applications, Victorian Electoral Commission enrolments and Ambulance Victoria memberships.

75

FINDING 15: The current process to register on the Australian Organ Donor Register could be more seamless and efficient to promote registration. This includes its integration into Victorian Government websites and with Medicare.

77

FINDING 16: Increased use of the myGov and Medicare apps during the COVID-19 pandemic to access vaccination certificates led to a surge in registrations on the Australian Organ Donor Register. This demonstrates that providing accessible registration options encourages people to record an organ and tissue donation decision.

77

RECOMMENDATION 4: The Victorian Government explore the creation of direct links to securely register on the Australian Organ Donor Register (AODR) when accessing Victorian Government services to, if feasible:

- enable registration details to be transferred to the AODR through a data bridge and not link people seeking to register to the federal DonateLife online form
- auto-populate fields for personal information held by Victorian Government services to make it quicker and simpler for people to register.

78

FINDING 17: The distinction between intent and consent registrations is unnecessary and removing it may allow for easier registration on the Australian Organ Donor Register.

78

RECOMMENDATION 5: The Victorian Department of Health advocate to the Australian Department of Health and Aged Care to remove the distinction between intent and consent registration on the Australian Organ Donor Register.

79

FINDING 18: Some statistics reported by Services Australia and the Organ and Tissue Authority regarding the number and percentage of Australians registered on the Australian Organ Donor Register include deceased people. These statistics would be more meaningful if they included living potential donors only.

80

FINDING 19: National public reporting of Australian Organ Donor Register data has little value in evaluating the success or helping to inform the development of awareness campaigns to increase registrations. For example, collecting data on the registration method used or what prompted registration would be useful.

80

RECOMMENDATION 6: The Victorian Department of Health advocate to the Australian Department of Health and Aged Care and Services Australia to improve public reporting of Australian Organ Donor Register data, including:

- using Medicare information to remove deceased people from the register
- the option to record what prompted someone to register regardless of registration method.

81

FINDING 20: As organ and tissue donation registration data is sensitive, private health information, any digital enhancements implemented by the Victorian Government to encourage people to record a donation decision on the Australian Organ Donor Register needs to be accompanied by appropriate confidentiality and security measures to maintain public trust.

82

Chapter 4 Donation conversations and family consent

FINDING 21: The delay between family experiences of organ and tissue donation processes and the publication of the Organ and Tissue Authority’s wave research reports into these experiences, may diminish their usefulness to inform and improve donation-related communication and processes. No studies have been undertaken on this in a Victorian setting since the COVID-19 pandemic.

87

RECOMMENDATION 7: The Victorian Department of Health work with the Organ and Tissue Authority (OTA) and DonateLife Victoria to explore ways to:

- maximise the usefulness of OTA’s wave research reports into family experiences of donation to inform and improve donation-related communication and processes in Victoria
- ensure non-English-speaking Victorian families’ recent experiences of organ and tissue donation-related communication and processes are being captured in OTA’s research.

88

FINDING 22: Registering an organ and tissue donation decision on the Australian Organ Donor Register provides clear direction to donor families and donation staff on a potential donor's wishes and substantially increases the likelihood that a family will consent to donation. Registration changes the nature of donation conversations by making it easier for families to honour and respect their deceased loved ones' wishes. **89**

FINDING 23: 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. Family discussion about donation changes the nature of donation conversations by making it easier for families to honour and respect their deceased loved ones' wishes. **92**

RECOMMENDATION 8: The Victorian Department of Health work with the Australian Department of Health and Aged Care and Services Australia to explore opportunities following registration on the Australian Organ Donor Register (AODR) to:

- automatically contact people, encouraging them to share their donation wishes with family and provide links to steps to help start family discussion about donation
 - provide an option to allow people to automatically share their donation decision with family members via an email sent by the AODR.
- 92**

FINDING 24: Involving a trained organ and tissue donation specialist in end of life communication and donation conversations with families significantly increases the likelihood that a family will consent to donation. **94**

FINDING 25: DonateLife Victoria has recently implemented an improved roster of donation specialists to respond to organ and tissue donation cases in Victoria, with most donation specialists located in metropolitan Melbourne and travelling to regional areas as required. Maintaining a cohort of appropriately qualified staff and actively managing the roster to avoid burnout remains important. **94**

RECOMMENDATION 9: The Victorian Government build capacity for DonateLife Victoria and the Donor Tissue Bank of Victoria to continually improve recruitment and retention strategies for organ and tissue donation specialists and report annually on the outcomes achieved. **94**

FINDING 26: The Organ and Tissue Authority (OTA) is responsible for training donation specialists. However, jurisdictional data about the number of attendees and the effectiveness of OTA’s family donation conversation workshops is not publicly available.

96

RECOMMENDATION 10: The Victorian Department of Health support DonateLife Victoria to work with the Organ and Tissue Authority to improve public reporting on donation specialist training, including by publishing jurisdictional level data about attendance and effectiveness of family donation conversation workshops.

96

FINDING 27: Poor health literacy and lack of knowledge about organ and tissue donation makes family donation conversations harder. Families with good health literacy and prior experience with organ and tissue donation are better equipped to handle donation conversations and decision making about consent.

98

FINDING 28: If clinicians and donation staff can meet with families face-to-face (using translators if required) this assists in establishing rapport and trust with families which positively impacts donation conversations and consent rates.

103

FINDING 29: Continuously improving support for donor families before, during and after the decision making process for organ and tissue donation consent is important and has the capacity to positively influence the community’s respect, understanding and trust of the donation system, which in turn could positively affect registration and consent rates.

103

FINDING 30: Transplant recipients and donor families can communicate through de-identified letters but respective Human Tissue Acts in Australia prevent them from meeting. Donor families and healthcare professionals have diverse views about the opportunity for transplant recipients and donor families to meet.

104

RECOMMENDATION 11: The Victorian Government discuss at a national level the opportunity for all jurisdictions to seek to amend respective Human Tissue Acts to allow consenting, adult transplant recipients and donor families to choose to meet.

104

FINDING 31: The *Human Tissue Act 1982* (Vic) prevents health professionals and hospital staff from verifying with Births, Deaths and Marriages Victoria (BDM) that a deceased donation occurred. This means BDM cannot acknowledge a donor in the death register or on a death certificate as is the case in the Australian Capital Territory. 106

RECOMMENDATION 12: The Victorian Government seek to amend the *Human Tissue Act 1982* (Vic) to allow health professionals and hospital staff to disclose information identifying a deceased donor for the purposes of including this information in the death register and on a death certificate with the consent of a donor's next of kin or authorised family member.

106

RECOMMENDATION 13: The Victorian Government seek to amend the *Births, Deaths and Marriages Registration Act 1996* (Vic) to provide a clear process to recognise a deceased donor (including a past donor) in the death register and on a death certificate.

106

FINDING 32: Clinicians and donation specialists need sufficient cultural knowledge to sensitively raise donation with First Nations families in clinical settings. This includes ensuring the right family members are present for donation conversations based on kinship systems and that there is an appropriate amount of time and space as part of the end of life process.

109

RECOMMENDATION 14: The Victorian Department of Health review the current support arrangements for end of life care services for First Nations patients and families to ensure Victorian Aboriginal Liaison Officers are involved to help donation specialists lead culturally appropriate donation conversations and to assist families with decision making.

110

FINDING 33: DonateLife Victoria should continue to facilitate the involvement of spiritual leaders in the organ and tissue donation process and accommodate cultural requirements to assist families involved in donation conversations where possible.

111

FINDING 34: Families may feel more comfortable when organ and tissue donation conversations occur between medical staff and families with a shared or similar cultural background. Clinicians and donation specialists need sufficient knowledge to sensitively raise donation with culturally and linguistically diverse families in clinical settings.

112

RECOMMENDATION 15: The Victorian Department of Health build capacity for DonateLife Victoria to ensure recruitment strategies will grow the cultural and ethnic diversity of the donation specialist workforce to reflect the State's multicultural population, and further the ability of donation specialists to lead culturally appropriate donation conversations and assist with family decision making.

112

Chapter 5 Awareness and education

FINDING 35: The requirement under the *Human Tissue Act 1982* (Vic) for organ and tissue donation advertising in Victoria to be approved by the Minister for Health restricts DonateLife Victoria’s ability to conduct awareness activities. **115**

RECOMMENDATION 16: The Victorian Government seek to amend the *Human Tissue Act 1982* (Vic) to remove the requirement for DonateLife Victoria (DLV) to obtain the Minister for Health’s approval for awareness activities or narrow the definition of advertising to exclude certain DLV awareness activities. **115**

FINDING 36: While investing in mass awareness campaigns that educate Australians about organ and tissue donation would encourage registration at scale, the Organ and Tissue Authority has not made any big investments in mass media over the last ten years. **116**

FINDING 37: In 2022, less than 20% of people were registered on the Australian Organ Donor Register in ten Victorian local government areas (LGAs), six of which (Wyndham, Hume, Melbourne, Melton, Whittlesea, Casey) are expected to see the largest population growth in metropolitan Melbourne from 2021 to 2036. These areas also have a high number of language communities with diverse language needs and low English proficiency. **118**

FINDING 38: In 2022, 34% or more of people were registered on the Australian Organ Donor Register in ten Victorian local government areas, nine of which are regional. This compares to a state average of 23%. **119**

FINDING 39: Mass awareness campaigns about organ and tissue donation should use postcode data to target localities with low donor registration rates and tailor messaging based on demographic data (including age, cultural and language diversity and religious affiliation). **119**

RECOMMENDATION 17: The Victorian Government advocate to the Australian Government for additional Organ and Tissue Authority funding to increase awareness campaigns about organ and tissue donation that use postcode data to target localities with low registration rates and tailor messaging based on demographic data. **119**

RECOMMENDATION 18: The Victorian Government consult with and support DonateLife Victoria to undertake targeted awareness campaigns about organ and tissue donation, using Victorian registration and demographic data, and publicly report on the effectiveness of the activities undertaken.

119

FINDING 40: People have a strong desire to make an informed decision about registering on the Australian Organ Donor Register and to understand the donation process. Awareness and education campaigns about donation should seek to include personal stories from donor recipients and donor families, as well as content to dispel myths and misconceptions about donation and encourage people to discuss donation with their family.

125

RECOMMENDATION 19: The Victorian Government ensure that all avenues it uses to promote organ and tissue donor registration include, wherever possible, personal stories from donor recipients and donor families, as well as content to dispel myths and misconceptions about donation and encourage people to discuss donation with their family.

125

FINDING 41: While many people know it is possible to become an organ donor, many are unaware they can also become a tissue donor. Donation campaign materials, Australian Organ Donor Registration avenues, and physical and digital cards (including driver licences) that evidence a person's donation decision should include reference to tissue wherever the word organ is used.

126

RECOMMENDATION 20: The Victorian Government consult with and support DonateLife Victoria to:

- include information about tissue donation and its importance in all donation awareness and campaign materials
- advocate to the Organ and Tissue Authority to increase its focus on tissue donation awareness, including by scoping the potential to add tissue to the name of the Australian Organ Donor Register.

127

FINDING 42: There are many differences between Victoria's multicultural and religious communities. One approach to raising awareness and education about organ and tissue donation and how to register on the Australian Organ Donor Register will not fit all communities.

129

FINDING 43: Awareness and education about organ and tissue donation should target and include all generations of families from multicultural and faith-based communities to assist them to have effective discussion about donation. **129**

FINDING 44: Building collaborative and consultative relationships with Victorian First Nations communities and Elders about organ and tissue donation is essential to ensure that community awareness about registration on the Australian Organ Donor Register and donation processes increases and is culturally appropriate. **131**

FINDING 45: Co-designed and tailored community engagement projects between diverse community leaders and organisations and the Victorian Government, modelled on those established during the COVID-19 pandemic to share public health information, would provide ideal opportunities to share information and talk about organ and tissue donation with diverse communities. **133**

RECOMMENDATION 21: The Victorian Government consult with community leaders, Elders and organisations to co-design and tailor engagement projects to provide opportunities to share information and talk about organ and tissue donation, including:

- the production of resources to engage with digitally disadvantaged Victorians through mail drops as well as easy-read and translated resources
- the provision of translated resources in different formats to promote registration and family discussion when Victorians engage with government touchpoints, including through driver licence applications and renewals
- programs to support intergenerational discussion in families from multicultural and faith-based communities
- a First Nations organ and tissue donation ambassador program. **134**

FINDING 46: Many young people support the idea of organ and tissue donation but across Australia only 10% of people aged 16 to 25 have registered a donation decision on the Australian Organ Donor Register. Providing donation-related awareness-building, education and discussion opportunities for younger Victorians will help them to make an informed decision about donation and share this with their family. **136**

RECOMMENDATION 22: The Victorian Government develop and deliver a program in conjunction with DonateLife Victoria and the Donor Tissue Bank of Victoria targeted at 15- and 16-year-olds to increase knowledge about organ and tissue donation to enable informed decision making and promote effective family discussions ahead of becoming eligible for driver licences, and publicly report on the outcomes achieved by the program. **136**

FINDING 47: Incorporating organ and tissue donation into formal education channels would help raise young people’s awareness and understanding about donation (including those from diverse backgrounds) and could encourage, empower and prompt young people to act on their intention and register on the Australian Organ Donor Register and share this with their family.

139

RECOMMENDATION 23: The Victorian Government include information about organ and tissue donation in the primary and secondary school curriculum.

139

RECOMMENDATION 24: The Victorian Department of Education promote awareness and family discussion about organ and tissue donation to Victorian schools during DonateLife Week, as well as consider how schools can use other touchpoints to share information about donation, such as via social media.

139

FINDING 48: Promotion, education and awareness of organ and tissue donation and registration in Victoria should use TV, radio, social media and online platforms as well as posters, billboards and pamphlets in public spaces to ensure broad reach across the community.

141

RECOMMENDATION 25: The Victorian Government enhance collaboration with DonateLife Victoria to increase the presence of promotional and educational material about organ and tissue donation through TV, radio, social media and online platforms as well as posters, billboards and pamphlets in public spaces, and publicly report on these initiatives and their effectiveness.

141

FINDING 49: Collaboration and partnerships with Victorian businesses, charities, not-for-profits, professional associations, unions and Lifeblood to encourage people to register on the Australian Organ Donor Register are key opportunities to increase registrations.

144

RECOMMENDATION 26: The Victorian Government assist DonateLife Victoria to collaborate and form partnerships to encourage people to register on the Australian Organ Donor Register with Victorian businesses, including farming and health insurers, charities, not-for-profits, professional and sporting associations, and unions.

144

RECOMMENDATION 27: The Victorian Department of Health support and encourage DonateLife Victoria and Lifeblood to work together to increase the promotion of organ and tissue donation through Lifeblood’s network, and publicly report on the outcomes achieved by these initiatives.

144

FINDING 50: Increasing public reporting on the outcomes achieved by awareness activities funded by the Organ and Tissue Authority about organ and tissue donation could help inform and improve future efforts, including those aimed to increase registration on the Australian Organ Donor Register and encourage family discussion about donation.

145

RECOMMENDATION 28: The Victorian Government advocate to the Organ and Tissue Authority (OTA) for increased transparency and accountability about OTA-funded donation awareness activities, especially those which aim to increase registrations and encourage family discussion.

145

Chapter 6 Living donation

FINDING 51: Minimising Australia’s reliance on international stem cell donors by increasing the number of domestic registered ideal donors would improve cost efficiency and produce more equitable outcomes for diverse patients, in particular for patients from First Nations, Pacific Islander and Southeast Asian communities.

154

FINDING 52: The Australian Bone Marrow Donor Registry receives less funding for registry services than the Australian Government pays to Germany each year for imported stem cell donations.

155

RECOMMENDATION 29: The Victorian Department of Health advocate through the national Health Ministers’ Meeting for increased Australian Government funding for the Australian Bone Marrow Donor Registry.

155

FINDING 53: Awareness about stem cell donation and the need for more registered stem cell donors is low. Prevailing myths and misconceptions about the donation process can be a deterrent to registration on the Australian Bone Marrow Donor Registry, even though clinical advancements mean most donations are stem cell (not bone marrow) and have minimal pain or side effects.

157

FINDING 54: Strength to Give—the Australian Bone Marrow Donor Registry’s donor-facing brand and campaign with a focus on recruiting stem cell donors through home-delivered cheek swabs—promotes evidence-based and modern recruitment practices to increase the number of registered stem cell donors. Expanding Strength to Give can help increase awareness of stem cell donations and encourage people to register to donate.

158

FINDING 55: Facilitated cheek swab collection at targeted community events with experienced and trusted partners would assist in increasing the number of ideal stem cell donors registered on the Australian Bone Marrow Donor Registry. **159**

FINDING 56: Opportunities to increase awareness of stem cell donations and how to register on the Australian Bone Marrow Donor Registry include using culturally appropriate resources, and school and higher education-based programs. **159**

RECOMMENDATION 30: The Victorian Government routinely use multiple government channels to promote awareness of stem cell donations and registration on the Australian Bone Marrow Donor Registry through the Strength to Give cheek swab campaign and blood donation. **159**

RECOMMENDATION 31: The Victorian Government support Lifeblood, the Australian Bone Marrow Donor Registry and stem cell donor recruitment organisations to extend the reach of stem cell donor awareness and recruitment campaigns, including support to facilitate cheek swab collection at community events. **159**

FINDING 57: The Victorian Government has a contract with Lifeblood to recruit stem cell donors. Lifeblood's current consent processes and network of blood donors limits its ability to recruit ideal stem cell donors. There are opportunities for the Australian and Victorian Governments, the Australian Bone Marrow Donor Registry and Lifeblood to increase collaboration to maximise opportunities for large scale stem cell donor recruitment, including the recruitment of younger Victorians and those from ethnically diverse backgrounds. **161**

RECOMMENDATION 32: The Victorian Government review the current arrangements for stem cell donor recruitment in Victoria and make changes to allow for the larger scale recruitment of stem cell donors. **161**

RECOMMENDATION 33: The Victorian Government support Lifeblood and the Australian Bone Marrow Donor Registry to ensure stem cell donor recruitment activities in Victoria target the recruitment of younger Victorians and those from ethnically diverse backgrounds through initiatives like education campaigns in schools or higher education institutions. **161**

FINDING 58: Australian Government funding and support for stem cell donor recruitment has been intermittent and delayed, negatively impacting the ability to recruit donors and build relationships in diverse communities. **162**

RECOMMENDATION 34: The Victorian Department of Health advocate through the national Health Ministers' Meeting for:

- immediate funding to expand Strength to Give and stem cell donor recruitment
- the immediate release of the \$1 million in stem cell donor recruitment funds agreed to in 2023
- a commitment to establish a permanent and ongoing funding mechanism for stem cell donor recruitment.

162

FINDING 59: The number of Victorian and Australian living kidney donors has decreased over the past ten years. But increasing living kidney donor rates can save lives, provide better early and long-term outcomes for patients who receive a transplant, reduce the time spent waiting for a kidney transplant and kidney transplant waitlists, and lead to cost savings by reducing dependence on kidney dialysis.

167

FINDING 60: Increasing support for living donors may help reduce some of the barriers and potential financial burden to becoming a living donor.

171

RECOMMENDATION 35: The Victorian Department of Health consider methods to provide greater support for living donors and advocate to the Australian Government for the *Supporting Living Organ Donors Program* to be expanded.

171

Chapter 7 Health settings and further opportunities to increase donation rates

FINDING 61: The number of deceased tissue donors in Victoria has decreased since 2015 and the Donor Tissue Bank of Victoria (DTBV) is at risk of running out of its stockpile of bone tissue. It is essential to increase the number of deceased tissue donors in Victoria for DTBV to operate efficiently at scale and meet demand in the Victorian market.

177

FINDING 62: Deceased tissue donation opportunities are being lost in Victoria because communication between different stakeholders and access to medical information is often delayed. There is a lack of awareness and understanding in the medical community about the Donor Tissue Bank of Victoria and the tissue donation process.

179

FINDING 63: Collaboration between DonateLife Victoria, the Donor Tissue Bank of Victoria and Victorian hospitals is essential for the identification and referral of potential deceased tissue donors and to increase understanding of tissue donation in the medical community.

180

RECOMMENDATION 36: The Victorian Department of Justice and Community Safety and Victorian Department of Health better support DonateLife Victoria and the Donor Tissue Bank of Victoria to increase understanding about tissue donation in the medical community and publicly report on progress.

181

RECOMMENDATION 37: The Victorian Government explore options and consult with other states with similar initiatives to:

- notify DonateLife Victoria, Melbourne Lions Eye Donation Service and the Donor Tissue Bank of Victoria (DTBV) about deaths that potentially involve organ and tissue and tissue-only donations in real time
- facilitate better sharing of hospital medical records and patient information with DTBV, which may involve seeking better working relationships between agencies in the Victorian Department of Health and Victorian Department of Justice and Community Safety (DJCS)
- consider the appropriateness of DTBV being situated within DJCS.

181

FINDING 64: Improving tissue governance and collaboration in the eye and tissue sector is recognised in the *Transition Action Plan (TAP)* for the draft *National strategy for organ donation, retrieval and transplantation* but it is unclear what action has been taken since the TAP was released in August 2022.

182

FINDING 65: The Donor Tissue Bank of Victoria (DTBV) has been unable to invest in research and development due to it making significant annual losses. DTBV's recent financial self-sufficiency presents an opportunity to invest in research and development to enhance and create tissue products and remain competitive in the market.

183

FINDING 66: The Melbourne Lions Eye Donation Service's facility for coordinating eye tissue donation, retrieval and testing is at capacity which may prevent it from meeting future increased demand for eye tissue.

184

RECOMMENDATION 38: The Victorian Department of Health monitor the capacity of the Melbourne Lions Eye Donation Service (LEDS) facility at the Royal Victorian Eye and Ear Hospital and consider the potential for expansion, relocation or a purpose-built facility to ensure LEDS has the capacity to meet future demand. **184**

FINDING 67: Supporting rural and regional hospitals to employ donation specialists part-time or in a dual role could help to embed an organ and tissue donation culture and improve donation knowledge for broader hospital staff. **186**

RECOMMENDATION 39: The Victorian Department of Health in consultation with DonateLife Victoria explore the potential for rural and regional hospitals to employ donation specialists part-time or in a dual role to better embed an organ and tissue donation culture and improve donation knowledge for broader hospital staff. **186**

FINDING 68: There is a lack of capacity in Victoria to facilitate tissue and eye retrieval in rural and regional Victoria, with logistical challenges often preventing retrieval and transport to Melbourne. Sometimes for tissue donations, a family incurs costs to transport their deceased loved one from a rural or regional area to the dedicated tissue retrieval mortuary in Southbank. **188**

RECOMMENDATION 40: The Victorian Government support the Donor Tissue Bank of Victoria to determine the feasibility of employing mobile tissue retrieval teams to travel to different sites, including in rural and regional locations, to retrieve and transport tissue donations. **188**

FINDING 69: Victorian hospitals have an opportunity to improve deceased organ and tissue donation rates by implementing routine procedures to ensure all patients at end of life have the chance to become donors. **190**

FINDING 70: There are several opportunities to increase organ donations from the existing potential donor pool by accepting a wider range of organs, for example, from older or less healthy donors. Extended criteria donation opportunities are restricted by current transplant unit capacity, technology and selectivity about organ suitability. **191**

FINDING 71: Machine perfusion technologies have many benefits, including extending organ preservation times that help to overcome logistical barriers that may prevent a deceased organ donation from occurring. There is opportunity to expand the use of current machine perfusion technology in Victorian hospitals and consider other emerging medical technology to improve deceased organ and tissue donation outcomes. **196**

FINDING 72: The Coroners Court of Victoria, DonateLife Victoria, the Victorian Institute of Forensic Medicine and Victorian hospitals providing organ and tissue donation services are working together to identify opportunities to increase understanding of each other’s roles and responsibilities, and to explore opportunities to streamline donation processes.

199

FINDING 73: Voluntary assisted dying (VAD) practices in Victoria present an opportunity for people approved for VAD to express interest and consent to organ and tissue donation. DonateLife Victoria is currently developing guidelines on donation and VAD.

200

FINDING 74: Making donation preferences a routine consideration in processes like advance care planning, wills and powers of attorney presents an opportunity to recognise people’s organ and tissue donation decisions and increase donation rates.

202

RECOMMENDATION 41: The Victorian Government explore ways to improve how organ and tissue donation is considered in government templates for advance care planning, wills and powers of attorney, including directly linking Victorians to register on the Australian Organ Donor Register and sharing links to help them talk to their family about donation.

202

Acronyms and terms

ABMDR	Australian Bone Marrow Donor Registry
ACT	Australian Capital Territory
ACT BDMR Act	<i>Births, Deaths and Marriages Registration Act 1997 (ACT)</i>
AHLO	Aboriginal Hospital Liaison Officers
ALO	Aboriginal Liaison Officers
ANAO	Australian National Audit Office
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
ANZETD	Australia and New Zealand Eye and Tissue Donation Registry
ANZICS	Australian and New Zealand Intensive Care Society
ANZICS DODC	Australian and New Zealand Intensive Care Society Death and Organ Donation Committee
ANZKX	Australian and New Zealand Paired Kidney Exchange
ANZLITR	Australia and New Zealand Liver and Intestinal Transplant Registry
ANZLKD	Australia and New Zealand Living Kidney Donation Registry
ANZOD	Australia and New Zealand Organ Donation Registry
AODR	Australian Organ Donor Register
Austin Health TIDCS	Austin Health, Transplant Infectious Diseases Clinical Service
BDM	Births, Deaths and Marriages
BETA	Behavioural Economics Team of the Australian Government
CALD	culturally and linguistically diverse
CBM	Cancellous Bone Matrix
CCV	Coroners Court of Victoria
CEO	Chief Executive Officer
Coroners Act	<i>Coroners Act 2008 (Vic)</i>
Cth	Commonwealth
DBD	donation after brain death
DCD	donation after circulatory death
DET	Victorian Department of Education and Training
DGS	Victorian Department of Government Services
DHAC	Australian Department of Health and Aged Care
DH	Victorian Department of Health
DIT	South Australian Department for Infrastructure and Transport
DJCS	Victorian Department of Justice and Community Safety
DLQ	DonateLife Queensland

DLV	DonateLife Victoria
dpmp	donors per million population
DSNC	Donation Specialist Nursing Coordinator
DTBV	Donor Tissue Bank of Victoria
DTP	Victorian Department of Transport and Planning
ECCV Committee	Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing
ED	emergency department
EY	Ernst & Young
FDC	Family Donation Conversation
GP	general practitioner
HIV	human immunodeficiency virus
HMM	Health Ministers' Meeting
HPC	haemopoietic progenitor cells
HSC	haemopoietic stem cells
HT Act	<i>Human Tissue Act 1982 (Vic)</i>
ICU	intensive care unit
ICV	Islamic Council of Victoria
IP	Implementation Plan
JOTSC	Jurisdictional Organ and Tissue Steering Committee
KTLDPMP	kidney transplant from living donors per million population
LEDS	Melbourne Lions Eye Donation Service
LGA	local government area
MAiD	medical assistance in dying
MBC	Monash Bioethics Centre
MCWH	Multicultural Centre for Women's Health
MOU	memorandum of understanding
NHMRC	National Health and Medical Research Council
NHS	United Kingdom, National Health Service
NSW	New South Wales
NT	Northern Territory
ONT	Spain, Organización Nacional de Trasplantes
OTA	Organ and Tissue Authority
PMP	per million population
PwC	PricewaterhouseCoopers
RACGP	Royal Australian College of General Practitioners
SA	South Australia
St Vincent's OTD	St Vincent's Hospital Melbourne, Organ and Tissue Donation Team

Acronyms and terms

TAP	Transition Action Plan
TGA	Therapeutic Goods Administration
UK	United Kingdom
US	United States
VAD	voluntary assisted dying
Vic	Victoria
VIFM	Victorian Institute of Forensic Medicine
WA	Western Australia
ZKRD	Germany, Zentralen Knochenmarkspender-Register Deutschland

Chapter 1

Introduction

People who become organ and tissue donors perform a selfless and generous act that saves and improves lives. In the words of Alfred Health, a major transplant provider and leading trauma hospital in Victoria, organ and tissue 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.¹

The Legal and Social Issues Committee (the Committee) undertook an *Inquiry into increasing the number of registered organ and tissue donors* to consider how Victoria can fully realise the potential of this gift.² **An individual's registration on the Australian Organ Donor Register (AODR) is important because it significantly increases the likelihood that a donation will proceed, honouring the donor's wishes.**³

At the time of this Inquiry, Victoria has a low percentage (23%) of its population registered on the AODR compared to the national average (36%).⁴ Raising awareness about organ and tissue donation and increasing the number of Victorians registered on the AODR has the potential to increase donations, save and improve lives, and produce significant health, economic and community benefits.

This chapter outlines the Committee's Inquiry process. It then explains how deceased and living donation works, and how to register to become a donor in Victoria. This chapter also considers why organ and tissue donation is important, along with the importance of registration, family discussions and consent.

1.1 Inquiry process

The Committee heard from a range of expert and community 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.⁵ Relevant Australian, Victorian and South Australian government departments also provided valuable evidence to the Inquiry.⁶

1 Alfred Health, *Submission 38*, received 1 June 2023, p. 2.

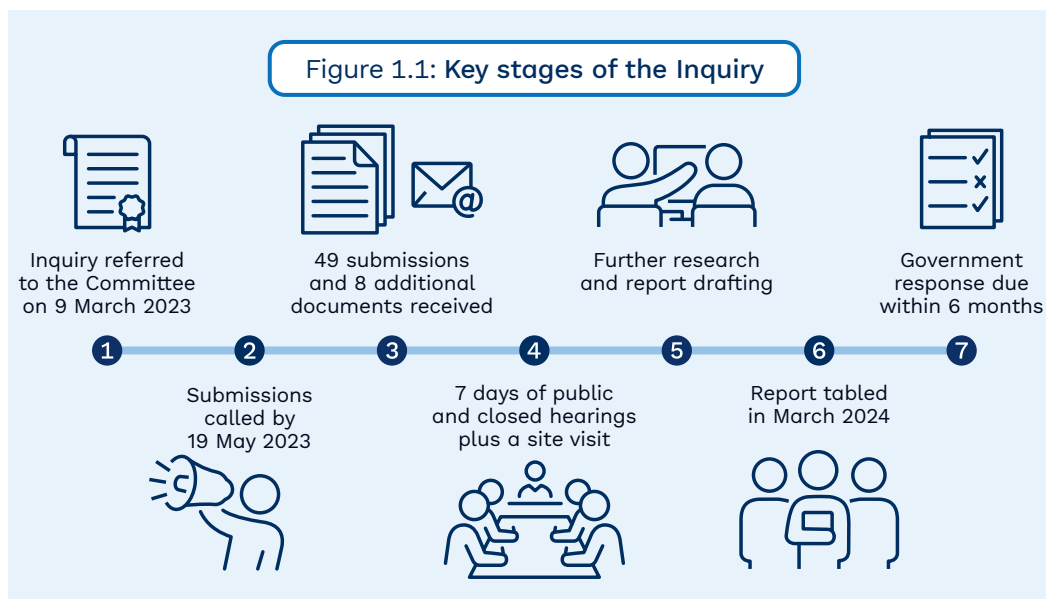
2 See the Committee's website for further guidance published on the scope of the Inquiry: <<https://www.parliament.vic.gov.au/organtissuedonor>>.

3 Organ and Tissue Authority, *Australian donation and transplantation activity report 2022, 2023*, p. 21. In 2022, families provided consent for donation to proceed 82% of the time if a person was registered on the AODR, compared to 39% when a person was not registered and the family did not know they wanted to be a donor.

4 Organ and Tissue Authority, *Australian donation and transplantation activity report 2022, 2023*, p. 22.

5 See Appendix A for a full list of submissions, additional information and public hearings.

6 The Committee received evidence from the Australian Department of Health and Aged Care; the Victorian Department of Health, Department of Transport and Planning and Department of Government Services; and the South Australian Department for Health and Wellbeing.



Source: Legislative Assembly Legal and Social Issues Committee, *Inquiry into increasing the number of registered organ and tissue donors*, n.d., <<https://www.parliament.vic.gov.au/organtissuedonor>> accessed 26 February 2024.

For the purposes of this report the Committee has relied on data from the Organ and Tissue Authority's (OTA) *Australian donation and transplant activity report 2022*, published on 21 February 2023,⁷ as the 2023 activity report was not available.

1.2 How does deceased donation work?

A person can be both a **deceased organ donor** and a **deceased tissue donor**.

Deceased organ donation includes kidneys, heart, lungs, liver, stomach, intestines and pancreas. It involves transplanting a viable organ from someone who dies (with family consent) to someone who is on the transplant waitlist. Deceased organ donation can occur if a person with well-functioning organs dies in hospital in specific situations. Organ transplants proceed if a person waitlisted matches the donor. Organs are matched based on blood group, compatibility, size and urgency.⁸ One deceased donor can donate organs to up to seven people and help many more through tissue donation.⁹

In Australia in 2022, approximately 1,400 people died in hospital (out of approximately 80,000 total deaths in hospital) in a way where organ donation was possible. This means around 2% of people who die in hospital each year have a chance to become an organ donor.¹⁰

⁷ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*.

⁸ Organ and Tissue Authority, *How does donation work?*, n.d., <<https://www.donatelife.gov.au/all-about-donation/how-does-donation-work>> accessed 13 September 2023; Better Health Channel, *Organ and tissue donation*, 11 January 2023, <<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/organ-and-tissue-donation>> accessed 13 September 2023.

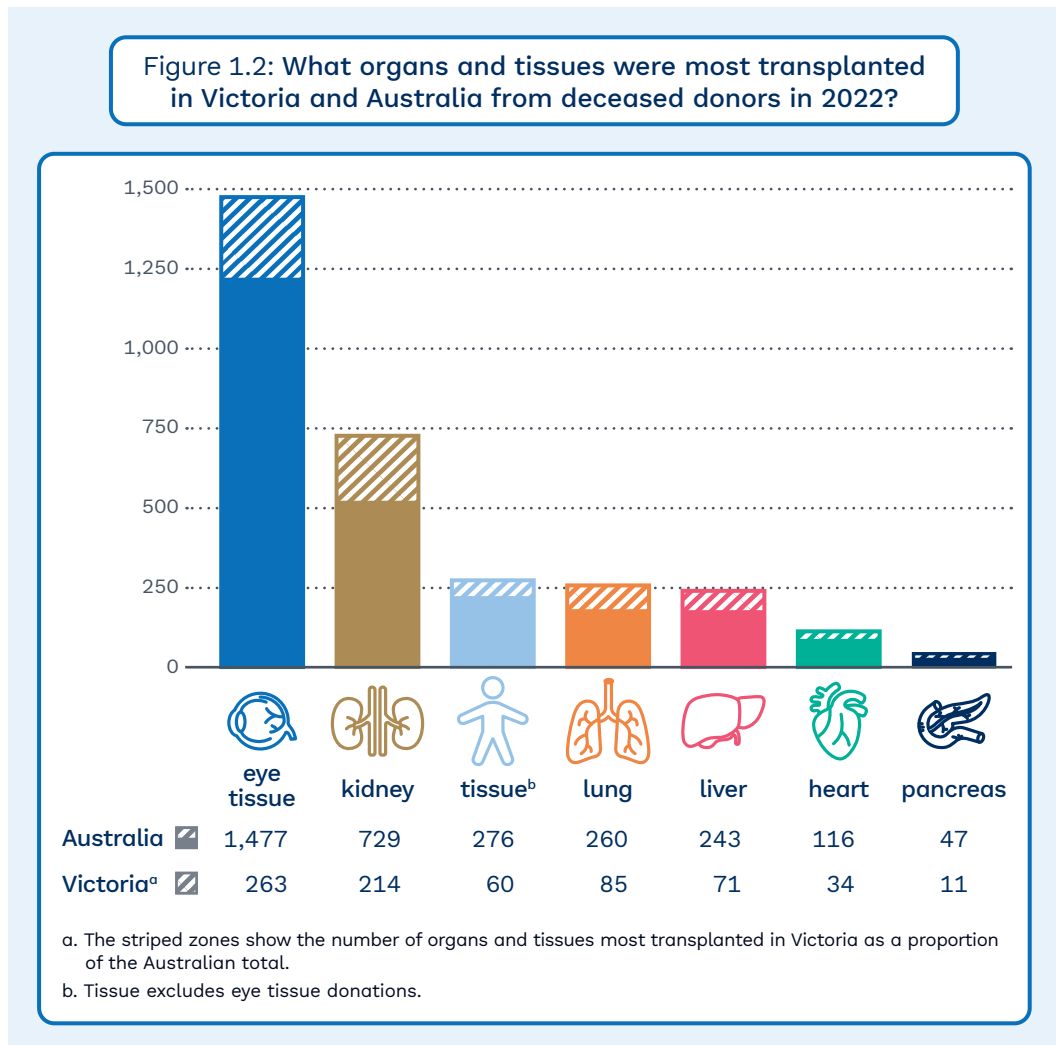
⁹ Organ and Tissue Authority, *Statistics in Australia*, n.d., <<https://www.donatelife.gov.au/all-about-donation/statistics-in-australia>> accessed 13 September 2023.

¹⁰ Ibid.

Deceased tissue donation includes heart valves and tissues, pancreas islets, bone and tendons, skin and eyes.¹¹ It involves retrieving tissue from someone who dies (with family consent) that is then stored as a product, available when someone needs it.¹² Tissue products include heart valves, bones, tendons, skin and parts of eyes.

Deceased tissue donation can usually occur up to 24 hours after death, meaning the person does not need to die in hospital.¹³

Across both organ and tissue donation, eye tissue is most frequently transplanted, followed by kidneys.¹⁴



Source: Australia and New Zealand Organ Donor Registry (ANZOD), *Monthly report on deceased organ donation in Australia, December 2022, 2023*, pp. 13-15; Australia and New Zealand Eye and Tissue Donation Registry (ANZETD), *Eye and tissue donation in Australia, monthly report December 2022: preliminary data, 2023*, pp. 11, 16.

11 Better Health Channel, *Organ and tissue donation*.
 12 Organ and Tissue Authority, *Eye and tissue donation awareness*, n.d., <<https://www.donatelife.gov.au/get-involved/eye-and-tissue-donation-awareness>> accessed 5 January 2024.
 13 Organ and Tissue Authority, *How does donation work?*
 14 While statistics on donors, donations and transplants are available (one donor can result in multiple donations/transplants), the Committee generally uses statistics on donors as they are most relevant to the Inquiry’s terms of reference.

The process for deceased organ and tissue donation is outlined in Figure 1.3 and the differences between organ and tissue donation are discussed in Section 1.3.

1.2.1 Registering to become a deceased donor

Australia has an **opt-in registration model** where a person registers their decision to donate their organs and tissues when they die on the AODR. The AODR is owned and administered federally by Services Australia on behalf of the Australian Department of Health and Aged Care.¹⁵

Anyone over 16 years old can register to donate, regardless of health. Individuals can register through an online form, a Medicare account through myGov or the Medicare app, or by post or phone. People can choose to donate all or specific organs and tissues, and through some registration methods can record an objection to donation.¹⁶ See Appendix B for a detailed summary of ways to register on the AODR.

When a potential donor is identified, medical professionals can access the AODR. The protocol for deceased organ donation is for medical professionals to check the AODR prior to a person's death in hospital, but after a prognosis that a person will die.¹⁷

Regardless of a person's registration status, consent from family is always sought when a person dies and their organs and/or tissues are suitable for donation.¹⁸ Consent is sought from the senior available next of kin, being the person's spouse or domestic partner, child over 18 years old, parent, or brother or sister over 18 years old.¹⁹

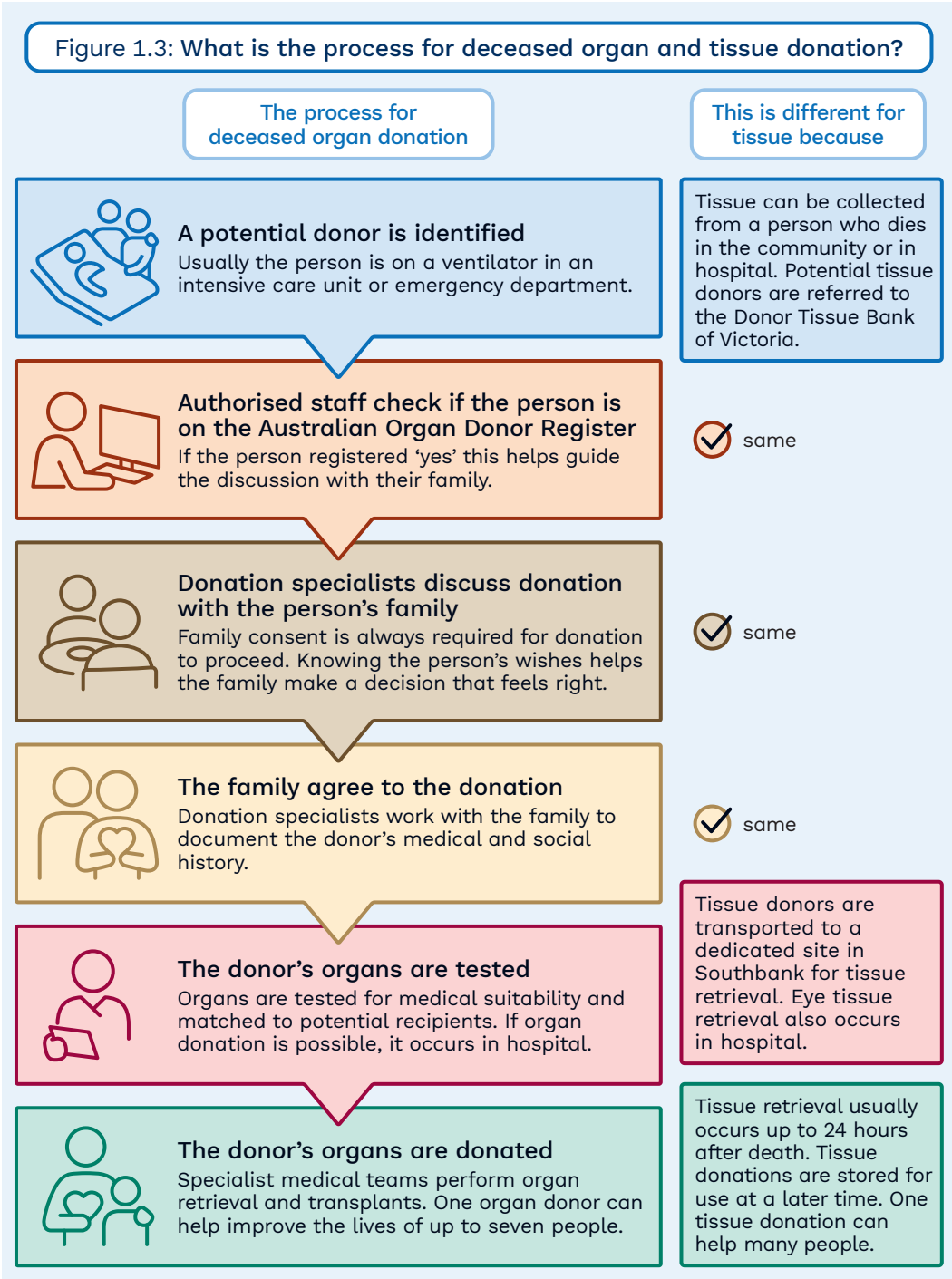
¹⁵ DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 3.

¹⁶ Organ and Tissue Authority, *Join the register*, n.d., <<https://www.donatelife.gov.au/register-donor-today>> accessed 13 September 2023; Better Health Channel, *Organ and tissue donation*.

¹⁷ Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 51; National Health and Medical Research Council, *Organ and tissue donation after death, for transplantation: Guidelines for ethical practice for health professionals*, 2007, pp. 26, 34.

¹⁸ DonateLife Victoria, *Submission 27*, p. 3.

¹⁹ *Human Tissue Act 1982* (Vic) s 3(1)(b).



Source: Lifeblood, *Organ and tissue*, n.d., <<https://www.lifeblood.com.au/organ-and-tissue>> accessed 13 December 2023; Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 42-43; Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 44; Organ and Tissue Authority, *How does donation work?*, n.d., <<https://www.donatelife.gov.au/all-about-donation/how-does-donation-work>> accessed 13 September 2023; Donor Tissue Bank of Victoria, *Discover: What is tissue donation?*, n.d., <<https://dtbv.org.au/discover>> accessed 13 December 2023.

Figure 1.4: Donation coordinators with eskies



Source: image supplied by DonateLife Victoria, 15 February 2024.

1.3 How is tissue donation different to organ donation?

Throughout the Inquiry the Committee learned about a general lack of awareness regarding tissue donation. Tissue donation is different to organ donation for several reasons.

One-to-many relationship: A single tissue donation can improve the health of up to 200 people.²⁰

Time: Tissue donations can be recovered up to 24 hours after death.²¹ Some tissue can be frozen for up to five years.²²

²⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, received 16 June 2023, p. 5.

²¹ *Ibid.*, p. 3.

²² Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 49.

Retrieval: Tissue can be recovered from a wider range of donors, including older people for eye tissue.²³ A person does not need to die in hospital to become a tissue donor and donations can be initiated by the donor’s family or through the coronial setting.²⁴ In Victoria, Donor Tissue Bank of Victoria (DTBV) nurses assess every death reported to the state coroner for potential tissue donation.²⁵ DTBV undertakes tissue retrieval at its dedicated site in Southbank adjacent to the state mortuary.²⁶

Storage and supply: Tissue is considered a product because it is stored and regulated by the Australian Therapeutic Goods Administration. The tissue donation process has greater safety and compliance obligations than organ donation.²⁷ Tissue banks supply tissue directly to surgeons on request.²⁸

Eye tissue donations: Even if the way a person dies precludes them from donating organs, many people can still become eye donors. Eye tissue does not need to be matched with the recipient (it must only be viable) and is easier to transport than organs.²⁹ Eye tissue donations can be ‘banked’ and stored, by being preserved in a ‘nutrient-rich media’ in an incubator for up to a month. Eye tissue can then be prepared according to a transplant surgeon’s request.³⁰

Speaking about the major positive health impact of tissue donations across the community, Brendan Sullivan, Head of Service at DTBV explained:

Tissue graft implants are ... far more widespread in the community than organ transplants and have a major positive health impact. Just to further draw that comparison, nationally in 2022 there were 454 organ donors and 1224 organ recipients. Referring to just deceased donors only—there are both deceased and living tissue donors—[in 2022 DTBV] ... had 58 tissue donors and supplied over 3280 human tissue allografts to Australian hospitals. That is one-eighth of the national number of organ donors for three times the national number of grafts just from Victoria, so ... it is a one-to-many relationship versus the one-to-few relationship in organ donation.³¹

23 Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 37.

24 Organ and Tissue Authority, *How does donation work*; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 10.

25 Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 43.

26 Brendan Sullivan, *Transcript of evidence*, p. 44.

27 *Ibid.*, pp. 38–39; Bronwyn Cohen, *Transcript of evidence*, p. 33; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 3–4.

28 Department of Health and Aged Care, *National Eye and Tissue Sector Framework, 2022*, p. 17.

29 Dr Heather Machin, Senior Project Manager, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 33.

30 Bronwyn Cohen, *Transcript of evidence*, p. 33; Dr Heather Machin, *Transcript of evidence*, p. 38.

31 Brendan Sullivan, *Transcript of evidence*, pp. 38–39.

1.4 How does living donation work?

Explored further in Chapter 6, living donation includes:

- **kidneys and, less frequently, liver**—organised by individual transplant units in hospitals, most commonly the donor is a blood relative or a close friend; or anonymous kidney donation is facilitated through the Australian and New Zealand Paired Kidney Exchange³²
- **tissue**—bone when undergoing joint replacement surgery,³³ placental tissue and amnion when women have an elective caesarean section³⁴ and heart valves collected from heart transplant recipients³⁵
- **breast milk, faecal microbiota, blood and plasma**—facilitated by Lifeblood³⁶
- **stem cell and bone marrow**—organised by the Australian Bone Marrow Donor Registry (ABMDR) for unrelated donors³⁷
- **egg, sperm and embryo**—Australia’s first public egg, sperm and embryo bank opened in Victoria in July 2023 to accept donations from the community.³⁸

32 Organ and Tissue Authority, *Understanding living donation*, n.d., <<https://www.donatelife.gov.au/all-about-donation/understanding-living-donation>> accessed 13 September 2023; Organ and Tissue Authority, *Australian and New Zealand Paired Kidney Exchange (ANZKX) program*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/ANZKX>> accessed 13 September 2023.

33 Organ and Tissue Authority, *Understanding living donation*; ANZETD, *Eye and tissue donation in Australia, monthly report July 2023: preliminary data*, 2023, p. 32.

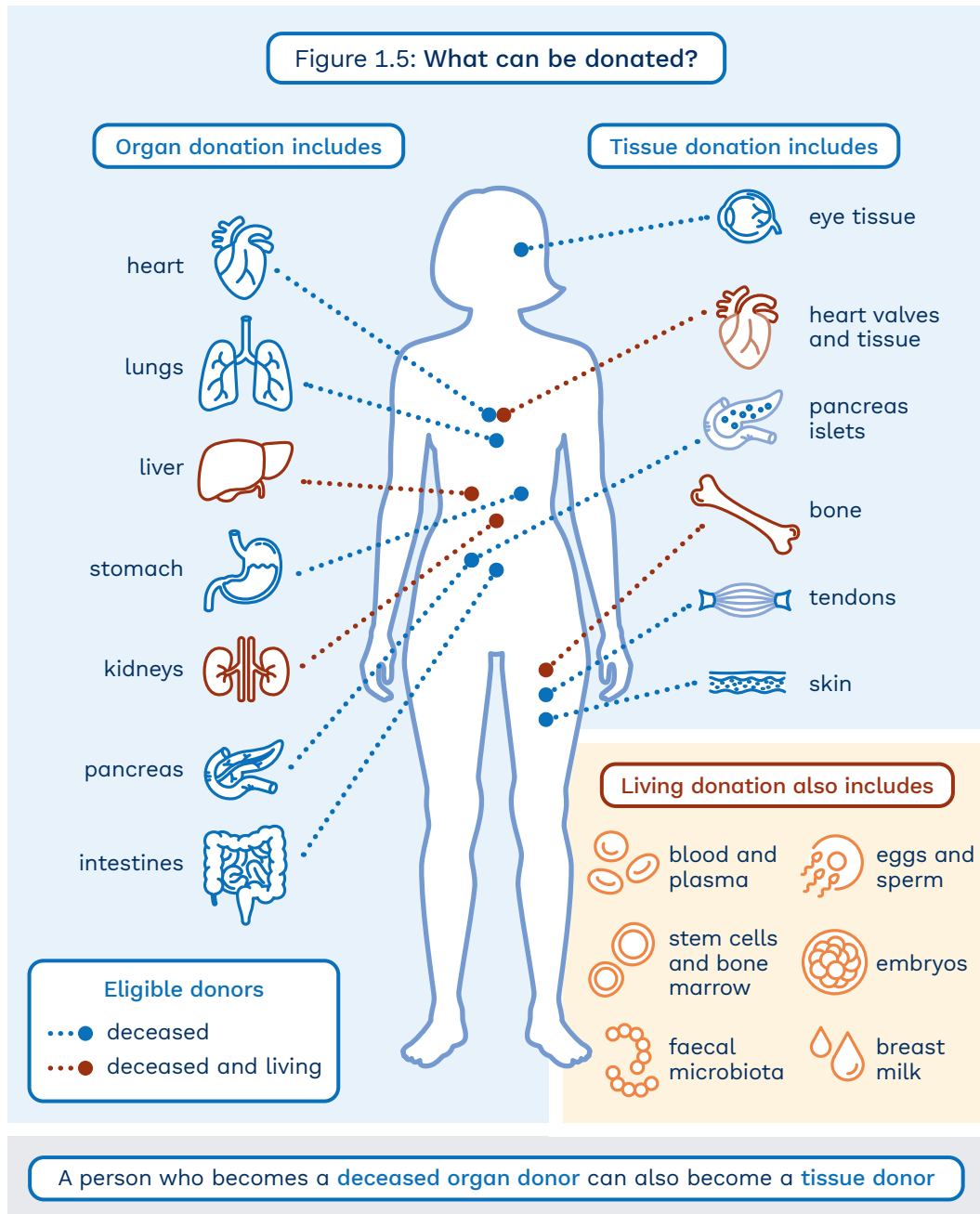
34 Australian Tissue Donation Network, *Placental tissue donation*, n.d., <<https://tissuedonationnetwork.org.au/programs/placental-tissue-donation>> accessed 16 November 2023; New South Wales Health, *NSW Tissue Bank*, n.d., <<https://www.seslhd.health.nsw.gov.au/services-clinics/directory/organ-and-tissue-donation-service/nsw-tissue-bank>> accessed 16 November 2023; ANZETD, *Eye and tissue donation in Australia, monthly report July 2023: preliminary data*, p. 32.

35 ANZETD, *Eye and tissue donation in Australia, monthly report July 2023: preliminary data*, p. 32; Victorian Institute of Forensic Medicine, *Annual report 2021–22*, 2022, p. 63.

36 Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 44.

37 Strength to Give, *How are you registering today?*, n.d., <<https://strengthtogive.org.au/register>> accessed 13 September 2023.

38 Department of Health, *Australia’s first public egg and sperm bank opens in Victoria*, media release, Victorian Government, Melbourne, 2 July 2023; Better Health Channel, *Egg, sperm and embryo donation*, 30 June 2023, <<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/egg-sperm-and-embryo-donation>> accessed 13 September 2023.



Source: Better Health Channel, *Organ and tissue donation*, 11 January 2023, <<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/organ-and-tissue-donation>> accessed 13 September 2023; Organ and Tissue Authority, *Understanding living donation*, n.d., <<https://www.donatelife.gov.au/all-about-donation/understanding-living-donation>> accessed 13 September 2023; Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 44; Strength to Give, *Frequently asked questions*, n.d., <<https://strengthtogive.org.au/faqs>> accessed 13 September 2023; Department of Health, *Australia's first public egg and sperm bank opens in Victoria*, media release, Victorian Government, Melbourne, 2 July 2023; Better Health Channel, *Egg, sperm and embryo donation*, 30 June 2023, <<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/egg-sperm-and-embryo-donation>> accessed 13 September 2023.

1.5 The importance of organ and tissue donation

Donation and transplantation have many substantial benefits. Organ donation significantly improves recipients' survival chances³⁹ and both organ and tissue donation enhance long-term quality of life.⁴⁰ It also benefits the community and healthcare system by shifting 'care from high-acuity, high-cost treatments required to sustain individuals with organ failure, to lower-acuity, lower-cost post-transplant care yielding superior outcomes.'⁴¹

Kidneys are the most frequently transplanted organ in Australia and serve as a good example of the importance of organ donation. Austin Health described kidney transplantation as 'a life-saving medical marvel' associated with 'a five to tenfold reduction in death, substantially improved quality of life and freedom to recreate, work and travel.'⁴² This is particularly relevant when comparing the cost and effectiveness of kidney transplants to dialysis.⁴³ Kidney transplantation:

- is a cheaper procedure than dialysis—a kidney transplant costs about \$100,000 for the initial year (with lower follow-up costs)⁴⁴ and dialysis costs up to \$85,000 per person per year⁴⁵
- reduces ongoing costs for the healthcare system—over the past 20 years, the number of dialysis recipients has more than doubled from close to 11,000 to 27,000 and dialysis is the most common cause of hospitalisation in Australia, accounting for 14% of hospitalisations in 2020–21⁴⁶
- performs natural functions more effectively than artificial methods⁴⁷
- improves recipients' long-term quality of life and health prospects⁴⁸
- is more convenient—allowing people with kidney failure to 'regain their freedom, enabling them to work, engage in recreational activities, and travel with greater ease'⁴⁹—dialysis, in comparison, requires hospital visits several times a week for several hours.⁵⁰

39 Austin Health, *Submission 34*, received 25 May 2023, p. 7; Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 26.

40 Austin Health, *Submission 34*, p. 7; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 5.

41 Austin Health, *Submission 34*, p. 7. See also Associate Professor Christopher Hogan, *Transcript of evidence*, p. 26.

42 Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 2.

43 Dialysis is a treatment to help remove extra fluid and waste products from the blood when the kidneys are not able to, see National Kidney Foundation, *Dialysis*, n.d., <<https://www.kidney.org/atoz/content/dialysisinfo#>> accessed 13 September 2023.

44 Name withheld, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 2.

45 Associate Professor John Whitlam, *Transcript of evidence*, p. 2. See also Associate Professor William Silvester, Chair, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 42.

46 Australian Government, Australian Institute of Health and Welfare, *Chronic kidney disease: Australian facts*, 14 December 2023, <<https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease/contents/treatment-and-management-of-chronic-kidney-disease/hospitalisations-for-chronic-kidney-disease>> accessed 6 February 2024; Associate Professor John Whitlam, *Transcript of evidence*, p. 2. See also Associate Professor William Silvester, *Transcript of evidence*, p. 42.

47 Austin Health, *Submission 34*, p. 4.

48 *Ibid.*, p. 4, with sources. See also Dr Aadhil Aziz, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 26.

49 Austin Health, *Submission 34*, p. 4, with sources. See also Dr Aadhil Aziz, *Transcript of evidence*, p. 26.

50 Dr Aadhil Aziz, *Transcript of evidence*, p. 26.

Liver transplants serve as a second good example of the importance of organ donation. Patients with liver failure who receive a transplant have promising prospects and survival rates. Austin Health provides liver transplant services for Victoria, Tasmania, and paediatric patients in South Australia. Austin Health described liver transplantation as a ‘beacon of hope’ for people with liver cancer and end-stage liver disease. With chronic liver disease increasing and liver cancer causing more cancer-related deaths in Australia (driven by the increased incidence of obesity and diabetes), liver transplants offer patients longer and better-quality lives.⁵¹

Skin transplants are a good example of the significant benefits of tissue donation. During the 2009 Black Saturday bushfires, DTBV supplied skin to Alfred Hospital to treat people who were severely burned.⁵² If more than 50% of the body surface is affected, transplantation of a patient’s own healthy skin to affected areas is difficult. Donated skin ‘stabilises the wounds, reduces infection and critical fluid loss, promotes healing’ and reduces long-term scarring. Using donor skin buys time for a patient’s own skin to be cultured and later grafted.⁵³ DTBV advised that up to 30 pieces of skin can be supplied for an individual patient, making maintaining reserves a challenge.⁵⁴ The Committee learned that in 2018–19 following the White Island volcano eruption in New Zealand, DTBV’s reserves of skin were fully depleted.⁵⁵

In addition to significant health and economic benefits, donation can also help families come to terms with the loss of a loved one.⁵⁶ DTBV explained how ‘[t]he gift of donation offers families the opportunity to salvage something positive from the tragic loss of someone they loved and to contribute back to the community.’⁵⁷ Chapter 4 discusses the experiences of families who have been asked to consider providing consent for donation.

1.5.1 Addressing growing waitlists and demand

While the deceased organ donation rate has increased in Victoria and Australia over the past ten years (see Figure 1.7), overall Australia’s organ waitlists have increased by 17%⁵⁸—outstripping a population increase of approximately 11%.⁵⁹

51 Austin Health, *Submission 34*, p. 4, with sources.

52 Professor Noel Woodford, Director, Victorian Institute of Forensic Medicine, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 41; Brendan Sullivan, *Transcript of evidence*, p. 38.

53 Donor Tissue Bank of Victoria, *Skin tissue*, n.d., <<https://dtbv.org.au/discover/types-of-tissue-that-can-be-donated/skin-tissue>> accessed 23 November 2023.

54 Brendan Sullivan, *Transcript of evidence*, p. 41.

55 *Ibid.*, p. 48; Victorian Institute of Forensic Medicine, *Annual report 2020–21*, 2021, p. 67.

56 Anna Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 21; David Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 21.

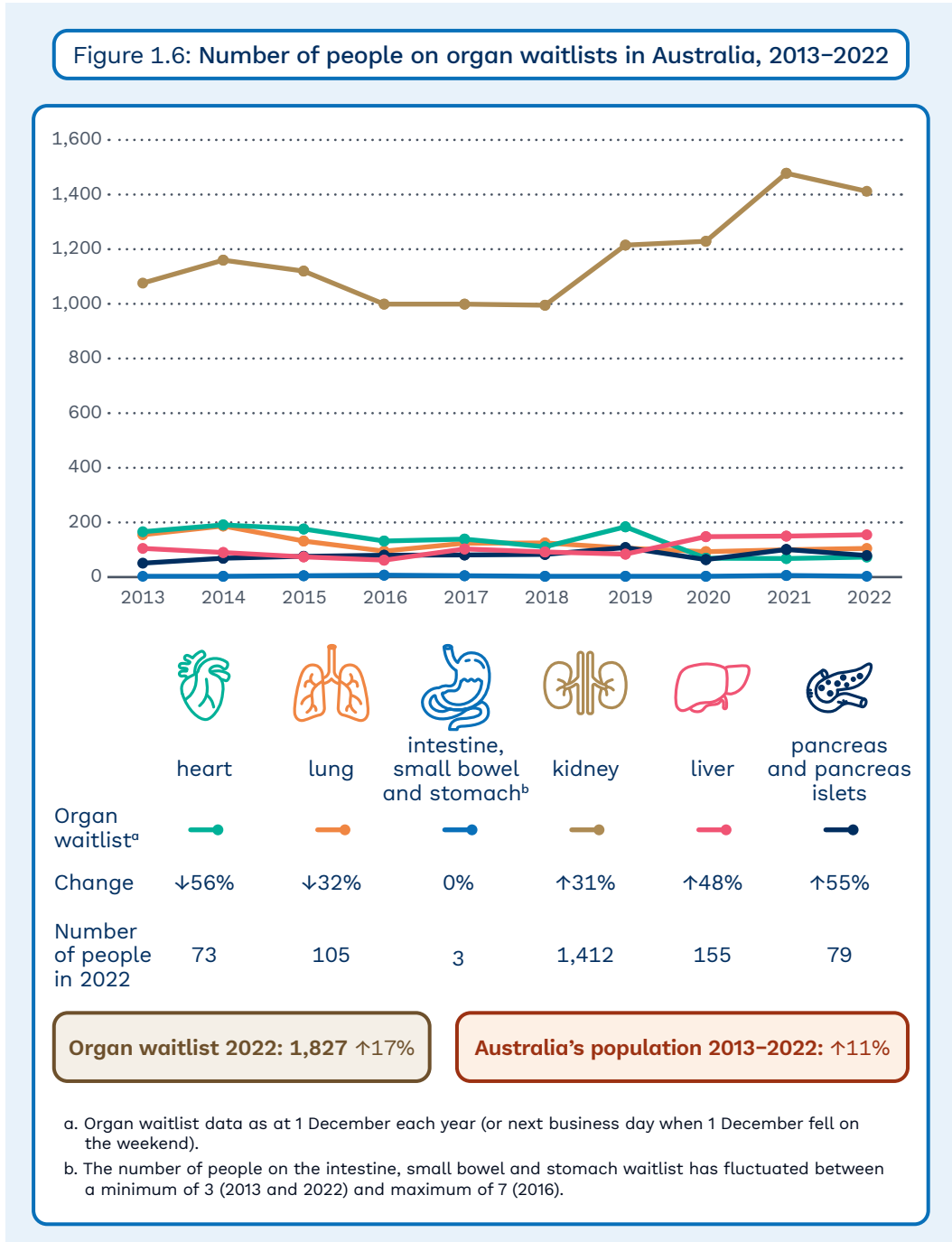
57 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 5.

58 Committee calculation for percentage increase in organ waitlists from December 2013 (1,556 people on waitlist) to December 2022 (1,827 people on waitlist): $(1827 - 1556) / 1556 \times 100 = 17.4$, see ANZOD, *Organ waiting list*, n.d., <<https://www.anzdata.org.au/anzod/publications-2/organ-waiting-list>> accessed 12 September 2023.

59 Committee calculation for percentage increase in population from December 2013 (23,319,400) to June 2023 (25,978,935): $(25,978,935 - 23,319,400) / 23,319,400 \times 100 = 11.4$, see Australian Bureau of Statistics, *National, state and territory population*, 2022, <<https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/jun-2022>> accessed 20 October 2023; Australian Bureau of Statistics, *Australian demographic statistics, Dec 2013*, 2014, <<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/3101.0Main+Features1Dec%202013>> accessed 20 October 2023.

The majority of waitlisted patients need a kidney transplant. Since 2013 liver and pancreas waitlists have experienced the biggest increases and heart and lungs a substantial decrease.⁶⁰

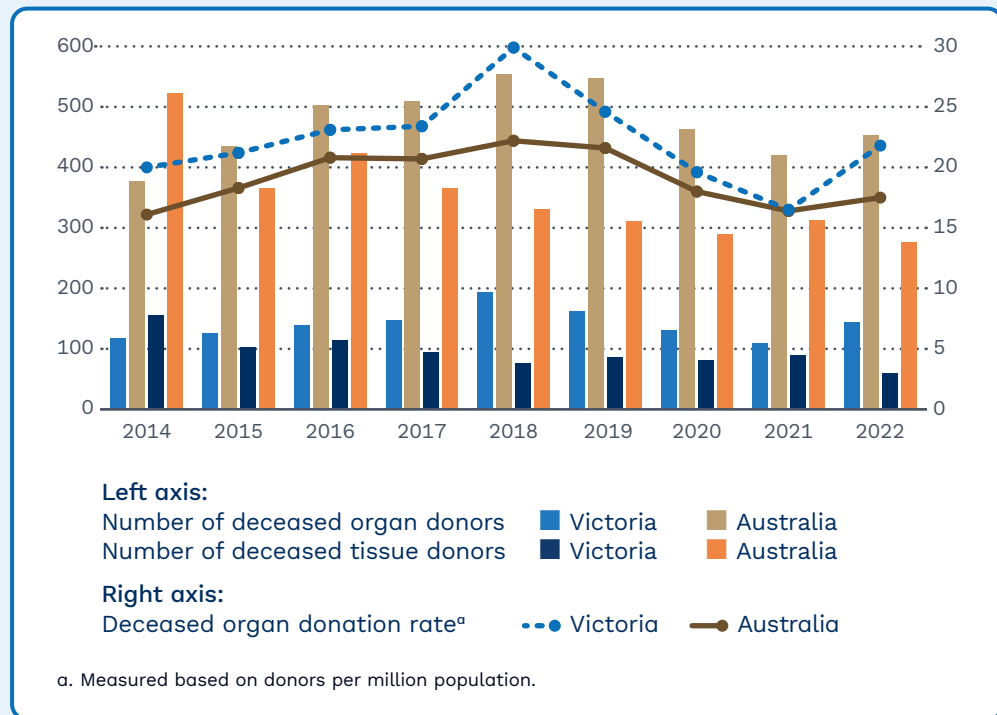
Figures 1.6 and 1.7 show recent trends in organ waitlists in Australia and the number of deceased organ and tissue donors and donation rates in Victoria and Australia.



Source: ANZOD, *Organ waiting list*, n.d., <<https://www.anzdata.org.au/anzod/publications-2/organ-waiting-list>> accessed 12 September 2023.

60 See Figure 1.6.

Figure 1.7: Number of deceased organ and tissue donors and donation rates in Victoria and Australia, 2014–2022



Source: ANZOD: *Annual report 2023, Chapter 2*, p. 3; *Annual report 2023, Chapter 10*, pp. 3–4; *Annual report 2018, Chapter 2*, p. 2; *Annual report 2018, Chapter 10*, p. 3; *Annual report 2017, Chapter 1*, p. 2; *Annual report 2017, Chapter 11*, p. 3; *Annual report 2016, Chapter 11*, p. 3.

The deceased organ donation rate fell during the COVID-19 pandemic to a low of 16.5 for Victoria and 16.4 for Australia—and while this rose slightly in 2022 it has not fully rebounded.⁶¹ This fall during the pandemic was partly attributed to a decrease in consent rates.⁶² Austin Health described ‘the pressing need for an increase in organ donation’ as ‘a matter of critical national urgency’ that ‘has been amplified by the COVID-19 pandemic’.⁶³ Austin Health advised:

The pandemic has constricted access to transplantation and extended waiting times across the nation, with Victoria shouldering a disproportionate share of this burden. In stark terms, while kidney transplant activity nationally decreased by 25% between 2019 and 2021, Victoria experienced a 33% drop in the same period. The kidney transplant waiting list has swollen by 16% in the three years between December 2019 and December 2022.⁶⁴

⁶¹ See Figure 1.7 at 2021.

⁶² St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, received 19 May 2023, p. 1.

⁶³ Austin Health, *Submission 34*, p. 3, with sources.

⁶⁴ *Ibid.*

Chapter 4 considers the impact of hospital safety measures implemented in response to the COVID-19 pandemic on families during donation conversations.

The deceased organ donation rate does not include tissue donors and donations, even though it is used as a common indicator of a country's success in donation and transplantation.⁶⁵ The number of deceased tissue donors in Victoria and Australia has decreased.⁶⁶

The need for tissue is not managed through waitlists, but domestic demand for tissue exceeds supply. The shortage of donated bone, skin, cardiac tissue and tendons means tissue must be imported from overseas. Demand could partly be met through more donors and donations.⁶⁷ Chapter 7 considers tissue donation statistics in more detail.

Organ waitlists do not show the full extent of demand for organs. In 2022, a further 15,000 Australians and 3,500 Victorians on dialysis could have benefited from health and quality of life improvements associated with a kidney transplant.⁶⁸ The Committee heard that patients may not be waitlisted where the chance of receiving a transplant is remote.⁶⁹ Patients are also withdrawn from waitlists if they are too sick to proceed with a transplant or die while waiting.⁷⁰

It is also important to look beyond dialysis numbers because not all organ failure can be treated with dialysis, like lung and liver failure.⁷¹ Austin Health stated delayed access to liver transplantation results in death, 'substantial morbidity and expensive hospitalisations among the waiting list cohort':

The mounting strain on liver transplantation access underpins the pressing need to intensify our efforts towards augmenting organ donor registrations, optimising donor utilisation, and investing in the requisite infrastructure and resources that will ensure a resilient transplantation sector.⁷²

65 Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support: ANAO report no. 33 2014–15*, 2015, p. 9; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, pp. 4–5; EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, pp. [89–90]; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, report for Australian Department of Health, 2015, pp. 35–36.

66 The number of deceased tissue donors in Victoria was 103 in 2015, compared to 60 in 2022 and in Australia was 364 in 2015, compared to 276 in 2022, see Chapter 7, Figure 7.1; ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, 2023, p. 8; Eye and tissue donation in Australia, *2015 year end report*, 2016, p. 6.

67 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 7, 9; PwC, *Final report: analysis of the Australian tissue sector*, report for Organ and Tissue Authority, 2016, p. ii.

68 Name withheld, *Submission 24*, received 18 May 2023, p. 1; Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), Australia summary, *ANZDATA 46th annual report 2023*, 31 August 2023, <<https://www.anzdata.org.au/report/anzdata-46th-annual-report-2023-data-to-2022>> accessed 23 October 2023; Organ and Tissue Authority, *Statistics in Australia*.

69 Name withheld, *Submission 24*, p. 1.

70 Ibid.; EY, *Review of the Australian organ donation, retrieval and transplantation system*, p. [45].

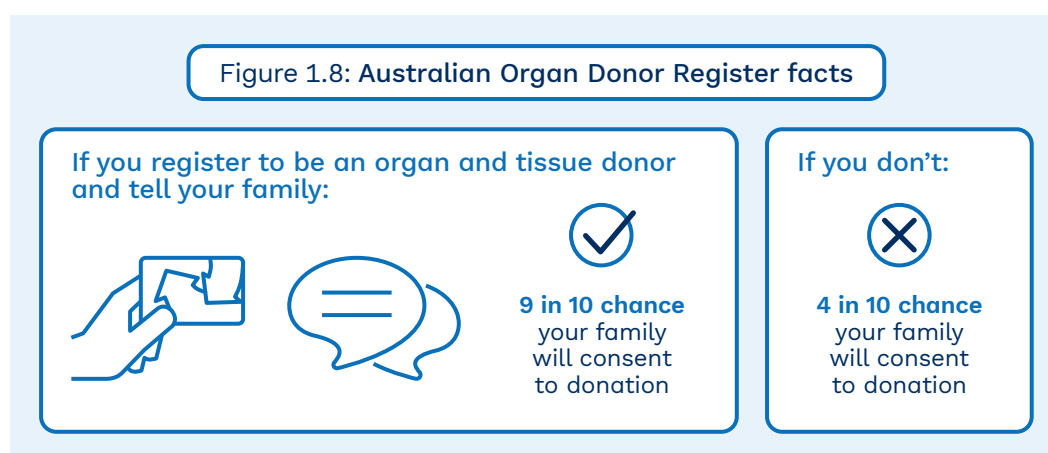
71 Name withheld, *Submission 24*, p. 2.

72 Austin Health, *Submission 34*, p. 4, with sources.

1.6 The importance of registration, family discussion and consent

Registration is important because it increases the likelihood of families providing consent for donation to proceed.⁷³ Families are more likely to provide consent if a potential donor was registered and the family knew about their wishes:

The trend over the past decade has been 9 in 10 families say yes to donation if their family member is registered, noting in 2022 it was 8 in 10. When the family member was not registered and the family was not aware, this drops to just 4 in 10.⁷⁴



Source: DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 3.

A person's registration status:

- allows them to have a say and exert personal agency, including about which organs and tissues they are comfortable donating⁷⁵
- guides the discussion donation specialists have with family members about a potential donation⁷⁶
- supports families to consent to donation.⁷⁷

⁷³ Organ and Tissue Authority, *Submission 31*, received 19 May 2023, p. 4.

⁷⁴ DonateLife Victoria, *Submission 27*, p. 3, with sources. The Committee notes the trend from 2015–2022 (excluding 2019) appears to be based on data reported in OTA yearly activity reports, Committee calculation: $(91 + 88 + 90 + 93 + 89 + 87 + 82) / 7 = 88.57$.

⁷⁵ Samantha Francis-Pester, *Submission 28*, received 19 May 2023, p. 1; Austin Health, *Submission 34*, pp. 2, 5.

⁷⁶ Alfred Health, *Submission 38*, p. 2; Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 18; DonateLife Victoria, *Submission 27*, p. 1; Chantel Bartolo, *Transcript of evidence*, p. 42; Name withheld, *Submission 24*, p. 6.

⁷⁷ Austin Health, *Submission 34*, pp. 2, 5.

1 Austin Health, for example, submitted that the AODR ‘plays a pivotal role in facilitating organ and tissue donation’ by ‘serving as a crucial tool to convey an individual’s intent’ that ‘significantly’ influences family consent. 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.’⁷⁸

More can be done to increase the number of people registered on the AODR. Since 2009, 2 million Australians registered a donation decision on the AODR but this does not result in a large percentage change in the registration rate due to population growth.⁷⁹ As Figure 1.9 shows, registration rates have increased slightly since 2015, by 4% in Victoria in line with the national increase.

Raising awareness and increasing the number of people from diverse groups registered on the AODR is also important. For example, young people aged 16 to 25 are underrepresented on the AODR with one of the lowest registration rates (10% compared to 36% nationally).⁸⁰ While there are no publicly available statistics on registration rates in culturally diverse and First Nations communities, the Committee consistently heard about the importance of providing appropriate resources to increase discussion and awareness of donation and transplantation in these communities.⁸¹ These challenges are considered throughout the report.

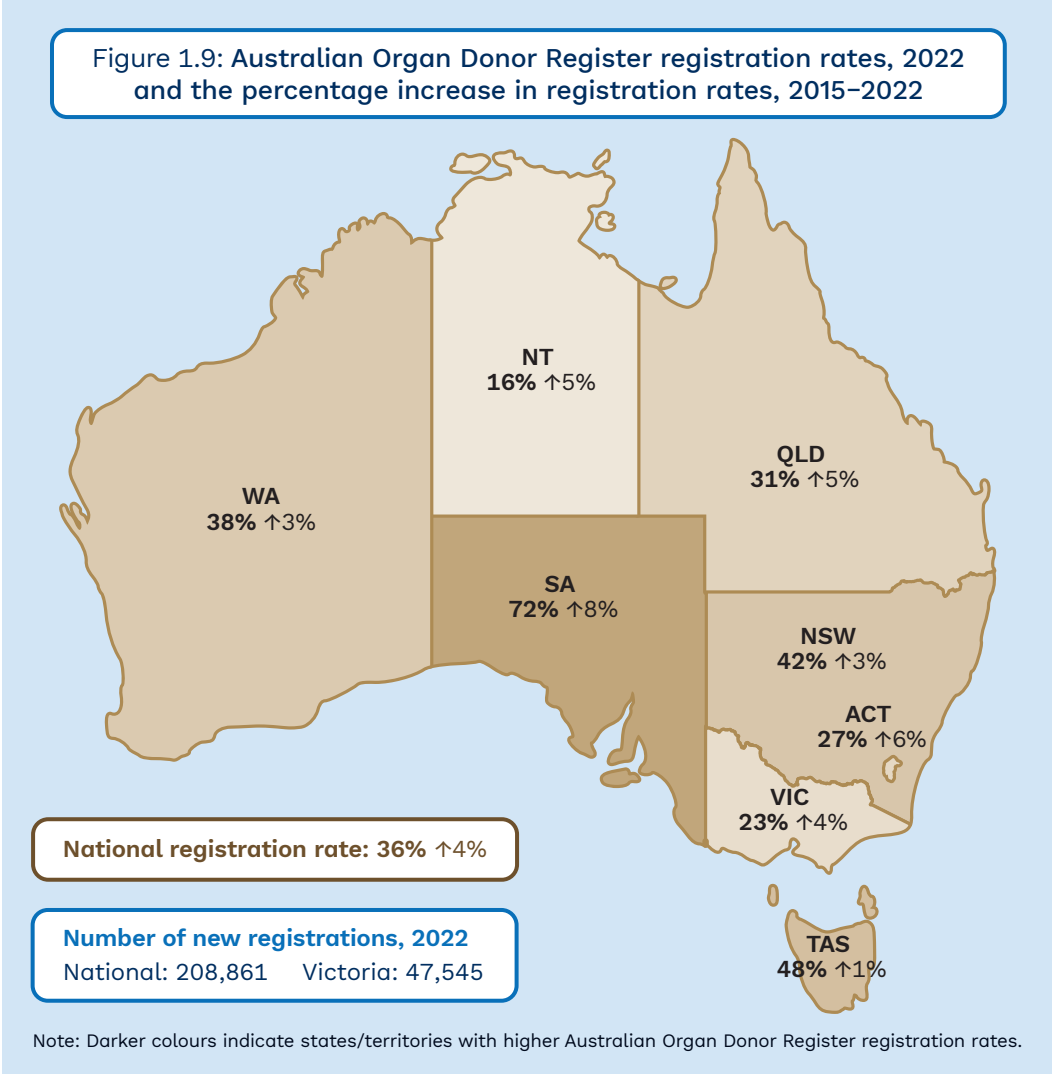
⁷⁸ Ibid.

⁷⁹ Organ and Tissue Authority, *Submission 31*, p. 4; Tony Holland, General Manager, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 12.

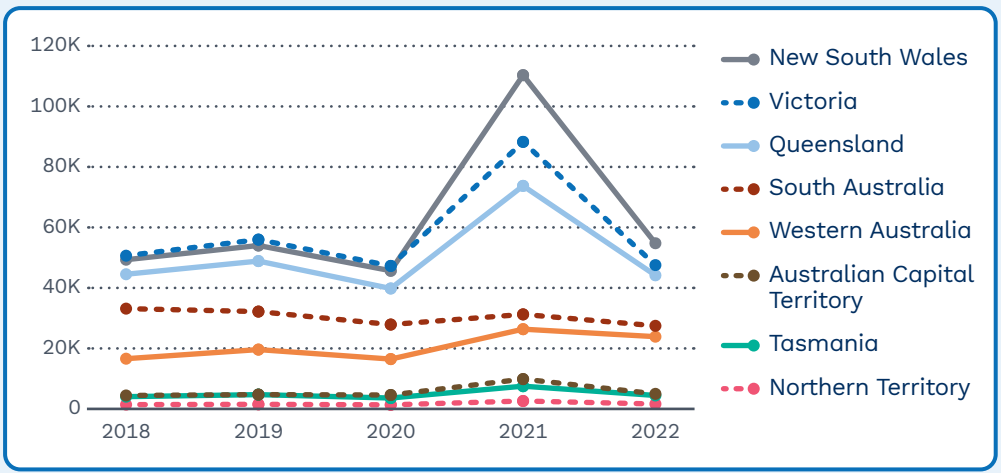
⁸⁰ Department of Prime Minister and Cabinet, *Improving organ donor registration among young adults*, report prepared by Behavioural Economics Team of the Australian Government, 2022, p. 5.

⁸¹ Transplant Australia, *Submission 23*, received 18 May 2023, pp. 11–12; Dr Brooke Huuskens and Dr Stacey Hokke, *Submission 32*, received 19 May 2023, p. 1; Organ and Tissue Authority, *Annual report 2021–22*, 2022, p. 31; Dr Rohit D’Costa, State Medical Director, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, pp. 6–7; Brianna Elms, National Manager, Communications and Engagement, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 18.

Figure 1.9: Australian Organ Donor Register registration rates, 2022 and the percentage increase in registration rates, 2015–2022



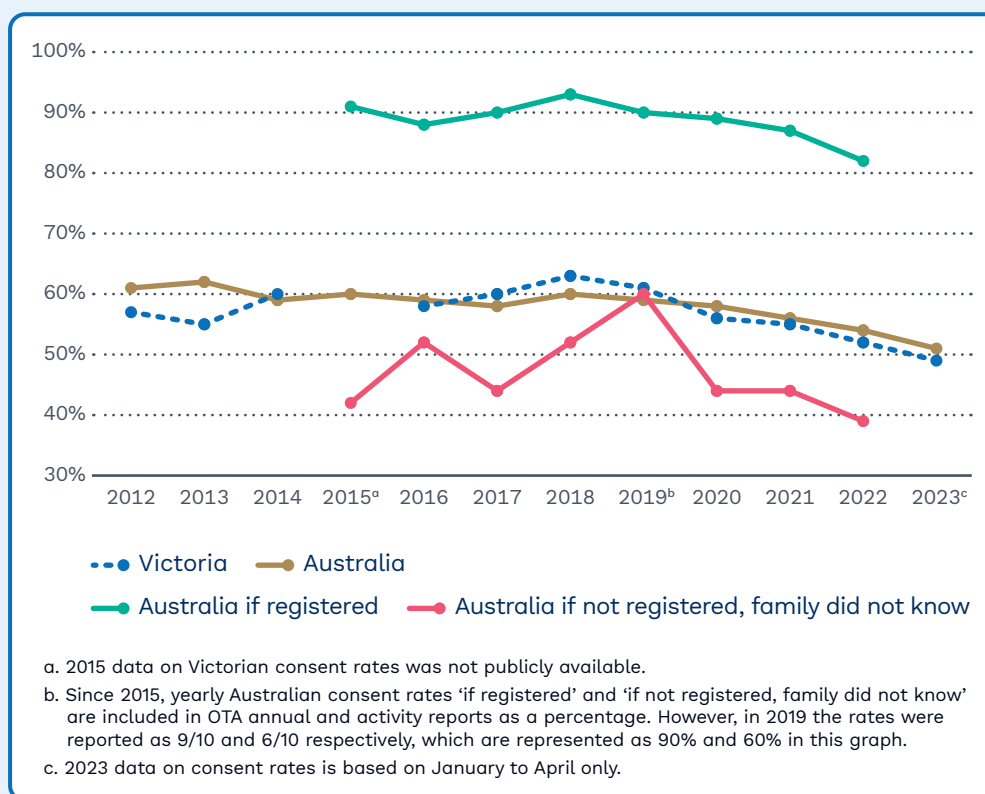
Number of new registrations in each state and territory, 2018–2022



Source: OTA: Australian donation and transplantation activity report 2015, p. 9; Australian donation and transplantation activity report 2016, p. 6; Australian donation and transplantation activity report 2017, p. 6; Australian donation and transplantation activity report 2018, p. 7; Australian donation and transplantation activity report 2019, p. 7; Australian donation and transplantation activity report 2020, p. 9; Australian donation and transplantation activity report 2021, p. 16; Australian donation and transplantation activity report 2022, p. 22.

Donation consent rates have decreased over the past approximately ten years, a trend accelerated by the COVID-19 pandemic.⁸² This occurred across Australia except for Tasmania.⁸³ In the context of declining consent rates, increasing registration on the AODR is important to ‘provide greater support to family members considering organ and tissue donation.’⁸⁴ Registration and family consent to donation are discussed throughout the report.

Figure 1.10: Donation consent rates in Victoria and Australia, 2012–2023



Source: Victoria and Australia consent rates: OTA, *Inquiry into organ and tissue donation in Western Australia* hearing, response to questions on notice received May 2023, p. 3 (note, some data provided by OTA in this reference is different to OTA’s annual activity reports, where discrepancies exist the most recent data is used); EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 34. ‘Australia if registered’ and ‘Australia if not registered, family did not know’ consent rates: OTA: *Australian donation and transplantation activity report 2015*, p. 9; *Australian donation and transplantation activity report 2016*, p. 6; *Australian donation and transplantation activity report 2017*, p. 6; *Australian donation and transplantation activity report 2018*, p. 7; *Australian donation and transplantation activity report 2019*, p. 7; *Australian donation and transplantation activity report 2020*, p. 9; *Australian donation and transplantation activity report 2021*, p. 16; *Australian donation and transplantation activity report 2022*, p. 21.

⁸² See Figure 1.10. See also Organ and Tissue Authority, *Annual report 2021–22*, pp. 2–3.

⁸³ Organ and Tissue Authority, *Inquiry into organ and tissue donation in Western Australia* hearing, response to questions on notice received May 2023, p. 3.

⁸⁴ Austin Health, *Submission 34*, p. 3, with sources.

1.7 The importance of increasing stem cell and living donors

In Australia there are two ways to register to donate stem cells through the ABMDR—a home delivered cheek swab kit through Strength to Give or when donating blood at a Lifeblood Donor Centre.⁸⁵ Stem cell donation is considered further in Chapter 6.

Stem cell transplants are used to treat blood cancers like leukaemia and lymphoma⁸⁶ and are generally a last resort for patients.⁸⁷ Some will find a stem cell donor match from a family member but over half need stem cells from a matched but unrelated donor.⁸⁸

Donors must be aged 18 to 35 to register but are not removed from the register until they are 60. Younger donors are preferred because they have fewer health complications and patients have better clinical outcomes with transplants from younger donors.⁸⁹ Males are ideal donors because they physically have more stem cells and this avoids any complications from pregnancy in females.⁹⁰

Bone marrow is a tissue inside bones and stem cells are found inside bone marrow. Stem cell and bone marrow transplants describe different processes: stem cell transplants use stem cells from a donor's bloodstream and bone marrow transplants use stem cells from a donor's bone marrow. The stem cells themselves are the same.⁹¹

Increasing the number of registered stem cell donors is vital, noting that over the past ten years blood cancer incidence has increased by 47%. In 2022, 53 people each day or one person every 27 minutes, meaning 19,403 Australians, were diagnosed with a blood cancer. Currently, 135,000 Australians live with a blood cancer, 16 die from blood cancer daily and 1 in 3 people diagnosed will not live a further 5 years after diagnosis.⁹²

Over 600 Australians with blood cancer require donated stem cells for a transplant each year. But **there are not enough Australians registered on the ABMDR to be stem cell donors and this is declining.**⁹³ The shortage of ideal registered donors means Australia is increasingly dependent on overseas donors.⁹⁴ In Australia around 3 in 4 stem cell donations, which are used to treat blood cancers, are sourced internationally.⁹⁵

85 Australian Bone Marrow Donor Registry, *Submission 43*, received 17 August 2023, p. 1; Australian Bone Marrow Donor Registry, *Strength to Give, cheek swabs*, n.d., <<https://strengthtogive.org.au/cheek-swabs>> accessed 12 October 2023.

86 Strength to Give, *Frequently asked questions*, n.d., <<https://strengthtogive.org.au/faqs>> accessed 13 September 2023.

87 Leukaemia Foundation, *Submission 20*, received 17 May 2023, p. 2.

88 *Ibid.*, p. 3.

89 Strength to Give, *Frequently asked questions*; Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 15 August 2023, p. 6.

90 Strength to Give, *Frequently asked questions*.

91 Peter MacCallum Cancer Centre, *Bone marrow and stem cell transplant: 'Bone marrow transplants' and 'stem cell transplants' describe the same process*, n.d., <<https://www.petermac.org/patients-and-carers/treatments/bone-marrow-and-stem-cell-transplant>> accessed 7 June 2023; Professor Jeff Szer, Director, Australian Bone Marrow Donor Registry, public hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 8.

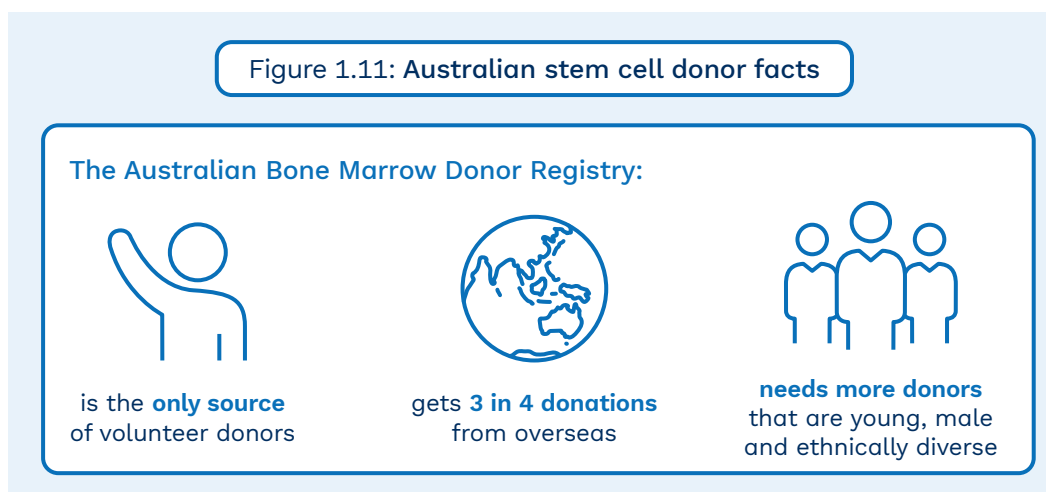
92 Leukaemia Foundation, *Submission 20*, p. 2.

93 *Ibid.*

94 Australian Bone Marrow Donor Registry, *Submission 43*, p. 1; Australian Bone Marrow Donor Registry, *Annual report 2021–22: connecting donors to patients*, 2022, p. 5.

95 Leukaemia Foundation, *Submission 20*, p. 3.

Figure 1.11: Australian stem cell donor facts



Source: Australian Bone Marrow Donor Registry, *Submission 43*, received 17 August 2023, p. 1; Leukaemia Foundation, *Submission 20*, received 17 May 2023, p. 3.

Living donation is equally important because it can reduce the time someone waits for a transplant.⁹⁶ From 2013 to 2022 the number of living kidney donors decreased for Australia by 30 to 224 and for Victoria by 8 to 75.⁹⁷

Living organ donations, which includes stem cells, are considered further in Chapter 6.

The number of living tissue donors has also declined but this is partly due to greater utility from deceased tissue donors. This is considered further in Chapter 7.

1.8 The Victorian context

Victoria's deceased organ donation rate is consistently above the national average and in 2022 it was the second highest state after Tasmania⁹⁸—for which Victoria provides support for organ retrieval and transplantation.⁹⁹ The Committee acknowledges the dedication and diligence of the many professionals in the Victorian health sector who make this possible. However, increasing the number of registered donors in Victoria remains important because in 2022:

- 23% of Victorians (compared to 36% of Australians) were registered to be donors and Victoria had the second lowest registration rate of all states and territories¹⁰⁰—this rate has only increased by 4% for Victoria and Australia since 2015¹⁰¹

⁹⁶ Transplant Australia, *Submission 23*, p. 12.

⁹⁷ See Chapter 6, Figure 6.4; ANZDATA, *Living kidney donation data report for Legislative Assembly Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, 2023, pp. 2–3.

⁹⁸ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, pp. 16–18.

⁹⁹ Professor Gregory Snell, Medical Head, Lung Transplant Service, Monash University and Alfred Hospital, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 19. Victoria also provides support for organ retrieval and transplantation to South Australia.

¹⁰⁰ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

¹⁰¹ Organ and Tissue Authority, *Australian donation and transplantation activity report 2015, 2016*, p. 9.

- regional areas had a higher average registration rate (30%) than metropolitan areas (22%)—and in the local government areas (LGAs) expecting to see the largest population growth in metropolitan Melbourne from 2021 to 2036 the average registration rate was even lower (13%)¹⁰²
- Australian families said yes to donation 82% of the time where a person was registered on the AODR—and chances of providing consent dropped significantly to 39% where a person was not registered and the family did not know they wanted to be a donor¹⁰³
- Victoria’s overall family consent rate for donation was 52%, meaning it was the third lowest state or territory—and Australia’s overall family consent rates have declined over the past ten years¹⁰⁴
- Australia’s overall organ waitlists increased by 17% from 2013, outstripping a population increase of approximately 11% over the same period¹⁰⁵
- Australian organ transplant recipients usually waited between six months and four years to receive their transplant, and some even longer, but one donor can result in up to seven people coming off the waitlist.¹⁰⁶

1.9 Committee publications relevant to the Inquiry

This **report** on the Inquiry is the result of research and consultation by the Committee. The Committee’s findings and recommendations focus on how Victoria can increase registrations on the AODR as well as improve rates of organ and tissue donation.

As part of the Inquiry the Committee has also published on its webpage:

- **a summary booklet** to share key learnings, aiming to assist in spreading awareness about the importance of registration and donation and dispel some of the myths about donation processes
- **an interactive timeline** to provide an overview of the history of donation and registration in Victoria and Australia, including several key milestones relevant to Victoria
- **an interactive heatmap** to show the estimated percentage of Victorians registered on the AODR by LGA.¹⁰⁷

¹⁰² See Chapter 5, Figures 5.1 and 5.2. See also the Committee’s website for an interactive heatmap that shows the estimated percentage of Victorians registered on the AODR by LGA that can be filtered by metropolitan and regional areas <parliament.vic.gov.au/organtissuedonor-reports>.

¹⁰³ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 21.

¹⁰⁴ *Ibid.*, p. 19; see Figure 1.10.

¹⁰⁵ See Section 1.5.1.

¹⁰⁶ Organ and Tissue Authority, *How does donation work?*

¹⁰⁷ See the Committee’s website for an interactive heatmap that shows the estimated percentage of Victorians registered on the AODR by LGA that can be filtered by metropolitan and regional areas <parliament.vic.gov.au/organtissuedonor-reports>.

Chapter 2

Landscape of donation in Victoria and Australia

Several federal and state bodies collaborate to deliver registration, donation and transplantation services across Victoria and Australia. State and territory governments deliver Australia's donation program in hospitals and through 'downstream services' (for example, tissue typing, retrieval surgery and transplant services) and grassroots community engagement activities.¹

This chapter summarises the organ and tissue donation landscape, including the sector's current structure, funding and performance reporting. It then outlines the legal and ethical framework for donation and summarises relevant current strategies, past reviews and inquiries.

2.1 Sector structure and funding

This section discusses the sector structure and funding streams for organ and tissue donation in relation to Victoria.

2.1.1 Australian Department of Health and Aged Care and Services Australia

The Australian Department of Health and Aged Care (DHAC) has policy and resourcing responsibility for donation under the federal Health portfolio.² Its main policy documents are the draft *National strategy for organ donation, retrieval and transplantation* (draft National Organ Strategy) and *Transition Action Plan* (TAP), and the *National Eye and Tissue Sector Framework* (Tissue Framework).³ DHAC also delivers a living organ donor support program, reimbursing people who donate a kidney or partial liver.⁴

1 Organ and Tissue Authority, *Submission 31*, received 19 May 2023, p. 2.

2 Ibid.; Department of Health and Aged Care, *Organ and tissue donation in Australia*, 20 April 2021, <<https://www.health.gov.au/topics/organ-and-tissue-donation/organ-and-tissue-donation-in-australia>> accessed 9 November 2023.

3 Department of Health and Aged Care, *What we're doing about organ and tissue donation*, 15 August 2022, <<https://www.health.gov.au/topics/organ-and-tissue-donation/what-were-doing-about-organ-and-tissue-donation>> accessed 14 September 2023.

4 Department of Health and Aged Care, *Supporting Living Organ Donors Program*, 2 June 2023, <<https://www.health.gov.au/our-work/supporting-living-organ-donors-program>> accessed 14 September 2023. Living donation is discussed in Chapter 6.

DHAC and Services Australia collaborate to administer the Australian Organ Donor Register (AODR)—the national register recording people’s decisions about becoming organ and tissue donors. While DHAC has policy responsibility for the AODR, Services Australia is responsible for managing the AODR database and reporting on AODR statistics.⁵ Authorised medical personnel are provided with access to the AODR to verify a person’s decision about donation.⁶

DHAC and Services Australia have not set any specific performance measures to evaluate the AODR’s efficiency or effectiveness.⁷

2.1.2 Organ and Tissue Authority

Established in 2009, the Organ and Tissue Authority (OTA) is the independent statutory authority leading Australia’s national approach to improve donation rates. OTA sits within the federal Health portfolio that is currently part of DHAC.⁸ OTA’s role is to:

- establish a consistent and coordinated national approach to delivering donation and transplantation and lead and drive the ongoing delivery of national reform⁹
- monitor implementation of the national approach in partnership with state and territory governments¹⁰
- fund (on behalf of DHAC) each state and territory government to deliver best practice donation systems in hospitals through a DonateLife agency¹¹
- work with state and territory governments, DonateLife agencies, the DonateLife Network, hospitals and the community to improve donation rates so more Australians have access to a transplant.¹²

5 Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 15 August 2023, p. 5.

6 Ibid., pp. 2-3; Services Australia, *Annual report 2022–23*, 2023, p. 74.

7 The only mention of the AODR in DHAC’s *Annual report 2021–22* is in relation to the sport and recreation objective in the federal Health portfolio, where it was noted: ‘Hosting the World Transplant Games 2023 is anticipated to inspire and encourage healthy, active lifestyles in transplant recipients and promote organ and tissue donation through the [AODR]’, see Department of Health and Aged Care, *Annual report 2021–22*, 2022, p. 98. Services Australia’s *Annual report 2022–23* only reports on the cumulative total numbers of registrations since the AODR began and enquiry line calls received, see Services Australia, *Annual report 2022–23*, p. 74.

8 Organ and Tissue Authority, *Who we are*, n.d., <<https://www.donatelife.gov.au/about-us/who-we-are>> accessed 9 November 2023; EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, p. [36].

9 EY, *Review of the Australian organ donation, retrieval and transplantation system*, p. [36]; Organ and Tissue Authority, *Submission 31*, p. 1 cover letter.

10 Organ and Tissue Authority, *Submission 31*, p. 1 cover letter.

11 Ibid.; Organ and Tissue Authority, *Find your local DonateLife agency*, n.d., <<https://www.donatelife.gov.au/find-your-local-donatelife-agency>> accessed 14 September 2023.

12 Organ and Tissue Authority, *About us*, n.d., <<https://www.donatelife.gov.au/about-us>> accessed 14 September 2023.

DonateLife is the 'Australian Government brand for all initiatives undertaken as part of the national program to increase organ and tissue donation for transplantation.'¹³

The national DonateLife Network consists of each state and territory DonateLife agency and hospital-based staff focused on increasing donation.¹⁴

National approach to organ and tissue donation

The national organ and tissue donation and transplantation reform program, announced in July 2008, committed \$151.1 million of Australian Government funding over four years to a national approach to donation.¹⁵ The two main objectives of this funding were to:

- improve the capacity and capability of the health system to maximise donation rates
- increase community awareness and stakeholder participation across Australia to promote donation.¹⁶

Following the implementation of the 2008 national reform program, which established OTA and DonateLife agencies in each jurisdiction, Australia's deceased organ donation rates significantly improved.¹⁷ OTA attributed this to its establishment and the DonateLife Network, as well as national public awareness initiatives to encourage AODR registration, better performance measuring and reporting, dedicated donation staff in hospitals and efforts to embed best practice in hospitals.¹⁸

¹³ Organ and Tissue Authority, *Annual report 2021-22*, 2022, p. 113.

¹⁴ *Ibid.*, p. 114; Organ and Tissue Authority, *Find your local DonateLife agency*; EY, *Review of the Australian organ donation, retrieval and transplantation system*, p. [37].

¹⁵ EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, report for Australian Department of Health, 2015, p. 12. It was preceded by all governments agreeing upon a 10-point national reform program in July 2006 with the goal of increasing 'safe, effective and ethical' tissue and organ donations for transplantation, along with \$28 million in Australian Government funding, see National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally: volume 1*, Australian Government Department of Health and Ageing, 2008, p. 11.

¹⁶ EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 12. These objectives were promoted through nine measures: 1. A new national approach and system—a national authority and network of organ procurement organisations; 2. Specialist hospital staff and systems dedicated to organ donation; 3. New funding for hospitals; 4. National professional awareness and education; 5. Coordinated ongoing community awareness and education; 6. Support for donor families; 7. Safe, equitable and transparent national transplantation process; 8. National eye and tissue donation and transplantation; 9. Additional national initiatives, including living donation programs, see Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support: ANAO report no. 33 2014-15*, 2015, pp. 31–32.

¹⁷ Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*, March 2012, p. 30; EY, *Review of the Australian organ donation, retrieval and transplantation system*, pp. [68–69]; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 13.

¹⁸ Organ and Tissue Authority, *Submission 31*, p. 2.

Performance reporting

OTA's current strategy is to return donation and transplantation activity to pre-pandemic levels. It aims to achieve this through three goals, each with three objectives.¹⁹ Relevant to this Inquiry, one goal is for more people to say yes to donation through the objectives:

Raise awareness: More Australians understand the need for organ and tissue donation and the benefits it gives to another person needing a transplant.

Increase family discussion: More Australians talk to their family about organ and tissue donation.

Increase registration: All Australians who want to be an organ and tissue donor register on the Australian Organ Donor Register.²⁰

OTA has set performance measures to monitor this strategy. These measures include:

- increasing the number of eligible Australians registered on the AODR from 36% of the population in 2022 to 46% in 2026 (2022 result: 36%)
- increasing the consent rate from 56% in 2022 to 66% in 2026 (2022 result: 54%).²¹

Past OTA strategies had similar objectives on increasing the number of donation opportunities, providing high quality support for families involved in the donation process, increasing family consent rates and enhancing systems and processes. Each strategy includes actions to achieve the stated objectives and performance criteria to review to identify forthcoming strategic objectives.²² The 2021 OTA strategy identified additional action areas to respond to the COVID-19 pandemic.²³

Funding arrangements and relevance to Victoria

OTA funds state and territory governments through the DonatLife Network. This supports around 260 donation specialist staff in over 90 hospitals to deliver best

¹⁹ Organ and Tissue Authority, *Strategy 2022-2027*, 2022, p. 4.

²⁰ Ibid., p. 6. The other two goals are 'Optimise opportunities: Donation and transplantation services deliver the best outcomes' and 'Enhance systems: Enable quality outcomes through information, technology and resources', see *ibid.*, pp. 7-8.

²¹ The other performance measures include increasing deceased organ donors per million population (dpmp) from 16.4 in 2022 to 23.3 in 2026 (2022 result: 17.5); increasing living dpmp from 7.8 in 2022 to 12.5 in 2026 (2022 result: 8.6); and increasing transplants per year from living and deceased donors from 1,377 in 2022 to 1,865 in 2026 (2022 result: 1,448), see Department of Health and Aged Care, *Australian Government Budget 2023-24 Paper No. 1.9 Health and aged care portfolio budget statements: Organ and Tissue Authority entity resources and planned performance*, 2023, pp. 410-411.

²² Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2025: strategic plan 2021-22 to 2024-25*, 2021, p. 2; Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2023: the 2019-20 to 2022-23 strategy*, 2019, p. 10; Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2021: the 2017-18 to 2020-21 strategy*, 2017, p. 3.

²³ Organ and Tissue Authority, *Progressing Australian organ and tissue donation and transplantation to 2025: strategic plan 2021-22 to 2024-25*, p. 4.

practice donation processes and the national approach in each jurisdiction.²⁴

To achieve this, OTA:

- provides grants to state and territory governments to support a DonateLife agency and dedicated donation hospital staff (in 2022–23, Victoria was allocated \$7.7 million of a total of \$31.2 million nationally (25%))
- contributes towards hospital donation costs through Organ Donation Hospital Support Funding, based on actual and intended donors and the cost to transfer a potential donor from a regional to a specialised hospital (in 2022–23, Victorian hospitals received \$1.9 million of a total of \$6.7 million nationally (28%)).²⁵

In effect, OTA funds hospitals for donation staff and reimbursement to undertake donation related activities, including staff time in the emergency department (ED) and intensive care unit (ICU), pathology and imaging, and the cost to transfer a potential donor from a regional to a specialised hospital.

OTA explained that jurisdictions can choose how to use funding through their DonateLife agency, but it is usually determined by hospital activity levels. Part of the funding is for a DonateLife agency manager and fractional state medical director, as well as specialist staff across education, communications and community awareness, donor family support, data, a clinical leadership team and hospital-based clinical staff.²⁶

Each state and territory funding agreement has key performance indicators and reporting requirements on donation activity and staffing. States and territories report back to OTA on a six-monthly basis against these performance indicators.²⁷

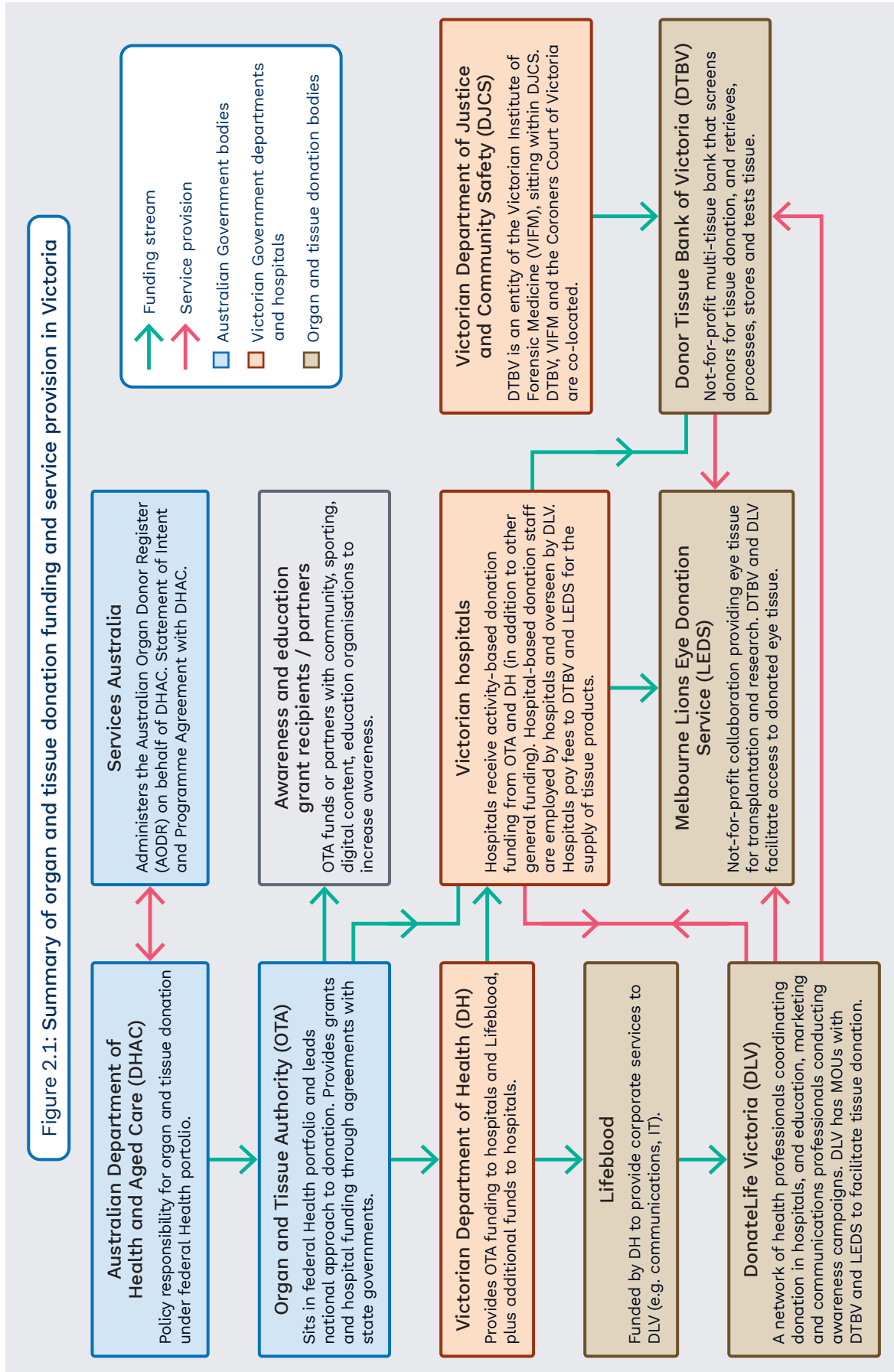
Figure 2.1 provides a high-level summary of these relationships.

²⁴ Organ and Tissue Authority, *Submission 31*, p. 1 cover letter; Organ and Tissue Authority, *Find your local DonateLife agency*; EY, *Review of the Australian organ donation, retrieval and transplantation system*, pp. [68–69].

²⁵ Organ and Tissue Authority, *Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 23 July 2023*, pp. 1–2.

²⁶ Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 17; Organ and Tissue Authority, *Submission 31*, p. 1 cover letter; Organ and Tissue Authority, *Find your local DonateLife agency*.

²⁷ Lucinda Barry, *Transcript of evidence*, p. 17.



Note: The Committee has used the sources referenced in Section 2.1 to create Figure 2.1. Stem cell donation funding and service provision is discussed in Chapter 6.

2.1.3 Victorian Government and Department of Health

State and territory governments deliver Australia's donation program in hospitals and through 'downstream services' (for example, tissue typing, retrieval surgery and transplant services) and grassroots community engagement activities.²⁸

The Victorian Government funds health services for shortfalls in OTA funding.²⁹ The Victorian Department of Health (DH) 'plays a major direct and indirect funding support role in every phase of the process of organ donation to transplantation'. This includes:

- funding for organ retrieval, organ perfusion and transplantation
- additional funds to health services to employ organ donation specialists
- contributions to the nationally funded centres for paediatric transplant patients
- funding for tissue typing costs.³⁰

In addition to funding shortfalls in OTA funding, in 2022–23 the Victorian Government funded \$13,860,690 to Lifeblood. Of this, \$8,490,401 was allocated to the 'Victorian Transplantation Immunogenetic Service for tissue typing', \$4,594,580 to DonateLife Victoria (DLV), \$475,650 to 'Blood Matters' and \$300,059 to 'Bone Marrow Donor centre'.³¹

DH works with health professionals, Lifeblood, DLV and hospitals to implement the national reform program.³² DH has no specific performance measures relating to donation and transplantation.³³

2.1.4 DonateLife Victoria network and hospitals that provide transplantation services

DLV is Victoria's state-wide DonateLife agency. It is responsible for:

- raising awareness of donation through a community engagement program
- encouraging Victorians to register on the AODR and discuss this with family.³⁴

²⁸ Organ and Tissue Authority, *Submission 31*, p. 2.

²⁹ Department of Health, *Inquiry into increasing the number of registered organ and tissue donors hearing*, response to questions on notice received 7 September 2023, p. 4.

³⁰ Department of Health, *Organ and tissue donation*, 20 July 2021, <<https://www.health.vic.gov.au/patient-care/organ-and-tissue-donation>> accessed 14 September 2023.

³¹ Department of Health, response to questions on notice, p. 4. Blood Matters is a program supporting best practice in blood management safety and governance, see Department of Health, *Blood matters*, 26 October 2023, <<https://www.health.vic.gov.au/patient-care/blood-matters-program>> accessed 9 November 2023.

³² Department of Health, *Organ and tissue donation*.

³³ Department of Health, *Annual report 2022–23*, Victorian Government, 2023.

³⁴ DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 1; Tony Holland, General Manager, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 1.

DLV works under the direction of OTA and DH and is fully government funded. In the DLV network, there are:

- 19 staff employed by Lifeblood to fulfil corporate functions including education, donor family support and marketing and communications³⁵
- 51 clinical staff (nursing and medical teams) based at 14 health services across Victoria,³⁶ including:
 - donation specialist nursing coordinators in major metropolitan hospitals
 - medical donation specialists predominately in metro areas
 - nurse donation specialists predominately in regional and outer-metro hospitals.³⁷

Six hospitals primarily provide transplantation services in Victoria: Alfred Hospital, Austin Health, Melbourne Health, Monash Medical Centre, Royal Children’s Hospital and St Vincent’s Health.³⁸ In ‘regional and outer-metropolitan’ areas, donation staff are located at hospitals in Albury, Ballarat, Bendigo, Geelong, Northern Hospital and Mornington Peninsula.³⁹ In total, 23 Victorian hospitals form part of the DLV network.⁴⁰

At a hearing, DLV advised that the network’s clinical staff includes:

- 34 nurses, 27 in the metro area and 7 in outer metro and regional areas (noting most donation activity occurs in metro areas)
- 14 doctors.⁴¹

While specialist donation staff are employed by hospitals, DLV provides oversight and professional training. Donation staff then embed best practice in their respective hospitals.⁴² Staffing allocation to each hospital is based on activity levels and staff travel between metro and regional areas as needed. DLV confirmed to the Committee that it is appropriately staffed for Victoria’s level of donation.⁴³

Hospitals have performance indicators relevant to donation as part of funding agreements with OTA. This includes the referral of patients at end of life in the ED or ICU to the relevant DonateLife agency, routine checking of the AODR and involvement

³⁵ DonateLife Victoria, *Submission 27*, p. 1; Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 1.

³⁶ DonateLife Victoria, *Submission 27*, p. 1; Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 1.

³⁷ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 4.

³⁸ Department of Health, *Organ and tissue donation*.

³⁹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 4.

⁴⁰ Organ and Tissue Authority, *Annual report 2022–23, 2023*, p. 7.

⁴¹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 4.

⁴² Laura Fleckner, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 20.

⁴³ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 5.

of a donation specialist nurse in donation conversations at the hospital.⁴⁴ Hospitals monitor their performance against key metrics through two main ways:⁴⁵

- a monthly dashboard showing how a hospital is tracking⁴⁶
- the DonateLife Audit—a retrospective yearly audit of all deaths in DonateLife Network hospitals to capture information on potential donations, missed donation opportunities and consent rates.⁴⁷

OTA shares dashboard reports with DonateLife agencies and hospital staff, ‘with hospital performance discussed in detail’ at six monthly ‘progress report meetings with each jurisdiction.’⁴⁸ OTA uses the DonateLife Audit to measure, monitor and report on donation outcomes, and assess the effectiveness of its clinical improvement program and strategic objectives. OTA disseminates an audit report to state health departments and DonateLife agencies to share with hospitals.⁴⁹

2.1.5 Lifeblood

Lifeblood, Australia’s blood, plasma, breast milk and other biological products donation service, is fully funded by the Australian and state governments.⁵⁰ Lifeblood performs several functions nationally in relation to organ and tissue donation, including:

- supporting the DonateLife Network by matching organs to patients, including by administering OrganMatch, the national waitlist and organ allocation system
- helping OTA securely manage data
- providing blood donors who are potential stem cell donors with information and testing blood samples in support of the Australian Bone Marrow Donor Registry
- providing transplantation and immunogenetics testing to meet current and future demand for stem cell and organ transplantation through tissue typing (testing blood for compatibility and matching) for organ transplants.⁵¹

44 Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, Parliament of Western Australia, Public Administration Committee, Public hearing, Perth, 17 May 2023, *Transcript of evidence*, p. 10; Organ and Tissue Authority, *Annual report 2021–22*, p. 18. Donation conversations and the role of donation specialist nurses are discussed in Chapter 4. Referral of potential donors as part of end of life care is discussed in Chapter 7.

45 Laura Fleckner, *Transcript of evidence*, p. 27.

46 Lucinda Barry, *Transcript of evidence*, p. 17. The monthly dashboard is provided to the biggest volume 30 hospitals.

47 Mark McDonald, National Manager, Analytics and Technology, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 17.

48 Organ and Tissue Authority, *Annual report 2022–23*, p. 41.

49 Ibid., pp. 42–43.

50 Lifeblood, *Who we are*, n.d., <<https://www.lifeblood.com.au/about/who-we-are>> accessed 7 June 2023.

51 Ibid.; Lifeblood, *Our services*, n.d., <<https://www.lifeblood.com.au/about/our-services>> accessed 7 June 2023. Lifeblood is also known as the Australian Red Cross Blood Service and a division of the Australian Red Cross Society. Organ and Tissue Authority, *OrganMatch*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/organmatch>> accessed 8 January 2024. OrganMatch is Australia’s ‘clinical transplant system that facilitates compatibility matching of recipients and donors for organ transplantation’.

Lifeblood's governance role in relation to DLV is 'slightly different' to other states.⁵² DLV receives OTA funding from Lifeblood through DH to employ agency staff—DLV's day-to-day management is outsourced to Lifeblood, largely in relation to shared services like human resources, information and communication technology and finance.⁵³

2.1.6 Donor Tissue Bank of Victoria and Melbourne Lions Eye Donation Service

The Donor Tissue Bank of Victoria (DTBV) is a not-for-profit entity of the Victorian Institute of Forensic Medicine (VIFM).⁵⁴ DTBV employs 22 staff, including six donation nurse specialists. DTBV is the 'largest tissue bank in Victoria, one of the largest in Australia and one of only three multi-tissue banks in the country'.⁵⁵ DTBV:

- screens donors for tissue donation
- retrieves, processes, stores and tests tissue for efficacy and safety
- supports and educates clinicians on the use of tissue products
- distributes tissue for transplantation in surgeries and burns care Australia-wide.⁵⁶

DTBV and DLV facilitate access to corneas for Victoria's eye bank: the Melbourne Lions Eye Donation Service (LEDS).⁵⁷ LEDS is a not-for-profit collaboration between the Centre for Eye Research Australia, Royal Victorian Eye and Ear Hospital (where it is also located), Lions Clubs of Victoria and Southern New South Wales, and The University of Melbourne.⁵⁸ It is one of Australia's largest providers of donated eye tissue for transplant and research.⁵⁹ In relation to corneas and other eye tissue, LEDS:

- establishes consent for donation

⁵² Tony Holland, DonatLife Victoria, *Transcript of evidence*, p. 4.

⁵³ Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 44.

⁵⁴ VIFM sits within the Victorian Department of Justice and Community Safety and is funded under the Forensic Justice Services output, see Department of Treasury and Finance, *Victorian Budget 2023–24 Paper No. 3: Service delivery*, Melbourne, 2023, pp. 85, 282. See also Figure 2.1.

⁵⁵ Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 38. Also operating in Victoria is Barwon Health Bone Bank, a small human tissue bank located at University Hospital Geelong, see Barwon Health Bone Bank, *Therapeutic Goods Order: standards for minimising infectious disease transmission via therapeutic goods that are human blood and blood components, human tissues and human cellular therapies: Consultation submission*, 2010, p. 1; and the Bone Marrow Institute Cord Blood Bank at the Royal Children's Hospital, where mothers can donate cord blood and this information is sent to the Australian Bone Marrow Donor Registry, see The Royal Women's Hospital, *Cord blood collection*, n.d., <<https://www.thewomens.org.au/patients-visitors/clinics-and-services/pregnancy-birth/cord-blood-collection>> accessed 12 December 2023.

⁵⁶ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, received 16 June 2023, p. 3.

⁵⁷ Donor Tissue Bank of Victoria, *About the DTBV*, n.d., <<https://dtbv.org.au/about>> accessed 14 September 2023; Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 50.

⁵⁸ Centre for Eye Research Australia, *The Lions Eye Donation Service*, n.d., <<https://www.cera.org.au/lions-eye-donation-service>> accessed 14 September 2023. LEDS covers its costs through private health insurance and from hospital budgets, see Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 40.

⁵⁹ Bronwyn Cohen, *Transcript of evidence*, p. 40; Centre for Eye Research Australia, *The Lions Eye Donation Service*.

- coordinates and performs donation surgery
- evaluates and distributes donations.⁶⁰

DLV works with DTBV and LEDS to facilitate tissue donation through memorandums of understanding.⁶¹

2.2 Legal and ethical framework for donation

Human Tissue Acts govern organ and tissue donation in each state and territory.⁶² In Victoria, the *Human Tissue Act 1982* (Vic) (HT Act) regulates the removal of tissue, organs and blood from living and deceased donors and tissue banks.⁶³ The ethical basis for donation in Victoria is that a person must be declared medically dead before donation is considered.⁶⁴ Death is defined in the HT Act.⁶⁵

The HT Act has been amended substantially three times, in:

- 1987, ‘to enable authorized persons other than medical practitioners to remove tissue from dead bodies’ and ‘all medical practitioners to certify death for the purposes of the Act if a life support system is not being used’⁶⁶
- 2009, to enable individuals aged 16 and 17 to consent to donate blood⁶⁷
- 2020, to establish ‘a process for authorising the carrying out of ante-mortem procedures for the purposes of donating human tissue after death’.⁶⁸

The National Health and Medical Research Council (NHMRC) guides ethical and clinical practice for donation in Australia and funds transplantation and donation research projects through a grants program.⁶⁹ NHMRC’s website states:

The availability of donor organs and tissues for transplantation relies mainly on the generosity of individuals, and their families, to donate. For a system of altruistic donation to flourish, it is important that donation processes are underpinned by ethical principles and values that safeguard donors and their families from exploitation and harm, and engender community faith in the system. Similarly, for the ongoing success of

⁶⁰ Centre for Eye Research Australia, *The Lions Eye Donation Service*.

⁶¹ Chantel Bartolo, *Transcript of evidence*, pp. 40, 50; Brendan Sullivan, *Transcript of evidence*, pp. 41, 46; Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 1. DTBV has no direct funding relationship with OTA but it is a member of OTA’s eye and tissue advisory committee.

⁶² Department of Health and Aged Care, *What we’re doing about organ and tissue donation*.

⁶³ Tissue is also regulated by the Therapeutic Goods Administration.

⁶⁴ Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 46.

⁶⁵ Department of Health, *Human Tissue Act 1982*, 1 June 2023, <<https://www.health.vic.gov.au/legislation/human-tissue-act-1982>> accessed 14 September 2023. Death is defined as irreversible cessation of circulation of blood in the body of the person or irreversible cessation of all function of the brain of the person.

⁶⁶ *Human Tissue Amendment Act 1987* (Vic).

⁶⁷ *Human Tissue Amendment Act 2009* (Vic).

⁶⁸ *Human Tissue Amendment Act 2020* (Vic). Ante-mortem procedures ‘determine, maintain or improve the viability of tissue’ before withdrawing cardio-respiratory support to ensure a person’s organs are suitable for donation after circulatory death.

⁶⁹ Department of Health and Aged Care, *What we’re doing about organ and tissue donation*.

the transplantation system, decisions about eligibility, suitability, and allocation must be ethically robust, transparent, and guided by ethical principles and values.⁷⁰

NHMRC has issued five guidelines on ethical practices for deceased and living donation which are being reviewed for currency, relevance and potential consolidation into a single guideline.⁷¹ NHMRC anticipated a draft revised guideline would be ready for public consultation in late 2023 or early 2024.⁷² At the time of this report public consultation had not begun.

2.3 Current strategies, plans and frameworks

This section summarises current strategies, plans and frameworks guiding donation in Australia—the draft National Organ Strategy, *Transition Action Plan* (TAP) and *Implementation Plan* (IP), and the *National Eye and Tissue Sector Framework* (Tissue Framework). OTA’s strategy is covered in Section 2.1.2.

2.3.1 Draft National Organ Strategy, Transition Action Plan and Implementation Plan

The Australian Government released the draft National Organ Strategy for consultation in 2022.⁷³ It was developed by the Jurisdictional Organ and Tissue Steering Committee comprised of Australian, OTA and state and territory government representatives.⁷⁴ The draft National Organ Strategy has four priority areas:

1. A national approach to optimise donation, retrieval and transplantation
2. Equitable access for Australians who would benefit from transplantation, with a focus on First Nations peoples⁷⁵ and those living in rural, regional and remote areas
3. Enhanced organ retrieval and transplantation capability and capacity to optimise transplant outcomes
4. Enhanced systems and data collection and reporting to drive clinical best practice.⁷⁶

⁷⁰ National Health and Medical Research Council, *Ethical guidelines on organ and tissue donation and transplantation*, n.d., <<https://www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-organ-and-tissue-donation-and-transplantation>> accessed September 2023.

⁷¹ Ibid.

⁷² National Health and Medical Research Council, submission to Parliament of Western Australia, Public Administration Committee, Inquiry into organ and tissue donation in Western Australia, 2023, p. 2.

⁷³ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation consultation*, n.d., <<https://consultations.health.gov.au/technology-assessment-access-division/consultation-draft-national-organ-strategy>> accessed 14 September 2023.

⁷⁴ Department of Health and Aged Care, response to written questions on notice, p. 3.

⁷⁵ The National Indigenous Kidney and Transplantation Taskforce was established in 2019 after the Australian Government created an expert panel to review the practical challenges and service gaps faced by First Nations patients receiving treatment for kidney disease. Key findings were incorporated into the draft National Organ Strategy, see Organ and Tissue Authority, *Submission 31*, p. 3.

⁷⁶ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, May 2022, p. 3.

DHAC advised the draft National Organ Strategy ‘will progress for agreement by health CEOs and Health Ministers’ with ‘[p]lanning of implementation activities’ to occur throughout 2023–24.⁷⁷

DHAC released the TAP in August 2022 to support the development and early delivery of the draft National Organ Strategy, IP and Tissue Framework. The TAP aims to consolidate and advance the priority areas of the draft Strategy through 13 actions to be progressed over a 12-month period with no additional resourcing.⁷⁸ One action directly relevant to the Committee’s Inquiry is to:

Consider options to improve donor registration to increase consent for donation ... including by leveraging existing processes, such as driver licence applications and renewals.⁷⁹

No progress update on the implementation of the TAP’s action items was publicly available at the time of this report. It is unclear if a progress update will be released.

The IP will complement the draft National Organ Strategy and detail actions to achieve the priority areas and goals. It will be published once the draft Strategy is finalised and approved by Health Ministers. The IP will be a ‘staged approach’ to implementing the final Strategy ‘based on feasibility, available resourcing and agreed prioritisation.’⁸⁰ It will be updated regularly and include ongoing governance arrangements, and evaluation, tracking and reporting mechanisms.⁸¹

2.3.2 National Eye and Tissue Sector Framework

All state and territory governments agreed to the Tissue Framework and it was published in August 2022. It has three objectives:

1. Safe and equitable access to life-saving and life-altering tissue and tissue-based product transplantation.
2. Supply is efficient, effective, ethically sourced and appropriate, and is supported by services that optimise altruistic donation opportunities.
3. The Australian eye and tissue sector is sustainable into the future.⁸²

The Tissue Framework seeks to achieve these objectives through:

- acknowledging the role of, and supporting the current strengths of, the eye and tissue sector in Australia’s health system

⁷⁷ Department of Health and Aged Care, response to written questions on notice, p. 3.

⁷⁸ Department of Health and Aged Care, *Transition Action Plan: National organ and tissue donation, retrieval and transplantation system*, 2022, pp. 2–3.

⁷⁹ Ibid., p. 8. The Committee notes DHAC’s response to the Committee’s written questions on notice provided some information about progress in relation to these action items. See Department of Health and Aged Care, response to written questions on notice, pp. 3–4.

⁸⁰ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, p. 12.

⁸¹ Ibid., pp. 12–13.

⁸² Department of Health and Aged Care, *National Eye and Tissue Sector Framework*, 2022, p. 5.

- better coordinating actions across the health system to consistently and sustainably ensure access to tissues and tissue-based products
- accommodating emerging priorities and innovations through flexibility
- complementing state, national and international policies.⁸³

The Tissue Framework will be updated following the release of NHMRC’s revised ethical guidelines, discussed in Section 2.2.⁸⁴

2.4 Past reviews and inquiries

Over the past 15 years, there have been multiple reviews and inquiries into organ and tissue donation, transplantation and registration,⁸⁵ to which Victorian stakeholders have made significant and meaningful contributions.⁸⁶

Several inquiry participants referenced these reviews and inquiries, with some suggesting a lack of subsequent communication and action,⁸⁷ and others noting that the implementation of recommendations could improve donation and registration rates.⁸⁸

This section summarises the relevant findings of four key reports and reviews that are significant to the Committee’s Inquiry. It then considers some of the reoccurring themes from other past national reviews that stood out to the Committee. An interactive timeline that includes all past reviews and inquiries relating to donation in Victoria and Australia is also available on the Committee’s webpage.⁸⁹

⁸³ Ibid., p. 1.

⁸⁴ Ibid.

⁸⁵ For example, Helen Opdam and William Silvester, ‘Potential for organ donation in Victoria: an audit of hospital deaths’, *The Medical Journal of Australia*, vol. 185, no. 5, 2006; National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*; Australian Healthcare Associates, *Final report: mid-point implementation review of the national reform package—a world’s best practice approach to organ and tissue donation in Australia*, report for Organ and Tissue Authority, 2011; Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*; Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support*; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*; PwC, *Final report: analysis of the Australian tissue sector*, report for Organ and Tissue Authority, 2016; PwC, *Review of the HPC sector—final report*, report for Australian Department of Health and Aged Care, 2018; EY, *Review of the Australian organ donation, retrieval and transplantation system*; Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, *Inquiry into human organ trafficking and organ transplant tourism*, December 2018.

⁸⁶ Professor Robert Jones, Liver Transplant Unit Director, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 30; Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 3–4, 11; Lucinda Barry, *Transcript of evidence*, p. 23; Professor Gregory Snell, Medical Head, Lung Transplant Service, Monash University and Alfred Hospital, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 18; Allan Turner, Managing Director, Zaidee’s Rainbow Foundation, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, pp. 38–39; Associate Professor William Silvester, Chair, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 42.

⁸⁷ For example, see Associate Professor John Whitlam, *Transcript of evidence*, p. 4; Associate Professor William Silvester, *Transcript of evidence*, p. 42; Allan Turner, *Transcript of evidence*, pp. 38–39.

⁸⁸ For example, see Austin Health, *Submission 34*, received 25 May 2023, p. 5; Victorian and Tasmanian Transplantation Committee, *Submission 39*, received 2 June 2023, p. 2.

⁸⁹ See the Committee’s website <parliament.vic.gov.au/organtissuedonor-reports>.

2.4.1 Victoria: 2012, Legislative Council Inquiry into organ donation

The Victorian Legislative Council Legal and Social Issues References Committee conducted an *Inquiry into organ donation in Victoria* and tabled a final report in March 2012. The report made 21 recommendations. However, there is no Victorian Government response to the report as this was not a requirement at the time.⁹⁰ Some key findings and recommendations included:

- Undue pressure should not be placed on the family of the recently deceased to obtain consent. Medical practitioners should continue to consult with families and current consent practices and legislation should be maintained.⁹¹
- Further data collection could help understand why families object to donation when people are registered, which could assist in targeted community awareness.⁹²
- The opt-in model should be maintained and there is a lack of clear evidence showing that opt-out models increase donation rates. While some individuals, particularly those with first-hand experience of donation and transplantation, supported opt-out, ‘the overwhelming evidence’ opposed its introduction.⁹³
- DH, DTBV and the Victorian Coroner ‘clarify their respective roles, legislative requirements and processes’ to ‘further facilitate timely tissue donations’.⁹⁴
- Regional Victoria experienced several constraints to deliver donation programs because of a lack of expertise and resources, and transport costs.⁹⁵ The Victorian Government should examine ways to improve regional access to collected tissues⁹⁶ and establish an effective and sustainable organ donation program in regional Victoria.⁹⁷
- Hospital transplantation units require additional resources so they can operate at maximum capacity, because the increase in donation rates was not accompanied by an increase in transplantation funding and staff resources.⁹⁸

The report also made several recommendations to enhance community awareness:

- National community awareness programs should continue to highlight the importance of family consent and early family discussions on donation.⁹⁹

⁹⁰ The requirement for tabling government responses was introduced in the Standing Orders in 2014.

⁹¹ Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*, p. 39.

⁹² Ibid.

⁹³ Ibid., p. 55.

⁹⁴ Ibid., p. 64.

⁹⁵ Ibid., p. 80.

⁹⁶ Ibid., p. 67.

⁹⁷ Ibid., p. 80.

⁹⁸ Ibid., pp. 83, 93.

⁹⁹ Ibid., p. 96.

- DLV and DTBV should increase public awareness of tissue donation as this had not improved to the same extent as organ donation through national reform.¹⁰⁰
- Awareness-raising organisations should coordinate campaign efforts to ensure a consistent and collaborative approach.¹⁰¹
- Additional resources should be directed to awareness and education campaigns to demystify and promote donation.¹⁰²
- The Victorian Government ‘consider ways to acknowledge and recognise the altruistic act’ of donation, including potentially on a donor’s death certificate.¹⁰³

While some progress has been made in implementing recommendations from the 2012 inquiry’s final report, the Committee received evidence that suggests further work is required to address persistent challenges, including:

- data collection about why families object to donation and recognising donors on death certificates (discussed in Chapter 4)
- increasing awareness about tissue donation and dispelling myths about the donation process (discussed in Chapters 5 and 7)
- the roles of DH, DTBV and the Victorian Coroner in the tissue donation process and regional organ and tissue donation (discussed in Chapter 7).

This Inquiry presents an opportunity for the Victorian Government to address these challenges to improve donation processes and increase the number of Victorians registered on the AODR.

2.4.2 Australia: 2016, Analysis of the tissue sector

This report, prepared by PwC on behalf of OTA and published in 2016, found that while the Australian tissue sector was diverse and undergoing rapid change, awareness of the changes was limited. This was a major concern because tissue is the most common transplant and there was a risk the sector would not be efficient or effective in ten years (2026).¹⁰⁴

It found the policy framework was not clear or transparent which may negatively impact public confidence in the tissue sector.¹⁰⁵ Some key challenges included:

- demand for tissue exceeding supply (with shortfalls often being filled through imported tissue and tissue products)
- long-term fiscal sustainability of tissue banks and low investment in research

¹⁰⁰ Ibid., p. 61.

¹⁰¹ Ibid., p. 98.

¹⁰² Ibid., p. 100.

¹⁰³ Ibid.

¹⁰⁴ PwC, *Final report: analysis of the Australian tissue sector*, pp. i-ii.

¹⁰⁵ Ibid., p. ii.

- a lack of shared objectives, frameworks and policies creating ambiguity
- inconsistency in clinical feedback loops meaning some tissue banks were not responsive to different needs.¹⁰⁶

The review identified the need for urgent, major and targeted change to the sector.¹⁰⁷ Recommendations included government recognition that the sector cannot meet domestic need in the medium to long-term and development of a clear national policy framework and taskforce with Ministerial backing and resourcing. Some of the elements recommended in a national policy framework included:

- a position on moving towards self-sufficiency in the sector and on exportation of tissue products
- better oversight and transparency mechanisms, data collection and reporting
- clarification of clinical standards and purposes
- better definition of the role and scope of services in each state and territory
- a review of funding arrangements and equity
- enhanced professional leadership and engagement in the sector.¹⁰⁸

While some progress has been made against the review's recommendations, the Committee received evidence that suggests further work is required to address persistent challenges in Victoria, including keeping up with demand and increasing investment in research. These challenges as well as the governance and logistics of the Victorian tissue sector are discussed in Chapter 7.

2.4.3 Australia: 2018, Review of the organ donation, retrieval and transplantation system

In 2018, DHAC engaged EY to review Australia's organ donation, retrieval and transplantation system.¹⁰⁹ The EY review's final report made 57 recommendations for reform. The key findings and recommendations relevant to the Committee's Inquiry are outlined below, followed by a brief analysis of their implementation.

Australian Organ Donor Register

The percentage of people registered on the AODR from 2008 to 2017 remained stagnant at around 32% of the Australian population.¹¹⁰ The EY review found that while the AODR remains a useful system for recording potential donors' consent, its accessibility is limited. For example, individuals experience difficulties with the

¹⁰⁶ Ibid., pp. ii–vii.

¹⁰⁷ Ibid., p. vii.

¹⁰⁸ Ibid., pp. viii–xii.

¹⁰⁹ EY, *Review of the Australian organ donation, retrieval and transplantation system*, p. [25].

¹¹⁰ Ibid., p. [103].

identity requirements.¹¹¹ Shortcomings of the AODR included limited aggregated data capability and difficult registration processes. The EY review recommended:

- changing the AODR from a register of consent to intent, which would reduce complex identification requirements and increase accessibility
- exploring other pathways for registration, such as the driver licence system and social media platforms
- implementing strategies to increase registrations on the AODR, particularly for First Nations and culturally diverse communities, with appropriate demographic data collection.¹¹²

Donation performance and governance

Aligning with the national reform program, Australia's world ranking for deceased organ donation performance rose from 28th in 2008 to 17th in 2016.¹¹³ This was partly attributed to improved utility of organs that were previously considered not medically suitable and enhanced efficiency and effectiveness of the donation process.¹¹⁴

Victoria had the highest growth rate in donations of any state or territory in Australia from 2009 to 2017 (220%). It also performed the most organ transplantations from 2009 to 2017 (alongside New South Wales), reflective of its population size compared to other jurisdictions.¹¹⁵ This growth caused downstream pressure for the transplantation sector, requiring an increased focus on capability and capacity strategies to relieve workforce pressures and effectively manage resources. The EY review recommended:

- the Australian Government develop a national strategy in collaboration with states and territories to maximise transplantation outcomes and a national workforce strategy for the sector¹¹⁶
- states and territories (through hospital networks) remain the primary vehicle for service delivery, but OTA lead strategic priorities and coordinate nationally¹¹⁷
- undertaking an epidemiological study to better understand the organ donation rates required to meet demand in Australia.¹¹⁸

¹¹¹ Ibid., pp. [103, 104]. There are two kinds of donor registration, intent and consent. These are discussed in Chapter 3, Sections 3.1.

¹¹² EY, *Review of the Australian organ donation, retrieval and transplantation system*, pp. [104-105].

¹¹³ Ibid., pp. [68-70]. Australia also had the highest percentage growth in the 9th year of reform (2016) when compared to other countries that had undertaken similar reform programs such as Spain, the United Kingdom and Portugal.

¹¹⁴ Ibid., p. [89].

¹¹⁵ Ibid., p. [47].

¹¹⁶ Ibid., p. [70].

¹¹⁷ Ibid., p. [10].

¹¹⁸ Ibid., p. [94].

Donations in rural and remote, First Nations and culturally diverse communities

The EY review found that rural and remote Australians faced significant barriers accessing transplantation despite higher rates of chronic organ disease and poorer health outcomes.¹¹⁹ Access to kidney transplants was considered a particular issue for rural and remote and First Nations communities.¹²⁰ Issues such as distance, cost and access to specialists and services meant that Australians in rural and remote areas were less likely to be waitlisted for and receive a kidney transplant.¹²¹

First Nations communities had higher demand for organ transplantation due to higher incidence and prevalence of end-stage kidney failure, but often poorer survival rates. First Nations communities experienced barriers to accessing kidney transplant waitlists and had lower (20%) family consent rates to donation than non-Indigenous families (67%).¹²² Lower donation rates were the result of poorer health precluding donation, poor health literacy about donation in health services, remote residency and community and cultural beliefs.¹²³

The review also reported that culturally and linguistically diverse communities experienced barriers to accessing a kidney transplant but data was ‘not available to adequately determine the extent of issues of inequity.’¹²⁴

The EY review made several recommendations in this space, including to:

- publish performance parameters for managing the kidney waitlist, including the number/proportion of First Nations and culturally diverse communities
- adopt a specific national First Nations and culturally diverse populations’ organ donation strategy to improve donation rates in these groups
- implement rural outreach programs and post-transplantation models of care.¹²⁵

Implementation

The Australian Government, through DHAC, works with OTA ‘to respond to reviews of organ and tissue donation’, including the EY review. The next phase of the EY review is ‘to develop a National Strategy through consideration of the final report’s recommendations and stakeholder consultation.’¹²⁶

¹¹⁹ Ibid., pp. [21–22].

¹²⁰ Ibid., pp. [78–81].

¹²¹ Ibid., pp. [21–22].

¹²² Ibid., pp. [12, 20–21].

¹²³ Ibid., p. [98].

¹²⁴ Ibid., p. [84].

¹²⁵ Ibid., pp. [11–14]. See also National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 151.

¹²⁶ Department of Health and Aged Care, *What we’re doing about organ and tissue donation*.

The AODR has not been changed to a register of intent and new ways to register have not been implemented. This is discussed in Chapter 3.

OTA has certain strategies to increase AODR registrations for diverse communities through its community awareness grants program. In 2021, OTA established a First Nations Engagement Group to raise awareness, knowledge and support for donation across First Nations populations.¹²⁷ Suggestions to improve awareness in diverse communities is discussed in Chapter 5.

OTA continues to provide strategic leadership and coordination nationally but the National Organ Strategy is in draft form and no epidemiological study to understand Australia's required rate of organ donation has been undertaken.

A priority of the draft National Organ Strategy is for equitable access to transplantation and post-transplantation care for First Nations and regional Australians.¹²⁸ The draft Strategy also recognises the importance of:

- improving family consent and AODR registration rates in First Nations and culturally diverse communities¹²⁹
- a nationally consistent approach to managing kidney transplant waitlists—including through more funding for OrganMatch, the national waitlist and organ allocation system.¹³⁰

2.4.4 Victoria: 2020, Review of organ donation and transplant services

Some inquiry participants noted a DH-commissioned review of Victorian organ donation and transplant services in 2020. For example, Austin Health recommended in a submission to:

Formulate and execute an implementation plan that incorporates recommendations from the Victorian Government Department of Health review ... along with pertinent Federal Government reviews. Crucially, this plan should prioritise enhanced resourcing and capacity building within retrieval and transplantation processes.¹³¹

Inquiry participants highlighted that while the review concluded in 2020 the report has not been disclosed publicly or shared with the medical community.¹³² Other inquiry participants who appeared at public hearings also confirmed to the Committee that they contributed to the review.¹³³

¹²⁷ Organ and Tissue Authority, *Annual report 2022–23*, pp. 23–24.

¹²⁸ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, pp. 7–8.

¹²⁹ *Ibid.*, p. 6.

¹³⁰ *Ibid.*, pp. 8, 10.

¹³¹ Austin Health, *Submission 34*, p. 2.

¹³² Austin Health, *Submission 34*, p. 5; Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 2; Associate Professor William Silvester, *Transcript of evidence*, p. 42; Lucinda Barry, *Transcript of evidence*, p. 15.

¹³³ Associate Professor John Whitlam, *Transcript of evidence*, pp. 3–4, 11; Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 23; Professor Gregory Snell, *Transcript of evidence*, p. 18.

DH advised the Committee that '[t]he report was an internal review of our operational activity and opportunities for improvement ... not necessarily a policy piece.'¹³⁴ Louise McKinlay, Acting Deputy Secretary of Commissioning and System Improvement Division at DH stated:

it was quite an operational review and it was basically around how we interface with the nationally funded centres, how we work with the national reform program et cetera, so it was really around how we continue to promote and support organ donation activities. It was not necessarily specifically around registrations; it was very much the how-to and what can we do more of. So what came out of that was around workforce, ongoing education, working with the broader community and then also some of the training programs, augmenting those. For instance, St Vincent's has a simulation training program, so we supported that to continue.¹³⁵

Louise McKinlay confirmed that to her understanding, all the recommendations were adopted.¹³⁶ DH also advised in response to a question on notice that:

The Ngamaru Health Advisory Report—Review of organ donation and transplant services 2020 (the Review) commissioned by the Department of Health has not been released. The Review focused on services e.g., organ retrieval and transplantation rates, funding models and workforce requirements. The Terms of Reference of the Review explicitly excluded 'programs to support and promote organ donations activities'. Consequently the 2020 Review is out of scope for this Inquiry.

Recommendations identified in Victoria are aligned with the ... (OTA) Strategic Plan 2021–22 to 2023–24 and Victoria participates in this work via the Jurisdictional Organ and Tissue Steering Committee (JOTSC).¹³⁷

DH outlined some of the work undertaken in Victoria to date in response to the review corresponds to OTA's strategic plan. This includes expanding OTA's role in relation to retrieval and transplantation (rather than focusing on donation):

The OTA has existing knowledge and expertise in place to support an expanded role in retrieval and transplantation including:

- community awareness and education programs
- a clinical governance framework to support best practice care
- data and analytics capability
- expert advisory committees that facilitate advice from across state and territory governments, the clinical sector including organ donation, retrieval and transplantation clinicians, and the community sector.¹³⁸

¹³⁴ Louise McKinlay, Acting Deputy Secretary, Commissioning and System Improvement, Department of Health, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, p. 4.

¹³⁵ *Ibid.*, p. 13.

¹³⁶ *Ibid.*

¹³⁷ Department of Health, response to questions on notice, pp. 2–3.

¹³⁸ *Ibid.*

Victorian stakeholders who contributed to the review advised that they had not been provided with the report or informed by DH about its recommendations, nor had it been appropriately released.¹³⁹ The Committee acknowledges there may be sensitivities around publishing or sharing the report in full, but encourages DH to share with the Victorian stakeholders who contributed to the review as much as possible of the report and its recommendations.

2.4.5 Other past national reviews

Some reoccurring themes that stood out to the Committee from other past national reviews and inquiries into donation included the need to improve:

- consent rates and donation specialist involvement in family conversations¹⁴⁰
- resourcing for clinical improvement strategies, donor identification and emerging technologies, such as organ perfusion (technology that preserves donor organs outside the body)¹⁴¹
- national communication, awareness and education about donation and registration, and collaboration between stakeholders and government to promote community awareness¹⁴²
- the transparency of community awareness grants selection processes¹⁴³ and the monitoring¹⁴⁴ and performance indicators used to assess the effectiveness of community awareness initiatives and professional education¹⁴⁵
- national data systems and reporting,¹⁴⁶ including for:
 - better publication of data and benchmarking and for each state and territory to clearly define responsibility for donation rates¹⁴⁷
 - OTA to publish the breakdown of state and territory funding.¹⁴⁸

These themes are addressed throughout the report.

¹³⁹ Associate Professor John Whitlam, *Transcript of evidence*, pp. 3–4, 11; Lucinda Barry, *Transcript of evidence*, p. 23; Associate Professor William Silvester, *Transcript of evidence*, p. 42.

¹⁴⁰ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, pp. 154, 160.

¹⁴¹ *Ibid.*, p. 151; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, pp. 8, 56.

¹⁴² National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 151; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 8; Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, *Inquiry into human organ trafficking and organ transplant tourism*, p. 96; Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support*, p. 16.

¹⁴³ Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support*, p. 16; EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 7.

¹⁴⁴ EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, pp. 45, 47.

¹⁴⁵ Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support*, p. 16.

¹⁴⁶ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 151; Australian National Audit Office, *Organ and tissue donation: community awareness, professional education and family support*, p. 91.

¹⁴⁷ EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 49; National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 151.

¹⁴⁸ EY, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p. 50.

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 notes that, at a federal level, the finalisation of the draft National Organ Strategy and IP can help progress the implementation of recommendations from past reviews. This includes those directed at increasing donation rates and improving the process for registering to be an organ and tissue donor on the AODR. This Inquiry also presents an opportunity to implement further improvements at a state level.

Chapter 3

Registering to be an organ and tissue donor

There is always more that can be done, and one of the biggest opportunities that we see to save more lives is to improve registration rates so that more people can receive a life-saving transplant.¹

People record their wishes about donating organs and tissues on the Australian Organ Donor Register (AODR). To ensure people make informed choices, the AODR and information about donation must be accessible and straightforward.

This chapter is in two parts. The first outlines current and historic registration processes as well as alternate models for donor registration, family consent and age requirements. The second considers suggestions to improve the current registration process to increase the number of Victorians registered.

Part 1: Current process and alternate models

3.1 Australian Organ Donor Register current process

Australia operates an opt-in registration model² where an individual registers to donate organs and tissues on the AODR. The Australian Department of Health and Aged Care (DHAC) has policy responsibility for the AODR and Services Australia manages it.³

Ways to register on the AODR include the DonateLife online form, Medicare through myGov or the Medicare app, or by post or phone.⁴ There are two kinds of donor registration:

- Intent for people aged 16 or older does not require a signature or identity authorisation and can be completed by the online form or phone. Phone intent

¹ Tony Holland, General Manager, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 2.

² This approach is informed by research, evidence and agreement between state and territory governments, see Government of Australia, *Response to the Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, Compassion, not commerce: an Inquiry into human organ trafficking and organ transplant tourism*, February 2021, p. 20.

³ Department of Health and Aged Care, *Inquiry into increasing the number of registered organ and tissue donors*, response to written questions on notice received 15 August 2023, p. 3.

⁴ Ways to register on the AODR are summarised in Appendix B.

registrations allow people to record which organs and tissues to donate or an objection.⁵

- Consent for people aged 18 or older requires a signed form or registration with Medicare details through myGov or the Medicare app. All consent registration methods allow people to record which organs and tissues to donate or record an objection. If people aged 16 to 17 register by these methods (printed form, MyGov and Medicare app) it is recorded as an intent registration.⁶

There is no difference between intent and consent registrations when a potential donor is identified in hospital—family is always asked to consent to donation.⁷

A physical AODR donor card is available for all intent and consent registered donors and a digital card can be accessed through the Medicare app.⁸

Only in South Australia (SA) can people agree to donation on a driver licence by ticking yes to an optional question when completing online and manual licence applications and renewals. This is transferred to the AODR as an intent registration and recorded on the person's SA driver licence.⁹ SA has the highest registration rate in Australia at 72% of the eligible population (compared to 23% in Victoria).¹⁰

5 Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to additional written questions on notice received 13 September 2023, p. 3.

6 Services Australia, *Annual report 2021–22, 2022*, p. 74; Department of Health and Aged Care, response to written questions on notice, p. 4.

7 Department of Health and Aged Care, response to written questions on notice, p. 3.

8 Services Australia, *How to register*, 30 May 2023, <<https://www.servicesaustralia.gov.au/how-to-register-australian-organ-donor>> accessed 18 September 2023.

9 South Australian Department for Health and Wellbeing, *Information about driver licence registrations for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, July 2023, p. 1.

10 Organ and Tissue Authority, *Australian donation and transplantation activity report 2022, 2023*, p. 22.

Figure 3.1: Current physical cards that symbolise a decision about donation in Australia

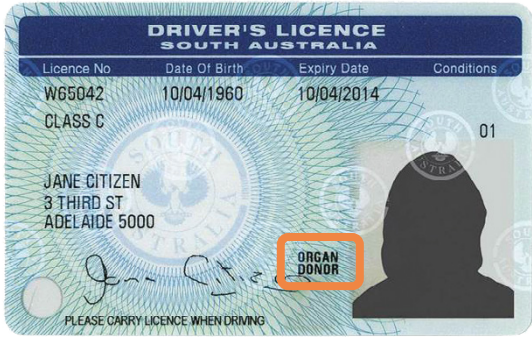
Current Australian Organ Donor Register Card

- Australians can record their donation decision on the AODR.
- Proof that a person has registered a **decision** about organ and tissue donation is then stated on AODR donor cards (digital AODR donor cards are available on the Medicare app).
- It includes intent and consent registrations on the AODR.



Current South Australia driver's licence

- South Australians can agree to donation on a driver licence by ticking yes to an optional question.
- **Organ donor** is then printed on South Australia driver licences.
- A person's decision is transferred to the AODR as an intent registration.



Source: Organ and Tissue Authority, Have you lost your donor card?, Facebook post, 12 January 2020, <<https://www.facebook.com/DonateLifeAustralia/photos/lost-your-organ-donor-card-dont-worry-computer-records-will-always-be-checked-in/10157102311982956>> accessed 27 November 2023; Justin Hendry, IT News, SA beats NSW to digital driver's licence rollout, 25 September 2017, <<https://www.itnews.com.au/news/sa-beats-nsw-to-digital-drivers-licence-rollout-473949>> accessed 27 November 2023. Orange boxes added to original images for emphasis.

3.1.1 Historic methods of donor registration

Prior to the establishment of the AODR in 2000, state jurisdictions managed individual donor registration databases, often recorded on driver licences and managed by a road transport authority. For Victoria:

- From 1991–2000, the Victorian Organ Donor Registry (responsibility of the Victorian Transplant Promotion Council) recorded intent registrations.¹¹
- In February 2000 (also the year the AODR was established), a tick box on potential donation was added to licence renewals by VicRoads (see Figure 3.2).¹² This was in conjunction with the Victorian Organ Donor Registry and an initiative of the Victorian Transplant Promotion Council.¹³
- In July 2001, the Victorian Government announced it would cease the state-based recording of donation decisions and transfer its records to the AODR.¹⁴ Anecdotal evidence indicates a significant number of records were lost during the data transfer (discussed further below).
- By October 2002, donor registration was discontinued through both the Victorian Organ Donor Registry and VicRoads licence renewal methods.¹⁵

The Victorian Department of Health (DH) advised that ‘[p]rior to the year 2000, Victorians were able to sign up as organ donors on a registry managed by VicRoads’.¹⁶ However, the Victorian Department of Transport and Planning (DTP) outlined that licence renewals included a tick box only ‘to enable Victorian licence holders to indicate their interest in obtaining more information about becoming an organ donor.’¹⁷ DTP confirmed ticking this box was an expression of interest, not a registration:

Essentially what VicRoads provided through their channels at the time was around an application process, so it introduced an application to register your interest. It was not the final registration process to be undertaken—the final stages. Essentially the

11 National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally: volume 1*, Australian Government Department of Health and Ageing, 2008, p. 128; Hon Peter Batchelor and Hon John Thwaites, *Licence system will drive organ donation rates up*, media release, Victorian Government, Melbourne, 24 February 2000; Department of Human Services, *\$1 million commitment to organ donation*, media release, Victorian Government, Melbourne, 1 July 2001. The July 2001 media release states the Registry was established in 1991. The February 2000 media release states the Registry was established in 1994. The Committee refers to the earlier of these dates for the purposes of this report. The Victorian Transplant Promotion Council no longer exists.

12 Department of Transport and Planning, *Submission 45*, p. 2.

13 Hon Geoff Craigie, Minister for Roads and Ports, submission to the Legal, Constitutional and Administrative Review Committee, Legislative Assembly of Queensland, Inquiry into the Transplantation and Anatomy Amendment Bill 1998, 1999; Hon Peter Batchelor and Hon John Thwaites, *Licence system will drive organ donation rates up*, media release; Department of Health and Aged Care, response to written questions on notice, p. 3.

14 Department of Human Services, *\$1 million commitment to organ donation*, media release.

15 Department of Health, *Submission 42*, received 25 July 2023, p. 2; Department of Human Services, *\$1 million commitment to organ donation*, media release; Department of Transport and Planning, *Submission 45*, p. 2.

16 Department of Health, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 7 September 2023, p. 4.

17 Department of Transport and Planning, *Submission 45*, p. 2.

department and VicRoads then passed that information on and then obviously the application process with that individual was then finalised in terms of their confirmation. It was essentially part of an application process that then enabled the [AODR] to actually then directly contact. We were essentially utilising our customer list, getting that initial confirmation and providing that centrally for them to then maintain that contact and then obviously maintain that data as well.¹⁸

DTP advised that in 2000 the Australian Health Insurance Commission,¹⁹ which administered the AODR at the time, requested the Victorian Government cease collecting donor information from licence holders. DTP indicated this was because of ‘community confusion about whether the tick box was an expression of interest for more information on organ donation or an authorisation to become a registered donor.’²⁰ DHAC identified that the Victorian records transferred to the AODR were ‘yes’ donation decisions.²¹ DH advised that aside from SA, all jurisdictions determined at the time ‘that the cost associated with processing and recording the information outweighed the benefits of continuing.’²²

The Committee notes ongoing confusion about whether donor status as recorded on Victorian driver licences was considered an intent registration and if it is a valid registration recorded on the AODR today.

¹⁸ Jacqui Sampson, Executive Director, Regulatory Programs and Services, Department of Transport and Planning, public hearing, Melbourne, 11 September 2023, *Transcript of evidence*, p. 5.

¹⁹ A Commonwealth statutory body that administered Medicare and the AODR at the time, see Health Insurance Commission, *Annual report 2004–05*, Commonwealth of Australia, 2005, pp. 18–19.

²⁰ Department of Transport and Planning, *Submission 45*, p. 2.

²¹ Department of Health and Aged Care, response to additional written questions on notice, p. 2.

²² Department of Health, *Submission 42*, p. 3.

Figure 3.2: Historic and current Victorian driver licence cards

Historic Victoria driver licence – potential organ donor

- 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.



Current Victoria driver licence – no donor option

- Since the early 2000s Victorians cannot record donation preferences when renewing a driver licence.
- Potential organ donor is **not** printed on current Victorian driver licences.



Source: Department of Transport and Planning, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 28 September 2023, p. 6; ABC News, *New security number to be introduced for all Victorian driver licences after recent cyber attacks*, 30 October 2022, <<https://www.abc.net.au/news/2022-10-30/vicroads-optus-driver-licence-cyber-attack/101594466>> accessed 5 December 2023. Orange box added to original image for emphasis.

FINDING 1: Victorians have not been able to record interest in becoming an organ and tissue donor on driver licences since the early 2000s. This is only possible in South Australia, where the driver licence donor registration system was continued.

Data transfer difficulties

Supported by state Road Transport Ministers, the Australian Government announced it would stop uploading state-based registrations to the AODR in 2005.²³ Existing records not meeting legal consent requirements were categorised as intent registrations.²⁴

²³ There was no formal agreement to continue transferring SA driver licence donor registration to the AODR, see EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, p. [44].

²⁴ Ibid.

The Committee learned during the Inquiry about concerns that not all Victorian records were uploaded to the AODR as intent registrations.²⁵ DonateLife Victoria (DLV) advised it received ‘anecdotal comments from the community ... suggesting that not all registrations were successfully moved’ and ‘[m]any people who remember signing up through their driver licence do not have any decision recorded on the AODR.’²⁶ DH also noted ‘some migration difficulties at that time.’²⁷

The Committee was unable to obtain a definitive answer on who was responsible for the data transfer,²⁸ the number of Victorians registered before and after the transfer, and how and when the transfer occurred.²⁹ Noting conflicting information from various stakeholders, the Committee ascertained that the transfer of Victorian intent registration data to the AODR included:

- data from two different sources (VicRoads and the Victorian Transplant Promotion Council³⁰) and multiple uploads over 2001–2002³¹
- an estimate of 400,000 to 440,000 records,³² but the breakdown in the source is unclear (just over 4,000 were from VicRoads³³ and 250,000 were from the Victorian Organ Donor Registry in July 2001,³⁴ which equals 254,000 not 400,000 to 440,000)
- checking for duplicates prior to upload.³⁵

Victoria may not have been the only state to experience data transfer difficulties. Approximately 4 million state-based registrations and several subsequent downloads

²⁵ Mark McDonald, National Manager, Analytics and Technology, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 19.

²⁶ DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 3.

²⁷ Department of Health, *Submission 42*, p. 2.

²⁸ For example, DH stated the data transfer was between VicRoads and the AODR and DTP stated it has no record of who transferred the data, but that it used a third-party provider, see Louise McKinlay, Acting Deputy Secretary, Commissioning and System Improvement, Department of Health, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, p. 11; Department of Transport and Planning, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 28 September 2023, p. 1; Jacqui Sampson, *Transcript of evidence*, p. 3.

²⁹ For example, DH advised Victoria discontinued state-based driver licence registrations in 2000 but did not outline when the transfer happened, see Department of Health, *Submission 42*, p. 2. The National Clinical Taskforce on Organ and Tissue Donation Taskforce’s 2008 final report stated that just over 410,000 VicRoads-based records had been downloaded as of December 2007 and current VicRoads data had not been transferred to the AODR, see National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 129. DLV advised it was not ‘able to source any information on what the registration rate was in Victoria under the VicRoads registry prior to moving to the AODR’, see DonateLife Victoria, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 6 July 2023, p. 2. OTA advised they were unsure exactly how many VicRoads registrations were migrated but would estimate between 300,000 and 320,000, noting that ‘some of the registrations that initially moved across may no longer be active’, see Mark McDonald, *Transcript of evidence*, p. 19. DTP advised it has no record of how and when the data transfer occurred, whether it was multiple uploads, and whether all records were transferred, see Department of Transport and Planning, response to questions on notice, p. 1. A submission from the Victorian Minister for Roads and Ports to a 1999 Queensland inquiry stated that VicRoads collected this information from drivers, but it was passed to the Victorian Transplant Promotion Council to store and manage so that onus was not placed on VicRoads to manage registration data, see Hon Geoff Craige, submission to the Inquiry into the Transplantation and Anatomy Amendment Bill 1998, p. 1.

³⁰ Department of Health and Aged Care, response to written questions on notice, p. 3.

³¹ Department of Health and Aged Care, response to additional written questions on notice, p. 2.

³² *Ibid.*; Department of Health and Aged Care, response to written questions on notice, p. 3; National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 129.

³³ Department of Transport and Planning, response to questions on notice, p. 1.

³⁴ Department of Human Services, *\$1 million commitment to organ donation*, media release. See also National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 128; Hon Peter Batchelor and Hon John Thwaites, *Licence system will drive organ donation rates up*, media release.

³⁵ Department of Health and Aged Care, response to additional written questions on notice, p. 2.

were transferred to the AODR, but a 2008 report identified that ‘quality concerns have remained regarding some of the data entered into the AODR through these downloads.’³⁶ Transplant Australia suggested around a million New South Wales (NSW) registrations were not uploaded because the privacy commissioner at the time identified that people’s registrations were private to the state and could not be used for the national system.³⁷ However, in comparison to Victoria’s estimated 400,000 to 440,000 records, just under 2.5 million NSW registrations were migrated to the AODR by December 2007.³⁸

A low percentage of Victoria’s population are registered donors (23% in 2022) compared to other states (Australia’s average was 36% in 2022).³⁹ Tony Holland, General Manager of DLV partly attributed this to the incomplete data transfer which meant Victoria started with a lower percentage of its population registered at the inception of the AODR.⁴⁰

FINDING 2: Not all Victorians who recorded their organ and tissue donation decision through a past state-based mechanism had this decision transferred to the Australian Organ Donor Register.

FINDING 3: Victoria has a lower percentage (23%) of its population registered on the Australian Organ Donor Register (AODR) compared to other states (36% national average). This is partly attributable to the incomplete data transfer of Victorian records to the AODR in the early 2000s.

DH acknowledged ‘that many people who registered pre-2000 may believe their initial registration is relevant’.⁴¹ DH identified an opportunity to increase registrations by encouraging Victorians to check their registration status.⁴² The Committee believes Victorians should be informed that their historical registration decision may not be recorded on the AODR.

As the process for checking registration status through the online form automatically registers a person on the AODR if they are not already,⁴³ any campaign or notification to encourage people to check or confirm their registration status should direct them to use their MyGov Medicare account or the Medicare app. This is important to ensure people do not register as a donor when they were not intending to do so.

³⁶ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 128.

³⁷ Chris Thomas, Chief Executive Officer, Transplant Australia, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 26.

³⁸ Mark McDonald, *Transcript of evidence*, p. 19; National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 129; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

³⁹ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

⁴⁰ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 2.

⁴¹ Department of Health, *Submission 42*, p. 2.

⁴² *Ibid.*, p. 3.

⁴³ Organ and Tissue Authority, *Join the register*, n.d., <<https://www.donatelife.gov.au/register-donor-today>> accessed 13 September 2023.

FINDING 4: There is confusion in the Victorian community about whether a previous record to become a potential organ and tissue donor on a driver licence is a valid registration on the Australian Organ Donor Register today.

RECOMMENDATION 1: Given uncertainty around historic Victorian driver licence donor registrations, the Victorian Government advise people 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 Australian Organ Donor Register using their MyGov Medicare account or the Medicare app.

3.2 Alternative models to register as a donor

As well as focusing on improvements to current registration processes as they operate in Victoria, some inquiry participants discussed alternate registration models, such as family consent requirements, changing the age to register and opt-out. The Committee received varied evidence on these topics and they are discussed below.

3.2.1 Family consent requirements

Some inquiry participants discussed whether families should be able to override the registered decisions of donors.⁴⁴ All inquiry participants recognised family cooperation is critical and that ignoring family consent could damage the donation system: families should approve of the donation and be respected and supported through a difficult mourning period.⁴⁵ This is particularly important because families are required to provide medical and social history to help determine donor suitability.⁴⁶

Some inquiry participants noted that people should have control over their own bodies⁴⁷ and a donor's registered decision should have the same standing as a will (people currently have greater control of their assets after death).⁴⁸ Transplant

⁴⁴ Transplant Australia, *Submission 23*, received 18 May 2023, p. 12; Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 18; Chris Thomas, *Transcript of evidence*, p. 22; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, received 16 June 2023, pp. 16–17; Cynthia Caruana, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 23.

⁴⁵ Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 45; Dr Beatriz Domínguez-Gil, General Director, Organización Nacional de Trasplantes, Spain, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 76; Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 45; Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 27–28; Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 30; Dr Aadhil Aziz, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 31; Transplant Australia, *Submission 23*, p. 11; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 16–17.

⁴⁶ Chantel Bartolo, *Transcript of evidence*, p. 45.

⁴⁷ Associate Professor Christopher Hogan, *Transcript of evidence*, p. 30; Dr Aadhil Aziz, *Transcript of evidence*, p. 30; Georgina Callaghan, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 19; Dr Joshua Ihle, *Transcript of evidence*, p. 23.

⁴⁸ Georgina Callaghan, *Transcript of evidence*, p. 19; Jeff Ryall, *Submission 46*, received 5 October 2023, p. 1.

Australia stated a person's registered donation decision should be respected; doing so would be in line with community expectations.⁴⁹ Other inquiry participants also drew an analogy between donation and advanced care directives, where people can provide either general directives or exact instructions to a medical decision maker that cannot be overridden.⁵⁰ Advance care planning is discussed in Chapter 7.

Alfred Health suggested two tiers of registration to place more weight on donors' views:

- A 'simple registration' option indicating a donor's wishes that could readily be declined by a donor's family.
- A more legally binding registration option with greater evidence requirements that would be harder to reject.⁵¹

In Alfred Health's experience, sometimes families regret saying no to donation but importantly, they never report regretting saying yes.⁵² Consequently, while any change would be 'bold' and require a concerted education campaign, it could help change how donation is perceived and support more families to say yes.⁵³

The ethics of more binding consent options, such as absolute consent, would also require weighing against possible negative pushback.⁵⁴

Other inquiry participants supported current family consent practices.⁵⁵ Leanne Campbell, the mother of Brett who donated organs after his death, stated: 'I will never put my name on a register where the potential to remove the families right to consent to ... donation exists.'⁵⁶ Dr Aadhil Aziz, General Practitioner (GP) and Co-Deputy Chair Victoria Faculty of the Royal Australian College of General Practitioners (RACGP) highlighted the need to be 'very careful' about changing laws and suggested change should not be based on an infrequent number of cases of families overriding donors' wishes.⁵⁷ Any changes to consent may also make the registration process more complex and efforts may be better directed towards education and promoting family discussion.⁵⁸

The AODR was changed in 2005 to record both intent and consent registrations, 'to ensure that the known wishes of the deceased, whether consenting or objecting, are respected and followed through'.⁵⁹ This change aimed to establish 'the autonomy

⁴⁹ Transplant Australia, *Submission 23*, p. 11.

⁵⁰ Dr Aadhil Aziz, *Transcript of evidence*, p. 30; Alfred Health, *Submission 38*, received 1 June 2023, p. 7.

⁵¹ Alfred Health, *Submission 38*, p. 7.

⁵² Georgina Callaghan, *Transcript of evidence*, p. 19.

⁵³ Dr Joshua Ihle, *Transcript of evidence*, p. 23.

⁵⁴ Robert Manning, *Submission 15*, received 6 May 2023, p. 13; Robert Manning, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 12.

⁵⁵ Donor Families Australia, *Submission 21*, received 17 May 2023, p. 3; Allan Turner, Managing Director, Zaidee's Rainbow Foundation, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 36.

⁵⁶ Leanne Campbell, *Submission 16*, received 7 May 2023, p. 1.

⁵⁷ Dr Aadhil Aziz, *Transcript of evidence*, pp. 29, 31.

⁵⁸ Tony Holland, General Manager of DonateLife Victoria, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 53; Robert Manning, *Transcript of evidence*, p. 12.

⁵⁹ Australian Health Ministers' Conference, Joint Communiqué: Transplant donor's wishes to prevail, media release, 28 January 2005, referenced in EY, *Review of the Australian organ donation, retrieval and transplantation system*, pp. [101-102].

and legally binding position of a registration ... [so] that a family would not be required to confirm or deny the recorded decision.⁶⁰ It is well documented that in practice there is no difference between intent and consent registrations and families are always asked for consent.⁶¹ Given the historical distinction between intent and consent registrations aimed to achieve similar goals to those suggested by inquiry participants, but are not adopted in practice, the Committee does not think there is sufficient evidence for consent practices to change.

FINDING 5: In practice there is no difference between intent and consent registrations on the Australian Organ Donor Register: families are always asked for consent when organ and tissue donation is considered. Family consent in the donation process is critical.

3.2.2 Changing the age to register

Prior to the AODR's creation in 2000, parents and guardians could register an intent decision for children.⁶² Zaidee's Rainbow Foundation questioned why people under 16 years old can no longer register a decision on the AODR and people aged 16 to 17 can only register intent.⁶³ The Foundation suggested children under 16 could help start family discussions about donation.⁶⁴

Cool Australia, an organisation developing educational resources for schools, supported removing the minimum age to register. Cool Australia noted that 'conversation and awareness is a huge part [of donation] ... [so younger people could] register their interest and then maybe receive some sort of follow-up email ... so that kids not only are enabled to feel like they are acting and helping but can also influence their parents or family members ... Sometimes student voice and power are overlooked'.⁶⁵ The Organ and Tissue Authority (OTA) explained that allowing children to register could normalise donation, and in practice, if a child is identified as a potential donor the family would always be approached for consent, like any other potential donor.⁶⁶

FINDING 6: Lowering the age to register on the Australian Organ Donor Register to include children under the age of 16 may encourage family discussion about, and normalise, organ and tissue donation.

⁶⁰ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 126.

⁶¹ *Ibid.*, p. 157, with sources; Department of Health and Aged Care, response to written questions on notice, p. 3; Dr Rohit D'Costa, State Medical Director, Donatelife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 9; Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*, March 2012, p. 35.

⁶² Zaidee's Rainbow Foundation, *Submission 13*, received 5 May 2023, p. 15; Lucinda Barry, *Transcript of evidence*, p. 19.

⁶³ Allan Turner, *Transcript of evidence*, p. 35.

⁶⁴ *Ibid.*, pp. 35, 36.

⁶⁵ Naomi Nicholas, Head of Community Engagement, Cool Australia, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 55, see also p. 58; Thea Stinear, Chief Executive Officer, Cool Australia, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 58.

⁶⁶ Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 28.

3.2.3 Opt-out registration model

Opt-out (also known as presumed or deemed consent) models mean it is generally assumed that all adults agree to donation.⁶⁷ If an adult does not agree or want to donate, they need to communicate this (usually on a register).⁶⁸ In practice, opt-out models still obtain family consent before a donation proceeds.⁶⁹

Some inquiry participants supported an opt-out model,⁷⁰ suggesting it could:

- help overcome barriers to registering like a lack of motivation or interest, or not having a Medicare card to hand⁷¹
- widen discussion, create awareness and change attitudes towards donation⁷²
- be preceded by an education and awareness campaign to ensure success.⁷³

The Managing Director of Zaidee's Rainbow Foundation, Allan Turner, has advocated for an opt-out model in Australia since 2015:

The opt-out system has many levels to it and moving parts. What this does is it allows the subject to be talked about with every person in this state no matter what the age. It provides the opportunity to bring this subject to the top of the media's attention for many years, not just a week as we have now, and the discussion in homes. It will have the ability to change our culture forever, and this is what we need.⁷⁴

The Committee heard that one of the main factors contributing to the success of opt-out models is the accompanying community education and awareness campaign.⁷⁵ Associate Professor Christopher Hogan, GP and Member of Victoria Faculty for RACGP, stated that an opt-out system is one option to address low registration rates and if it fails, the 'discussion generated by such legislation will significantly heighten community awareness about registering' to donate.⁷⁶ Challenging people to make a choice may create opportunities for discussion and result in more people agreeing to donate.⁷⁷

⁶⁷ Jordan Parsons and Bonnie Venter, 'Deemed consent for organ donation in Northern Ireland', *The Lancet*, vol. 12, 2022, p. 1.

⁶⁸ Organ and Tissue Authority, *Organ and tissue donation opt-in and opt-out consent systems*, Fact sheet, n.d., <https://www.donatelife.gov.au/sites/default/files/2022-02/OTA_2021ActivityReport_Opt-in_Opt-out_Factsheet_Feb2022-Final.pdf> accessed 7 February 2024.

⁶⁹ Zaidee's Rainbow Foundation, *Submission 13*, p. 10; Lucinda Barry, *Transcript of evidence*, p. 28.

⁷⁰ Leonard Dark, *Submission 5*, received 3 April 2023, p. 1; Alison Mackay, *Submission 8*, received 5 April 2023, p. 1; Name withheld, *Submission 9*, received 7 April 2023, p. 1; Chris Healy, *Submission 12*, received 2 May 2023, p. 1; Zaidee's Rainbow Foundation, *Submission 13*, p. 1; Name withheld, *Submission 14*, received 5 May 2023, p. 1; Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 53.

⁷¹ Alison Mackay, *Submission 8*, p. 1.

⁷² Allan Turner, *Transcript of evidence*, p. 33; Associate Professor Christopher Hogan, *Transcript of evidence*, pp. 22, 30; Dr Aadhil Aziz, *Transcript of evidence*, pp. 29, 30.

⁷³ Zaidee's Rainbow Foundation, *Submission 13*, p. 3; Allan Turner, *Transcript of evidence*, p. 36.

⁷⁴ Allan Turner, *Transcript of evidence*, p. 33.

⁷⁵ Zaidee's Rainbow Foundation, *Submission 13*, p. 3; Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 13.

⁷⁶ Associate Professor Christopher Hogan, *Transcript of evidence*, p. 22.

⁷⁷ *Ibid.*, p. 30.

Other inquiry participants noted that moving to an opt-out model appears like a simple and quick fix, but in practice, donation processes in countries with opt-out models operate similarly to Australia's opt-in model.⁷⁸ Research also does not conclusively show opt-out models increase donation and transplantation rates.⁷⁹ OTA noted that a move to opt-out in Australia would need to be carefully considered because it carries some risk. It would have to be accompanied by substantive investment in community messaging, which could be complex due to Australia's cultural diversity.⁸⁰

Inquiry participants who did not support an opt-out model considered it could:

- compromise the idea of donation as a gift⁸¹
- create confusion and alienate people who are already registered⁸²
- reduce the weight and value attributed to a person's donation decision (for example, it is more powerful to tell a family that their loved one took the time to register than to tell a family that they did not opt-out)⁸³
- negatively affect consent rates⁸⁴
- cause problems if consent is assumed without a person knowing the implications, making family discussion and consent more important (an issue because donation consent rates are declining)⁸⁵
- result in public 'backlash with a risk of significant adverse publicity'⁸⁶
- be an issue as the donation and transplant sector depends on public trust⁸⁷
- adversely affect culturally diverse communities and people from a non-English-speaking background, requiring substantive investment in community messaging for Australia's diverse communities⁸⁸
- take some time for results.⁸⁹

⁷⁸ ANZICS Death and Organ Donation Committee, *Submission 41*, received 19 June 2023, p. 6; Associate Professor Helen Opdam, *Transcript of evidence*, p. 29; Graham Harrison, *Submission 25*, received 18 May 2023, p. 4.

⁷⁹ Associate Professor Helen Opdam, *Transcript of evidence*, p. 29; Transplant Australia, *Submission 23*, p. 9; Government of Australia, *Response to the Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, Compassion, not commerce: an inquiry into human organ trafficking and organ transplant tourism*, pp. 20–21; Department of Health, *Submission 42*, p. 3, with sources; Professor Robert Jones, Liver Transplant Unit Director, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 9–10. It can be difficult to determine what improvements to donation rates are the result of policy change, or the result of investment in education campaigns and other clinical improvements, see for example Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 13.

⁸⁰ Associate Professor Helen Opdam, *Transcript of evidence*, pp. 29–30.

⁸¹ Catholic Archdiocese of Melbourne, *Submission 19*, received 16 May 2023, pp. 1 cover letter, 3–4; Rev Dr Paschal Corby, *Submission 29*, received 19 May 2023, p. 2.

⁸² Transplant Australia, *Submission 23*, p. 9; Chris Thomas, *Transcript of evidence*, p. 23.

⁸³ Name withheld, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 5.

⁸⁴ Transplant Australia, *Submission 23*, p. 10.

⁸⁵ Donor Families Australia, *Submission 21*, p. 5.

⁸⁶ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 6.

⁸⁷ Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 10.

⁸⁸ Associate Professor Helen Opdam, *Transcript of evidence*, pp. 29–30; Transplant Australia, *Submission 23*, p. 9.

⁸⁹ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 13.

A 2018 Commonwealth committee *Inquiry into organ trafficking and organ transplant tourism* recommended ‘further investigation of other countries donation programs, including Opt-Out organ donation programs to determine whether such a program could be appropriate for the Australian health system.’⁹⁰ The Australian Government response indicated ‘[t]he current Australian position of ‘opt-in’ has been informed by research, evidence and discussions with state and territory governments’ and that:

Experience in other countries shows that systems which compel organ donation, such as ‘opt out’ models, are not necessarily the reason for increased donation rates. Research shows that better long-term results are achieved through systemic approaches that educate and involve hospitals, clinicians, donor families and the general public.⁹¹

Several international jurisdictions implemented opt-out models. OTA identified that it is difficult to compare Australia to these countries because of differences in ‘health care systems, population size and demographics, population mortality, community attitudes and the relative starting points for national reform’, as well as the COVID-19 pandemic.⁹²

Some key learnings from the United Kingdom (UK) and Spain are discussed in Case Studies 3.1 and 3.2.

Case Study 3.1 United Kingdom, National Health Service (NHS) Blood and Transplant

The UK recently moved to an opt-out system (with family consent requirements) but maintained opt-in registrations. The UK established an opt-in model in 1994, with 28.6 million citizens registered (43% of the population). Most opt-in registrations are through a driver licence (73%) and this model is maintained alongside opt-out because the consent rate for opt-in registrations is higher (90%).

Driven by government (with bipartisan support) after broad consultation to substantiate public support, opt-out legislation was introduced in Wales in 2015, England in 2020, Scotland in 2021 and Northern Ireland in 2023. Opt-out decisions were registered by 2.5 million UK citizens: Wales has an opt-out rate of 6.4%, England 3.7%, Scotland 3.2% and Northern Ireland 0.4%. People can opt-out via the website or app. People cannot opt-out via a driver licence because there is a timelag for this to be recorded on the register.

(Continued)

⁹⁰ Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, *Inquiry into human organ trafficking and organ transplant tourism*, December 2018, p. 96.

⁹¹ Government of Australia, *Response to the Parliament of Australia, Joint Standing Committee on Foreign Affairs, Defence and Trade, Compassion, not commerce: an inquiry into human organ trafficking and organ transplant tourism*, pp. 20–21.

⁹² Organ and Tissue Authority, *Submission 31*, received 19 May 2023, p. 5.

Case Study 3.1 Continued

While change was slow, Wales has experienced a statistical increase in the consent rate (it was 58% in 2015–16 and 77% in 2018–19, but dropped to 61% in 2022–23). However, Wales has a smaller and less diverse population than other UK countries. Simultaneous to introducing opt-out legislation, Wales invested in clinical staff who talk to families to obtain consent as well as a comprehensive media, promotion and education campaign.

In England, the opt-out launch was more challenging because the COVID-19 pandemic reduced opportunities for engagement and promotion. The consent rate dropped from 69% in 2021 to 61% in 2022–23 but this cannot be conclusively attributed to either the pandemic or the opt-out legislation. Anecdotally, the consent rate decrease seemed to be due to a general level of dissatisfaction and distrust in the health system following the pandemic rather than the opt-out legislation. Some key learnings from the UK include:

- The best way to increase registrations is to make it easier, for example, by prompting people when interacting with government to complete a different task. UK opt-in registrations spiked when people accessed vaccination certificates through an app. This is similar to the experience in Victoria, discussed in Section 3.4.1. NHS Blood and Transplant is seeking to simplify ways to register because multiple avenues can be confusing. For example, GP registrations are paper-based and electronic systems are generally easier.
- Promotion in hospitals is not always effective because a choice to register is a values-based decision representing who you are, rather than a health decision.
- Education campaigns should engage with digitally disadvantaged and diverse groups, for example, through mail drops, easy-read and translated resources. Investment must be sustained to support a cultural shift. Social media and school education are also important to increasing registration (discussed in Chapter 5).
- Culturally diverse, lower socio-economic and young people opted out at higher rates. Misinformation spread on social media partly contributed. But the opt-out legislation also opened discussion and engagement with cultural and faith-based leaders, strengthening NHS's relationships with diverse communities.

Source: Dale Gardiner, Associate Medical Director Deceased Organ Donation; John Richardson, Assistant Director Organ Donation; Derek Manas, Associate Medical Director, Organ Donation; Lisa Mumford, Head of Organ Donation and Transplantation Studies; Phil Walton, Project Lead, Deemed Consent Legislation; Cathy Miller, Head of Education and Professional Development, NHS Blood and Transplant, UK, public hearing, 25 July 2023, *Transcript of evidence*, pp. 41–47; NHS Blood and Transplant, *Welsh Health Minister celebrates that 'Opt-out organ donation scheme has transformed lives'*, 3 December 2020, <<https://www.organdonation.nhs.uk/get-involved/news/welsh-health-minister-celebrates-that-opt-out-organ-donation-scheme-has-transformed-lives>> accessed 2 November 2023; NHS Blood and Transplant, *Organ and tissue donation and transplantation activity report 2022–23*, 2023, p. 148.

Case Study 3.2 Spain, Organización Nacional de Trasplantes (ONT)

Spain operates a presumed consent model with no register to opt-out for people who prefer not to donate. However, Dr Beatriz Domínguez-Gil, General Director of Spain's ONT explained to the Committee that Spain has 'never strictly applied the presumed consent model' because it feared being seen as 'the owner of the organs' without considering the views of individuals and families, particularly if individuals had not expressed their wishes. Instead, Spain's approach is set out in secondary legislation and donor coordinators check the advance care directives registry which generally specify a person's wishes. This information is presented to the family, who confirms the wishes of the deceased and that donation is consistent with their values:

So in reality we are much closer to an opt-in system than to an opt-out system.

Dr Domínguez-Gil advised that Spain's success is attributed to other factors, like the key role of donor transplant coordinators and extensive professional training (discussed in Chapter 4), and the process to identify donors and use of extended donor criteria (discussed in Chapter 7). Other elements of Spain's system were noted by inquiry participants as best practice, including medical professionals' approach to obtaining family consent which treats families and donors with 'utmost respect'. The introduction of the opt-out system led to donation being seen as 'the normal option' which, accompanied by hospital system improvements, enabled Spain's status as a world leader in donation. DLV stated Victoria has begun to implement some of Spain's successful strategies through Australia's national program.

Dr Domínguez-Gil expressed that opt-out is often perceived as successful, and while it can be if the community supports the change, it can also create tension. Dr Domínguez-Gil does not credit the opt-out model as driving Spain's success, but rather investment in hospital systems, donor identification and professional training:

... the key for success is not a change in the legislation but essential changes in the way the system is organised and tackled.

In reference to introducing an opt-out model in Australia, Dr Domínguez-Gil stated that while it looks appealing and could result in media attention, 'there are more profound changes that are more critical.'

Source: Dr Beatriz Domínguez-Gil, General Director, Organización Nacional de Trasplantes, Spain, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 71–73, 76; Dr Rohit D'Costa, State Medical Director, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 14; Donor Families Australia, *Submission 21*, received 17 May 2023, p. 7.

FINDING 7: Evidence from international jurisdictions suggests that higher organ donation rates can be better achieved through: improvements to organ and tissue donation hospital systems and donor identification; investment in professional training and clinical staff who talk to families to obtain family consent; and better community awareness about donation—rather than by introducing an opt-out system.

Part 2: Suggestions for improvement

This section discusses process barriers to registration and ways to improve the AODR through simplification and better access.

23% of Victoria’s eligible population is currently registered on the AODR and OTA aims to increase this to 50% by 2027—this equates to an additional 1.4 million Victorian registrations, which would require a mass registration drive.⁹³

Most inquiry participants supported the focus on improving AODR registration numbers.⁹⁴ For example, Austin Health submitted, ‘[g]iven the direct influence of AODR registration on eventual organ and tissue donation, amplifying the number of individuals registered on the AODR is a vital strategy’.⁹⁵ DHAC also advised that the Australian Government, OTA and state and territory governments are investigating options to boost registration numbers, including through driver licence registrations.⁹⁶

Tony Holland of DLV stated:

There is always more that can be done, and one of the biggest opportunities that we see to save more lives is to improve registration rates so that more people can receive a life-saving transplant.⁹⁷

Tony Holland further observed that Victorian registration rates do not keep up with population growth and have not changed significantly over the past five years. Since 2018, an average of 58,000⁹⁸ Victorians register each year which only equates to a 4% increase in the percentage of the population registered since 2015.⁹⁹ Tony Holland advised DLV would need 300,000 to 400,000 new registrations a year to make a substantial difference, rather than to ‘barely hover’ at general population growth.¹⁰⁰

⁹³ Ibid., p. 6; Organ and Tissue Authority, *Strategy 2022–2027*, 2022, p. 9.

⁹⁴ For example, see Tony Holland, DonatLife Victoria, *Transcript of evidence*, p. 2; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2 cover letter; Transplant Australia, *Submission 23*, p. 13; Donor Mate, *Submission 36*, received 31 May 2023, p. 3.

⁹⁵ Austin Health, *Submission 34*, received 25 May 2023, p. 5.

⁹⁶ Department of Health and Aged Care, response to written questions on notice, p. 4.

⁹⁷ Tony Holland, DonatLife Victoria, *Transcript of evidence*, p. 2.

⁹⁸ Committee calculation: $(50651 + 55974 + 47274 + 88278 + 47545) / 5 = 57944.4$, see Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22; Organ and Tissue Authority, *Australian donation and transplantation activity report 2019*, 2020, p. 7.

⁹⁹ The percentage of Victoria’s population registered on the AODR has increased from 18.8% in 2015 to 23% in 2022 (4%), see Organ and Tissue Authority, *Australian donation and transplantation activity report 2015*, 2016, p. 9; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

¹⁰⁰ Tony Holland, DonatLife Victoria, *Transcript of evidence*, pp. 12, 15.

FINDING 8: An average of 58,000 Victorians register on the Australian Organ Donor Register each year. However, this does not equate to a large percentage increase in Victoria's population registered due to population growth.

In contrast, several inquiry participants did not consider the AODR the most effective way to increase donation activity, with some highlighting it has not effectively increased registrations over the past 15 years and that registration rates do not reflect community attitudes (surveys indicate 80% of the community support donation).¹⁰¹ Others suggested there is no direct link between registration levels and donation levels.¹⁰² For example, Victoria has a low registration rate but a high donation rate compared to other jurisdictions.¹⁰³

While acknowledging the importance of registration on the AODR, most inquiry participants identified that to increase the actual number of donations and transplants, consideration should be given to elements beyond registration.¹⁰⁴ These elements are discussed throughout the report and demonstrate the need for a holistic approach to donation and transplantation.

3.3 Donor registration through driver licences

Despite state and territory governments discontinuing driver licence donor registration in the 2000s, there is renewed interest to return to this system.

3.3.1 Benefits

Many inquiry participants expressed support for reintroducing donor registrations through the driver licence system,¹⁰⁵ with some noting SA's high registration rate as

¹⁰¹ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 5; Donor Families Australia, *Submission 21*, p. 2; Samantha Francis-Pester, *Submission 28*, received 19 May 2023, p. 2; Leanne Campbell, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 14.

¹⁰² Brian Myerson, *Submission 33*, received 22 May 2023, p. 3; Robert Manning, *Submission 15*, p. 16.

¹⁰³ Brian Myerson, *Submission 33*, p. 1.

¹⁰⁴ Leanne Campbell, *Submission 16*, p. 1; Melbourne Lions Eye Donation Service, *Submission 18*, received 12 May 2023, p. 2; Donor Families Australia, *Submission 21*, p. 2; Transplant Australia, *Submission 23*, p. 6; Graham Harrison, *Submission 25*, p. 1; DonateLife Victoria, *Submission 27*, p. 9; Samantha Francis-Pester, *Submission 28*, p. 2; Brian Myerson, *Submission 33*, p. 3; Austin Health, *Submission 34*, p. 1; Associate Professor John Whitlam, *Transcript of evidence*, p. 2; Alfred Health, *Submission 38*, p. 1; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 1; Dr Rohit D'Costa, DonateLife Victoria *Transcript of evidence*, pp. 2–3.

¹⁰⁵ Leah Macey, *Submission 6*, received 5 April 2023, p. 1; Melbourne Lions Eye Donation Service, *Submission 18*, p. 1; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2 cover letter; Transplant Australia, *Submission 23*, p. 1; Name withheld, *Submission 24*, received 18 May 2023, p. 6; Austin Health, *Submission 34*, p. 5; Donor Mate, *Submission 36*, pp. 1, 3; ANZICS Death and Organ Donation Committee, *Submission 41*, p. 5; DonateLife Victoria, *Submission 27*, p. 7; Alfred Health, *Submission 38*, p. 8; Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 31; Phillip Waters, General Manager, Deaf Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 34; Associate Professor John Whitlam, *Transcript of evidence*, p. 2; Associate Professor Christopher Hogan, *Transcript of evidence*, p. 22; Dr Bindiya Sethi, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 22; Associate Professor William Silvester, Chair, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 38; Dr Rosalind Beadle, Research Fellow, College of Medicine and Public Health, Flinders University, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 11; Chris Thomas, *Transcript of evidence*, p. 22; Allan Turner, *Transcript of evidence*, p. 37; Name withheld, *Transcript of evidence*, p. 5.

evidence of this model's success. Inquiry participants highlighted that driver licence registrations provide:

- the ability to register without having Medicare or a Medicare number to hand¹⁰⁶
- 'a regular opportunity to enquire into drivers' intentions and preferences'¹⁰⁷
- a simpler way to register that pushes donation to people's front of mind¹⁰⁸
- 'a trigger for discussion' in families¹⁰⁹ (especially for different communities, like deaf and hard of hearing¹¹⁰) and for young people comparing each other's licence photos¹¹¹
- a regular reminder about donation as drivers often carry their licence¹¹²
- 'concrete evidence' of a person's intent and a 'source of information' to the donor's family¹¹³
- emergency staff or police with the ability to easily identify donors, something that may not be possible with digital licences (suggesting both physical and digital licences showing donor status could be beneficial).¹¹⁴

Inquiry participants, including DH, highlighted a misconception that many people think that registration still happens through a driver licence.¹¹⁵ DLV reported that even people aged in their 30s, who never could register through this method, believe they signed up as donors when receiving a licence. DLV contended that this natural association means the best long-term strategy to improve registrations and the easiest starting point is to re-introduce the driver licence system—it would be 'the single thing that will make the most significant impact to registration, over time.'¹¹⁶

FINDING 9: Many Victorians associate registering to become an organ and tissue donor with driver licences, even though they have not been able to register to be a donor when applying for a driver licence since the early 2000s.

¹⁰⁶ Dr Stacey Hokke, Research Fellow, Judith Lumley Centre, School of Nursing and Midwifery, La Trobe University, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 62.

¹⁰⁷ Alfred Health, *Submission 38*, p. 8.

¹⁰⁸ Transplant Australia, *Submission 23*, p. 8; Dr Rosalind Beadle, *Transcript of evidence*, p. 11.

¹⁰⁹ Associate Professor William Silvester, *Transcript of evidence*, p. 38; Name withheld, *Submission 24*, p. 7; Dr Rosalind Beadle, *Transcript of evidence*, p. 11.

¹¹⁰ Philip Waters, *Transcript of evidence*, p. 35.

¹¹¹ Alfred Health, *Submission 38*, p. 8.

¹¹² Name withheld, *Submission 24*, p. 7.

¹¹³ Alfred Health, *Submission 38*, p. 8; Dr Aadhil Aziz, *Transcript of evidence*, p. 29.

¹¹⁴ Dr Aadhil Aziz, *Transcript of evidence*, pp. 25–26.

¹¹⁵ Stuart Chesneau, *Transcript of evidence*, p. 51; Lucinda Barry, *Transcript of evidence*, p. 20; Allan Turner, *Transcript of evidence*, p. 37; Department of Health, *Submission 42*, p. 2; DonateLife Victoria, *Submission 27*, p. 7. See also National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 155.

¹¹⁶ DonateLife Victoria, *Submission 27*, p. 7. See also Tony Holland, DonateLife Victoria, *Transcript of evidence*, pp. 2, 10–11.

Driver licences also provide an opportunity to register on a mass scale, with DTP advising that 99.9% of Victoria's eligible population holds a driver licence.¹¹⁷ DTP has widespread access to Victorians to promote donation based on the number of licence holders and the periodic cycle of licence renewals.¹¹⁸

Inquiry participants advised that driver licence registrations can help the message about donation reach diverse communities and provide them with more opportunities to register easily. This includes young people, multicultural and First Nations communities, and deaf and hard of hearing people.¹¹⁹ An additional benefit of either the AODR donor card or driver licence with a donor indicator for deaf and hard of hearing people is that it can help hospital staff and families know a person wants to be a donor, helping to overcome potential communication barriers.¹²⁰ This could equally apply to people who do not speak English.

FINDING 10: 99.9% of Victoria's eligible population holds a driver licence, meaning the option to register to be an organ and tissue donor through the State's driver licence system presents an opportunity to increase Victorian registrations on the Australian Organ Donor Register on a mass scale.

3.3.2 Challenges

Some inquiry participants noted challenges associated with a return to the driver licence donor registration system, including that:

- driver licences are only renewed every three or ten years,¹²¹ meaning opportunities to engage are limited to these intervals
- it may not result in an immediate increase in AODR numbers and there are no solid models on how quickly registration rates would rise¹²²
- it could be expensive and time consuming.¹²³

It was also noted that driver licence donor registrations may not be suitable for young people as it associates driving with death and can be confronting. However, this highlights the importance of many touchpoints promoting donation from an early age (for example, in schools) to ensure young people are not confronted when they

¹¹⁷ Department of Transport and Planning, response to questions on notice, p. 3. See also Transplant Australia, *Submission 23*, p. 8.

¹¹⁸ Jacqui Sampson, *Transcript of evidence*, pp. 1, 12.

¹¹⁹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, pp. 10–11; Dr Rosalind Beadle, *Transcript of evidence*, p. 11; Philip Waters, *Transcript of evidence*, p. 34.

¹²⁰ Philip Waters, *Transcript of evidence*, p. 35.

¹²¹ Catholic Archdiocese of Melbourne, *Submission 19*, p. 2; VicRoads, *Renew your licence*, 2 October 2023, <<https://www.vicroads.vic.gov.au/licences/renew-replace-or-update/renew-your-licence>> accessed 2 November 2023.

¹²² Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 12; Robert Manning, *Submission 15*, p. 16.

¹²³ Robert Manning, *Submission 15*, p. 16.

receive a driver licence.¹²⁴ Incorporating donation into formal education channels and encouraging registration at multiple touchpoints are discussed in Chapter 5.

3.3.3 Implementation

Inquiry participants who supported reintroducing driver licence donor registrations suggested:

- capitalising on the trial of digital licences in parts of Victoria¹²⁵
- including the option to register intent on licence applications and renewals¹²⁶
- including other licence systems, for example, fishing or boating¹²⁷
- it be accompanied by a public awareness campaign to ensure people know what donation is, as well as education material targeted to specific audiences.¹²⁸

3.3.4 ‘Yes’ only intent registrations

Inquiry participants identified driver licence donor registrations should:

- operate as an intent registration and still require family consent¹²⁹
- only include the ability to select ‘yes’ through a tick box—objections should still be done through existing AODR registration avenues (meaning if the box was not ticked, no decision would be recorded, as is the case in SA).¹³⁰

SA driver licence donor registrations operate as an intent registration only. A person wanting to register consent or object in SA must use a consent registration channel.¹³¹ Similarly, people in the United States (US) can only register ‘yes’ through a driver licence which has helped the country achieve a donor registration rate of 60%.¹³² Transplant Australia described how the US system contributes to high registration and consent rates:

The case for a mass registration platform is really compelling, and it is not a case of ‘We put a link to the organ donor register on a website’; it is actually embedding it into the drivers licence system. That is the hallmark of the American system and it works so well. They have got some states where 70 to 80% of the population have signed up

¹²⁴ Dr Stacey Hokke, *Transcript of evidence*, p. 61; Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, received 19 May 2023, pp. 10, 13.

¹²⁵ Transplant Australia, *Submission 23*, p. 13; Alfred Health, *Submission 38*, p. 8; Chris Thomas, *Transcript of evidence*, p. 27.

¹²⁶ Name withheld, *Submission 24*, p. 6.

¹²⁷ Leah Macey, *Submission 6*, p. 1.

¹²⁸ DonateLife Victoria, *Submission 27*, p. 7; Philip Waters, *Transcript of evidence*, p. 34.

¹²⁹ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 5.

¹³⁰ *Ibid.*; Chris Thomas, *Transcript of evidence*, pp. 22, 26–27.

¹³¹ South Australian Department for Health and Wellbeing, *Information about driver licence registrations for Victorian Legislative Assembly’s Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, pp. 1–2.

¹³² Transplant Australia, *Submission 23*, p. 8; Allan Turner, *Transcript of evidence*, p. 37; Dr Aadhil Aziz, *Transcript of evidence*, p. 23; Health Resources & Service Administration, *Organ donation statistics*, October 2023, <<https://www.organdonor.gov/learn/organ-donation-statistics>> accessed 3 November 2023.

to organ [and tissue] donation through their drivers licence system ... If that person was 45 years old and they signed up when they were 17 years old and every five, 10 years they recommitted to it, it is a pretty compelling case to say that they believed in organ [and tissue] donation and that person's decision should be respected.¹³³

The past driver licence approach in Australia included the option to consent and object to donation, for all states and territories except SA. More Australians registered an objection to donate than otherwise would if they registered through the AODR.¹³⁴ This could have been due to people feeling compelled to answer the donor registration question and consequently ticking 'no' as a safe or easy choice because they were unsure of the implications or were under time pressure, even if they supported donation.¹³⁵

For example, NSW still operated a separate registry to the AODR via its road traffic authority in 2008 (distinct from SA which accepted registrations via a driver licence but used the AODR). With 69% of NSW's population recording a registration decision, the rate of donor objection (30%) exceeded 'the rate implied by public attitudinal studies, which repeatedly show[ed] very high levels of community support.'¹³⁶ In comparison, only 0.2% of the Australian population registered an objection on the AODR. An unintended effect of people objecting to donation on a driver licence when they may have supported it was that sometimes donation did not occur even with family consent.¹³⁷ At the time, it was recommended NSW investigate transforming its state register 'into a mechanism for direct registration to the AODR rather than maintaining a separate database.'¹³⁸ Transplant Australia believes NSW should have amended licence registrations to only include the option to agree to donation.¹³⁹

FINDING 11: Historical experiences of registering to be an organ and tissue donor through driver licences indicate that including the option to object to donation may have unintended consequences and result in missed donation opportunities. For example, where a person selects 'no' to donation because they are unsure of the implication even though they support donation.

3.3.5 Embedded registration process

Donor registrations should be embedded in driver licence applications and renewals and not redirect people to the online form to register.¹⁴⁰ DLV advocated for a 'direct

¹³³ Chris Thomas, *Transcript of evidence*, p. 22.

¹³⁴ Ibid., p. 26; National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 127; Transplant Australia, *Submission 23*, p. 8.

¹³⁵ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 127.

¹³⁶ Ibid.

¹³⁷ Ibid.

¹³⁸ Ibid., p. 157.

¹³⁹ Chris Thomas, *Transcript of evidence*, p. 26.

¹⁴⁰ Ibid., p. 27; Transplant Australia, *Submission 23*, p. 13; DonateLife Victoria, *Submission 27*, p. 7.

data bridge' from the Victorian driver licence system to the AODR: 'For the user, the ideal situation would be to register with simply one click.'¹⁴¹

In SA, if a person answers 'yes' to the registration question when renewing a licence, this is recorded on the driver licence database managed by the Department for Infrastructure and Transport (DIT). DIT transfers this information via encrypted files to the AODR monthly. DIT informs licensees this will occur and adds a donor indicator to photo permits or licences (see Figure 3.1).¹⁴² Notably, DIT holds donor information on its database, but records are not sent to the AODR in real time.¹⁴³ The Committee notes that digital driver licences have been available throughout SA since 2019.¹⁴⁴

DTP advised Victoria's licence registry database is solely focused on roads and road safety and driver licences have two primary purposes: a credential to drive and identity confirmation. This means any change to incorporate donation would be a government policy decision about the purpose of driver licences, including digital ones.¹⁴⁵ Scoping would be needed on feasibility, technology, consent and information privacy considerations.¹⁴⁶ DTP also suggested the potential for people to change, select specific organs and tissues, or object to donation via a driver licence would require capability for real-time AODR updates to ensure the AODR reflects a person's most recent choice.¹⁴⁷

The ability to add a donor indicator to a driver licence may also complicate the real-time transfer of data to the AODR if DTP is required to hold donor information in its database. Further analysis would help determine the most effective way to transfer driver licence donor registration data to the AODR.

3.3.6 Entering Medicare details

DLV advocated for driver licence donor registrations to not request Medicare details.¹⁴⁸ However, evidence from DHAC shows Medicare details increase the likelihood of finding a unique match to ensure a donation decision is correctly recorded on the AODR. DHAC stated, '[I]imiting information to demographic details, such as name and date of birth, risks multiple individuals being identified who have the same details.'¹⁴⁹

¹⁴¹ DonateLife Victoria, *Submission 27*, p. 7.

¹⁴² South Australian Department for Health and Wellbeing, *Information about driver licence registrations for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, pp. 1–2.

¹⁴³ *Ibid.*

¹⁴⁴ Government of South Australia, *Go digital with a digital licence*, 29 July 2019, <<https://service.sa.gov.au/news?a=573540>> accessed 16 February 2024.

¹⁴⁵ Jacqui Sampson, *Transcript of evidence*, pp. 4, 6. The Committee notes that from mid-August 2022, the Victorian Government entered into a joint venture partnership in relation to VicRoads registration and licencing, see VicRoads, *VicRoads modernisation*, n.d., <<https://www.vicroads.vic.gov.au/about-vicroads/vicroads-modernisation>> accessed 16 February 2024.

¹⁴⁶ Jacqui Sampson, *Transcript of evidence*, pp. 6, 8.

¹⁴⁷ *Ibid.*, pp. 8–9.

¹⁴⁸ DonateLife Victoria, *Submission 27*, p. 7.

¹⁴⁹ Department of Health and Aged Care, response to written questions on notice, p. 5.

The draft *National strategy for organ donation, retrieval and transplantation* (draft National Organ Strategy) recognises the importance of increasing AODR registrations to enable more donations. It states all governments have agreed ‘through the Transition Action Plan [TAP], to consider options to support increased consent for donation through leveraging other processes, such as driver licence applications and renewals, to increase donor registration *without compromising the integrity of AODR data*.¹⁵⁰ The progression timeframe for the TAP was August 2023 and there is no public update on this action.

The Committee recognises that the integrity of AODR data is critical to the success of donation and transplantation in Australia and to maintaining trust in the system. Medical professionals need to be confident that the AODR record they are viewing matches that of a potential donor. For this reason, the value of continuing to request Medicare details from a person who is registering to be a donor is that it increases the likelihood of a donation decision being correctly recorded on the AODR. The accuracy of AODR data is also important to inform targeted community awareness campaigns (see Section 3.5).

To ensure the integrity of AODR data, any scoping undertaken by the Victorian Government to allow Victorians to register on the AODR should consider how to appropriately ensure a unique match can be found. For example, by potentially integrating Medicare details with driver licence donor registrations, or as is the case in Germany for potential stem cell donors, consent could be requested for current residential addresses to be obtained using relevant government authorities.¹⁵¹

FINDING 12: Registering to be an organ and tissue donor on the Australian Organ Donor Register using a Medicare number increases the likelihood that a unique match is found and a person’s donation preferences are accurately recorded.

RECOMMENDATION 2: The Victorian Government scope the capability of the State’s driver licence system to allow Victorians to register on the Australian Organ Donor Register (AODR) when applying for or renewing a driver licence. This should include a ‘yes’ registration option only and ways to maximise the finding of a unique record match on the AODR.

¹⁵⁰ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, May 2022, p. 6. Emphasis added.

¹⁵¹ Dr Joannis Mytilineos, Chief Medical Officer, Zentrales Knochenmarkspender-Register Deutschland, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, pp. 20, 24–25.

3.4 Interactions with government services

Introducing regular registration options or prompts at government service touchpoints was raised by a diverse range of inquiry participants.¹⁵² Suggestions included allowing direct registration on the AODR from, or incorporating information about the AODR and donation into routine activities like:

- interactions with government agencies and websites¹⁵³
- applications and renewals for Victorian Seniors Cards, Victorian proof of age cards, rental bonds and enrolments and memberships with the Victorian Electoral Commission and Ambulance Victoria (state responsibilities)¹⁵⁴
- registrations, applications or enrolments for a passport, Medicare card, tax file number or myGov (federal responsibilities)¹⁵⁵
- government templates on enduring powers of attorney and advance care directives (discussed in Chapter 7).¹⁵⁶

Incorporating these prompts can motivate people to register, rather than expecting or encouraging them to seek out the AODR on their own initiative.¹⁵⁷ It can also generate family discussion about donation and educate people about what they are registering for.¹⁵⁸

Inquiry participants also recommended incorporating donor registration into the Service Victoria website and app.¹⁵⁹ The Service Victoria website and app (and Victorian Seniors Card) already promote donation,¹⁶⁰ but there is scope to improve reach and functionality.¹⁶¹

The Department of Government Services (DGS) (responsible for Service Victoria) has trialled two pathways to accessing donation information through the Service Victoria website and app. Early in 2023, the Service Victoria website homepage (Figure 3.3) and app linked directly to the DonateLife registration page. Currently on the Service Victoria website, 'Organ donation' is located under the 'Find a service' then 'health and care' drop down menu options. In the app, 'Organ donation' is located under the 'Health and

¹⁵² Leah Macey, *Submission 6*, p. 1; Organ and Tissue Authority, *Submission 31*, p. 6; Austin Health, *Submission 34*, p. 2; Alfred Health, *Submission 38*, p. 9; Dr Brooke Huuskens, Senior Lecturer, Centre for Cardiovascular Biology and Disease Research, La Trobe University, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 62; Dr Stacey Hokke, *Transcript of evidence*, p. 62; Brendan Sullivan, *Transcript of evidence*, p. 44; Dr Rohit D'Costa, Victorian Representative, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 41; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2.

¹⁵³ Tony Holland, *Lifeblood*, *Transcript of evidence*, p. 54; Alfred Health, *Submission 38*, p. 9; Robert Manning, *Submission 15*, p. 16.

¹⁵⁴ DonateLife Victoria, *Submission 27*, p. 8; Donor Mate, *Submission 36*, p. 1; Dr Rohit D'Costa, *Transcript of evidence*, p. 3; Alfred Health, *Submission 38*, p. 9; Tony Holland, *DonateLife Victoria*, *Transcript of evidence*, pp. 9, 11.

¹⁵⁵ Donor Mate, *Submission 36*, pp. 1-2.

¹⁵⁶ Alfred Health, *Submission 38*, p. 9.

¹⁵⁷ Transplant Australia, *Submission 23*, pp. 5, 8; Donor Mate, *Submission 36*, p. 2.

¹⁵⁸ Tony Holland, *DonateLife Victoria*, *Transcript of evidence*, p. 11; Dr Rohit D'Costa, *DonateLife Victoria*, *Transcript of evidence*, p. 11.

¹⁵⁹ Robert Manning, *Submission 15*, p. 16; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2; DonateLife Victoria, *Submission 27*, p. 8.

¹⁶⁰ Department of Health, *Submission 42*, p. 1.

¹⁶¹ DonateLife Victoria, *Submission 27*, p. 8.

care' and 'Health' links.¹⁶² Both the website and app link to a Victorian DH webpage on donation and then to the DonateLife registration page.

Figure 3.3: Former direct link to DonateLife registration page on Service Victoria homepage



Source: image taken from Wayback Machine internet archive, *Service Victoria*, 23 February 2023, <<https://web.archive.org/web/20230223034658/https://service.vic.gov.au>> accessed 8 January 2024. Orange box added to original image for emphasis.

While DGS provided limited data to the Committee about the results delivered by these pathways, the former direct link to the DonateLife registration page saw more individual user clicks. The Service Victoria:

- homepage linking directly to the DonateLife registration page resulted in 231 clicks from February to March 2023 from the website and 30,835 clicks from February to September 2023 through a promotional tile on the app
- link to the Victorian DH's donation page under the 'Health and care' drop down resulted in 56 clicks from April 2023 to October 2023 from the website and 160 clicks from mid-July to October 2023 through the app.¹⁶³

¹⁶² Service Victoria, *Health and care*, n.d., <<https://service.vic.gov.au/find-services/health-and-care>> accessed 16 January 2024; Service Victoria app, version 1.36.0, accessed 16 January 2024. A later version of the Service Victoria app also includes a new 'Register as an organ donor' tile on the homepage directly linking to the DonateLife online form, see Service Victoria app, version 1.40.0, accessed 22 February 2024.

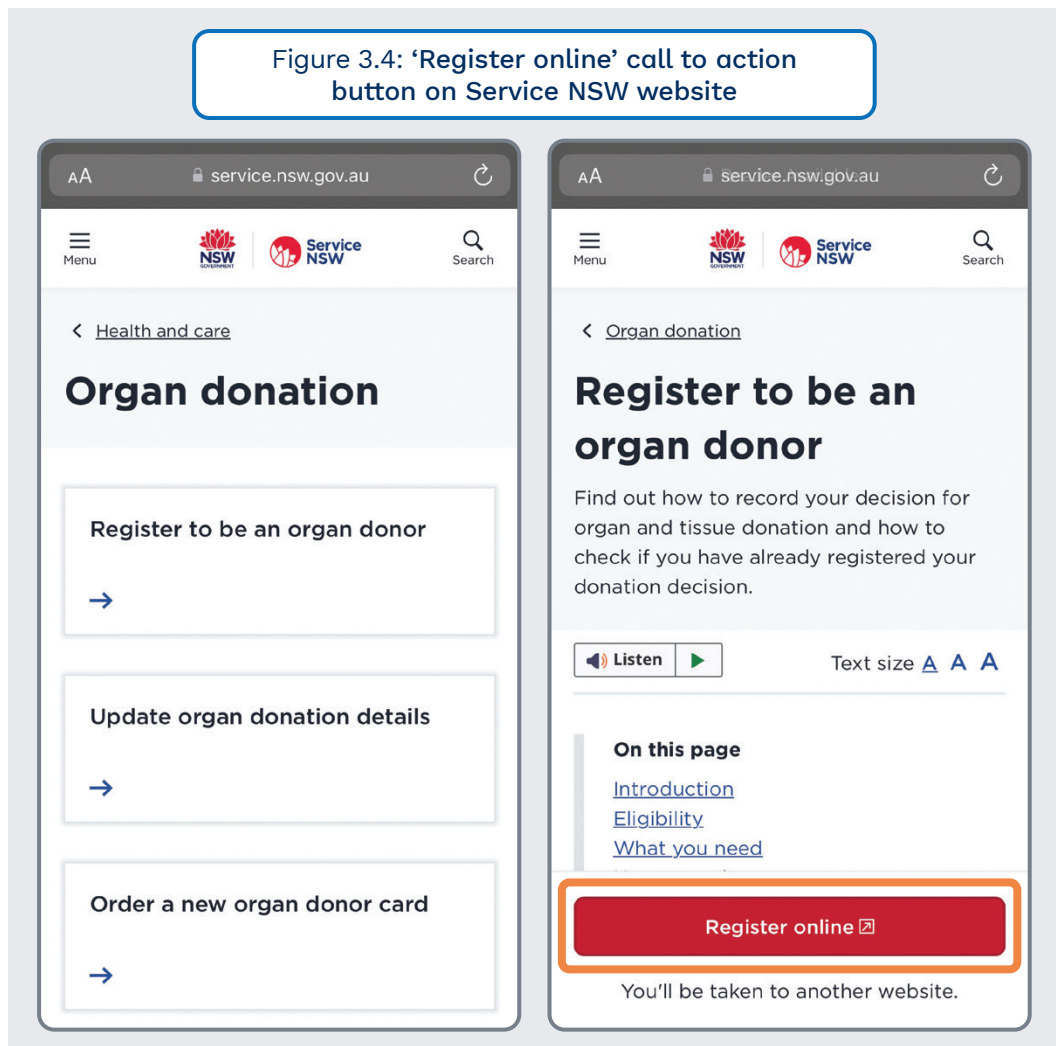
¹⁶³ Department of Government Services, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 26 October 2023, p. 4. These statistics represent total views not usage or unique visitors.

DGS advised it continues to work with DH to consider opportunities to promote donation.¹⁶⁴

DLV also suggested that while the registration link on the Seniors website and Service Victoria app receive ‘substantial click-throughs’, conversion to registration would increase if the process was simplified.¹⁶⁵

Some inquiry participants identified the introduction of donor registration on the Service NSW app and website as an example of best practice.¹⁶⁶ A key difference between the Service NSW and Victorian websites is that NSW’s includes a ‘Register online’ call to action button (Figure 3.4).

3



Source: Service NSW, *Organ donation and Register to be an organ donor* (mobile accessible versions), 7 November 2023, <<https://www.service.nsw.gov.au/services/organ-donation>> and <<https://www.service.nsw.gov.au/transaction/register-be-organ-donor>> accessed 27 November 2023. Orange box added to original image for emphasis.

164 Ibid., p. 2.

165 DonateLife Victoria, *Submission 27*, p. 8.

166 Robert Manning, *Submission 15*, p. 16; Tony Holland, Lifeblood, *Transcript of evidence*, p. 54.

In November 2022, Service NSW and DonateLife NSW ran a four-week campaign promoting the AODR and donation on the Service NSW app. Social media channels and a 'register now' prompt to over 5 million Service NSW customers on the app's homepage resulted in 2,500 new registrations.¹⁶⁷ In 2022, NSW averaged 1,053 new registrations a week.¹⁶⁸ While 2,500 registrations over the four-week campaign may seem low compared to the weekly average, the Committee notes that 29% of new registrations across Australia in 2022 happened during DonateLife Week.¹⁶⁹ At the time of this report, donor registration was no longer an option on the Service NSW app homepage but a link to the Service NSW donation webpage is available under the 'Support services', 'Health and care' then 'Organ donation' menu options.

The VicRoads website has information on how to register to become a donor.¹⁷⁰ Nearly 50,000 individual users have accessed the VicRoads donation webpage, with 42% clicking the registration button that redirects them to the online form.¹⁷¹ VicRoads also posts a printed donor registration form with physical driver licence renewal notices (not issuances). DTP advised that customers who receive renewal notices online via the VicRoads portal also receive donation information. In the 2022–23 financial year, VicRoads delivered approximately 1 million DonateLife brochures across a database of over 5 million licence holders.¹⁷² The effectiveness of this method is not measured by DTP.¹⁷³

There are opportunities for DTP to expand engagement in this space, noting other core channels that could be used to promote donor registration include the VicRoads online portal (4.1 million users), customer database (5 million registered licence holders) and call and customer centres.¹⁷⁴

DLV explained its work with VicRoads on awareness activities has experienced some success but has 'failed to make a significant impact to registration.'¹⁷⁵

FINDING 13: There are multiple ways for the Victorian Government to increase the promotion of the Australian Organ Donor Register through government channels, including the Service Victoria website and app, proof of age card applications, Victorian Electoral Commission enrolments and Ambulance Victoria memberships.

¹⁶⁷ Organ and Tissue Authority, *Annual report 2022–23*, 2023, p. 27.

¹⁶⁸ Committee calculation: $54,769 / 52 = 1,053.25$, see Organ and Tissue Authority, *Annual report 2022–23*, 2023, p. 27; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

¹⁶⁹ Committee calculation: $60,000 / 208,861 = 0.287$, see Organ and Tissue Authority, *Annual report 2022–23*, pp. 21, 27.

¹⁷⁰ Department of Health, *Submission 42*, p. 1.

¹⁷¹ Committee calculation: $(20,843 / 49,619) \times 100 = 42\%$, see Department of Transport and Planning, response to questions on notice, p. 2.

¹⁷² Department of Transport and Planning, *Submission 45*, p. 1.

¹⁷³ Jacqui Sampson, *Transcript of evidence*, p. 4.

¹⁷⁴ *Ibid.*, p. 12.

¹⁷⁵ DonateLife Victoria, *Submission 27*, p. 7.

FINDING 14: Using a prominent ‘Register online’ call to action button on Victorian Government websites and apps that provide an easily accessible and simple link to register on the Australian Organ Donor Register is an opportunity to increase registrations.

RECOMMENDATION 3: The Victorian Government increase its promotion of the Australian Organ Donor Register through the creation and use of a prominent ‘Register online’ call to action button on the Service Victoria website and app, as well as multiple other government channels, for example, proof of age card applications, Victorian Electoral Commission enrolments and Ambulance Victoria memberships.

3.4.1 Making it simple to register

Making it easy and accessible to register on the AODR, ‘like ticking a box’, will encourage more registrations.¹⁷⁶ DLV noted introducing links between different avenues to register and the AODR need to be seamless.¹⁷⁷ DLV described current processes as ‘clunky’ and suggested any state government database requiring identity verification could ask people if they would like to be a donor and then that decision could be transmitted straight to the AODR.¹⁷⁸ DLV advocated for stopping the two-step process (for example, when a website links to the online form or requires a person to find identity documents), stating this often ‘kills’ registrations as not everyone clicks through to register or returns to the process.¹⁷⁹ DLV noted that a better approach would involve a ‘data bridge’ so that AODR registrations on government websites is an automatic process with Medicare details.¹⁸⁰ Section 3.6 discusses cyber security and privacy in relation to the management of data.

Providing a Medicare number was identified as a barrier to registering because people often do not have their Medicare number on hand,¹⁸¹ especially young people.¹⁸² A Medicare number is required to verify the identity of a person through every registration method except the paper form and phone number.¹⁸³ The online form requires a Medicare number because it enables efficient and real time identity validation through an interface to Services Australia.¹⁸⁴ The Committee notes that while the requirement for Medicare details may result in some people not completing a registration, it assists to maintain the integrity of AODR data (see Section 3.3.6).

¹⁷⁶ Lucinda Barry, *Transcript of evidence*, p. 16. Providing detailed and clear information about donation when registering on the AODR is discussed in Chapter 5.

¹⁷⁷ Dr Rohit D’Costa, ANZICS Death and Organ Donation Committee, *Transcript of evidence*, p. 41; Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 8; DonateLife Victoria, *Submission 27*, p. 8.

¹⁷⁸ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 9. See also Tony Holland, Lifeblood, *Transcript of evidence*, p. 52.

¹⁷⁹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 10.

¹⁸⁰ *Ibid.*, p. 8; DonateLife Victoria, *Submission 27*, p. 8.

¹⁸¹ DonateLife Victoria, *Submission 27*, p. 7.

¹⁸² Dr Stacey Hokke, *Transcript of evidence*, p. 62.

¹⁸³ Department of Health and Aged Care, response to written questions on notice, pp. 4, 7.

¹⁸⁴ *Ibid.*, p. 4.

One inquiry participant reported that they could not register as the AODR system did not recognise their valid Medicare number.¹⁸⁵ DHAC advised that Services Australia was not aware of any technical issues preventing someone from registering on the AODR.¹⁸⁶

The 87% increase in new registrations during the COVID-19 pandemic when more people accessed the Medicare app¹⁸⁷ demonstrates that unless registration is quick, simple and direct, people may not register even if they support donation.¹⁸⁸ The number of registrations surged in the pandemic when the MyGov and Medicare app were used to show vaccination status (see Chapter 1, Figure 1.9).

In the Medicare app, 'Organ donation' appears directly below 'Proof of vaccination'. Users who select 'Organ donation' can then register on the AODR, or if they are registered, they can change their preferences or order a donation card (see Figure 3.5). Over 60,000 Victorians registered in five months between June and October 2021 using this method, more than ever recorded in a full year.¹⁸⁹ In total in 2021, Victoria recorded 88,278 registrations.¹⁹⁰ This fell when vaccination certificates were no longer required.¹⁹¹

¹⁸⁵ Name withheld, *Submission 10*, received 14 April 2023, p. 1.

¹⁸⁶ Department of Health and Aged Care, response to written questions on notice, p. 6.

¹⁸⁷ Lucinda Barry, *Transcript of evidence*, p. 16; Organ and Tissue Authority, *Submission 31*, p. 5.

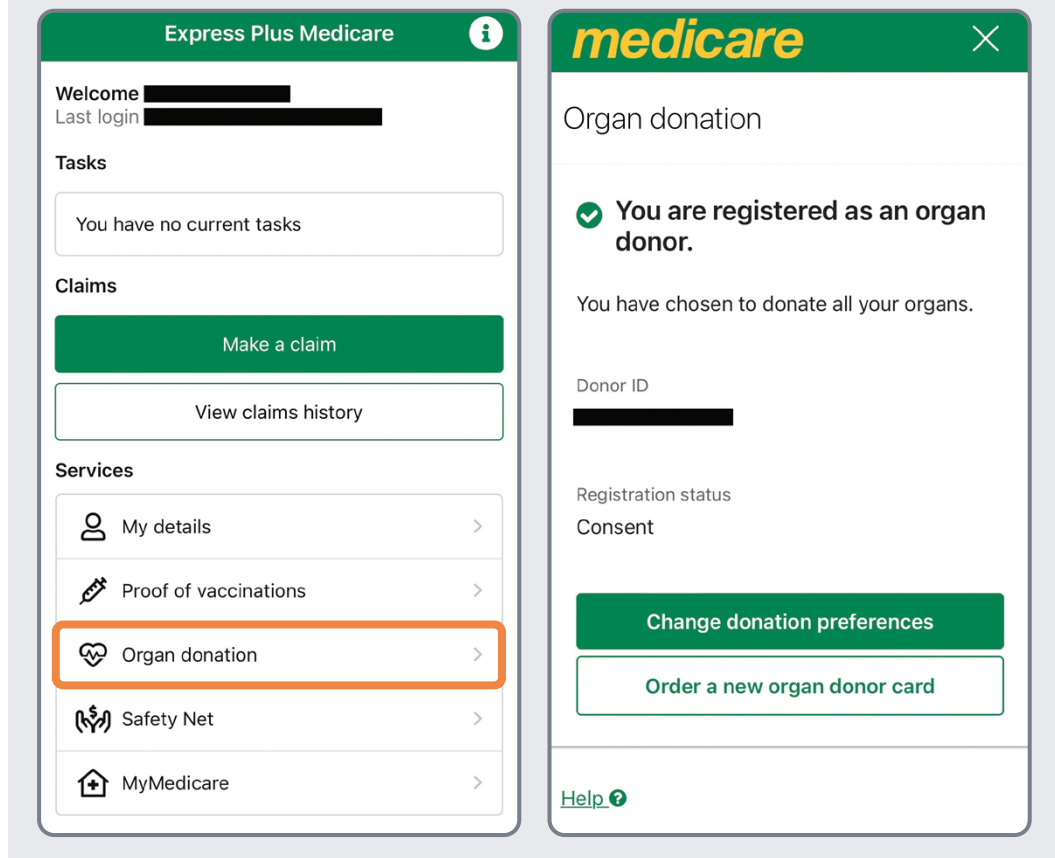
¹⁸⁸ Lucinda Barry, *Transcript of evidence*, p. 20; Associate Professor John Whittlam, *Transcript of evidence*, p. 2; Stuart Chesneau, *Transcript of evidence*, p. 52.

¹⁸⁹ DonateLife Victoria, *Submission 27*, p. 5.

¹⁹⁰ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 22.

¹⁹¹ Donor Mate, *Submission 36*, p. 2.

Figure 3.5: Donor registration on the Medicare app



Source: Express Plus Medicare app, version 4.12.0 (1), accessed 30 November 2023. Orange box added to original image for emphasis.

FINDING 15: The current process to register on the Australian Organ Donor Register could be more seamless and efficient to promote registration. This includes its integration into Victorian Government websites and with Medicare.

FINDING 16: Increased use of the myGov and Medicare apps during the COVID-19 pandemic to access vaccination certificates led to a surge in registrations on the Australian Organ Donor Register. This demonstrates that providing accessible registration options encourages people to record an organ and tissue donation decision.

RECOMMENDATION 4: The Victorian Government explore the creation of direct links to securely register on the Australian Organ Donor Register (AODR) when accessing Victorian Government services to, if feasible:

- enable registration details to be transferred to the AODR through a data bridge and not link people seeking to register to the federal DonateLife online form
- auto-populate fields for personal information held by Victorian Government services to make it quicker and simpler for people to register.

3.4.2 Intent and consent registration

Removing the distinction between intent and consent may make the registration process simpler. A 2008 report into organ and tissue donation identified the distinction was ‘confusing and diminish[ed] the public’s understanding of, and confidence in the registration process’.¹⁹² A 2018 review of the organ donation system also recommended shifting the AODR’s focus from a record of consent to intent to reduce ‘the requirement for complex identification protocol, and thus increase the accessibility and ease of the use of potential donor registration’.¹⁹³ This shift could allow for better exploration of ‘alternative pathways for registration ... such as linking with the driver’s license based system and social media platforms’ to ‘improve the reach of the AODR and streamline the process’.¹⁹⁴ Dr Rohit D’Costa, State Medical Director of DLV explained:

I think philosophically we have considered this distinction between consent and intent to be irrelevant and have now looked at ways to actually just make it easier for people to have their intent known, because I do not think what we are seeking is a standard of informed consent ... in the community ... we know that people want their wishes and decisions to be respected, so the best way to do that is an intent to be reflected ...¹⁹⁵

Further, as registration has become more streamlined, ‘the default is just you are in or out’—rather than consenting to all or specific organs and tissues being donated.¹⁹⁶ DHAC did not provide a reason for the intent and consent distinction being maintained.¹⁹⁷

FINDING 17: The distinction between intent and consent registrations is unnecessary and removing it may allow for easier registration on the Australian Organ Donor Register.

¹⁹² National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally*, p. 157, with sources.

¹⁹³ EY, *Review of the Australian organ donation, retrieval and transplantation system*, pp. [104–105].

¹⁹⁴ *Ibid.*, p. [104].

¹⁹⁵ Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 9.

¹⁹⁶ *Ibid.*, pp. 11–12.

¹⁹⁷ Department of Health and Aged Care, response to written questions on notice, p. 3.

RECOMMENDATION 5: The Victorian Department of Health advocate to the Australian Department of Health and Aged Care to remove the distinction between intent and consent registration on the Australian Organ Donor Register.

3.5 Data reporting

Data collection and reporting on the AODR appears fragmented and not fit-for-purpose.

A Programme Agreement between DHAC and Services Australia states intent and consent registration breakdowns by state, age and gender are published and then used to 'review and evaluate the effectiveness of each registration channel.'¹⁹⁸ Public reporting only reflects intent and consent, and data on the registration channel used and selection of specific organs and tissues is not disseminated.¹⁹⁹

OTA publishes registration figures and the national and state percentage of the population registered in annual activity and performance reports. With Services Australia approval, OTA also publishes local government area 'level registration data for external campaign activity on an ad-hoc basis to communication partners.'²⁰⁰ Services Australia provides OTA with de-identified data monthly on donor IDs, month and year of birth, gender, postcode, intent or consent registration, objection to donate and initial registration channel.²⁰¹

Services Australia's website reports aggregate statistics on the total number of intent and consent registrations by age, jurisdiction and gender.²⁰² Services Australia's annual report notes the cumulative total number of registrations since the AODR's creation, broken down by intent and consent, as well as enquiry line calls received.²⁰³ A person is not removed from the AODR when they pass away.²⁰⁴ This means the cumulative total of registrations published includes registered people who are now deceased.²⁰⁵

One of OTA's performance measures is the percentage of eligible Australians registered on the AODR (referred to as the registration rate). For the 2022 calendar year this was reported as 36%, which can be calculated using the 2021–22 cumulative total of registrations in Services Australia's annual report.²⁰⁶ This means the registration rate

¹⁹⁸ Ibid.

¹⁹⁹ Ibid., p. 5.

²⁰⁰ Ibid.

²⁰¹ Ibid.

²⁰² Ibid.

²⁰³ Services Australia, *Annual report 2021–22*, p. 74.

²⁰⁴ Department of Health and Aged Care, response to written questions on notice, p. 5.

²⁰⁵ Department of Health and Aged Care, response to additional written questions on notice, p. 4.

²⁰⁶ At June 2022, the cumulative total of donor AODR registrations (including deceased people) was 7,450,599, see Services Australia, *Annual report 2022–23*, 2023, p. 74 and Australian population aged 16 and above was 20,926,116, see Australian Bureau of Statistics, Table 8 Estimated resident population, by age and sex—at 30 June 2022, *National, state and territory population, Mar 2023*, 14 September 2023, <<https://www.abs.gov.au/statistics/people/population/regional-population-age-and-sex/latest-release>> accessed 5 December 2023. Committee calculation: (7,450,599 / 20,926,116) x 100 = 35.6%.

reported by OTA appears to include deceased people. A more meaningful measure would report on the registration rate of living potential donors only.

To maintain the integrity of AODR data and allow for more meaningful reporting on registration rates, Medicare details can be used to accurately match records on the AODR and remove people when they die.

FINDING 18: Some statistics reported by Services Australia and the Organ and Tissue Authority regarding the number and percentage of Australians registered on the Australian Organ Donor Register include deceased people. These statistics would be more meaningful if they included living potential donors only.

In Victoria, DH and DLV meet quarterly and discuss key data, including the number of new registrations each quarter and progress towards an annual target, media activity and coverage, and registration pathway breakdown (for example, Service Victoria app, VicRoads or Seniors Card).²⁰⁷

The Committee believes public data reporting on registration could be improved at a national level. Reporting on intent and consent registrations is not meaningful if this distinction has no practical value for encouraging registration and donation (see Sections 3.1 and 3.4.2). Public reporting on the cumulative total of registrations, that includes people who are now deceased, and enquiry line calls received, also has little value without further detail.

The online form is the only registration method that records data on what prompted registration and this information 'is not disseminated outside of the OTA.'²⁰⁸ DHAC advised this data is not recorded for other registration methods to ensure the registration process is as streamlined and efficient as possible to encourage registrations; adding it would make the registration more complex and slower.²⁰⁹

Understanding what prompted people to register would provide valuable data to develop evidence-based registration campaigns—the Committee does not believe the addition of an optional question after registration would adversely impact the complexity of the registration process. Publishing data on the channels used to register would also help implement evidence-based and tailored awareness campaigns to maximise opportunities to increase registration on the AODR.

FINDING 19: National public reporting of Australian Organ Donor Register data has little value in evaluating the success or helping to inform the development of awareness campaigns to increase registrations. For example, collecting data on the registration method used or what prompted registration would be useful.

²⁰⁷ Department of Health, response to questions on notice, pp. 4–5.

²⁰⁸ Department of Health and Aged Care, response to written questions on notice, p. 5.

²⁰⁹ Department of Health and Aged Care, response to additional written questions on notice, p. 3.

RECOMMENDATION 6: The Victorian Department of Health advocate to the Australian Department of Health and Aged Care and Services Australia to improve public reporting of Australian Organ Donor Register data, including:

- using Medicare information to remove deceased people from the register
- the option to record what prompted someone to register regardless of registration method.

Inquiry participants also raised the need to collect AODR registration information for different communities, like deaf and hard of hearing, people with disability and culturally diverse communities. This would help to tailor awareness campaigns.²¹⁰ A 2018 review of the organ donation system similarly recommended capturing data on the use of the AODR by different demographic groups, particularly First Nations peoples and ‘other groups of non-European heritage ... to inform strategies to improve registration rates.’²¹¹ The draft National Organ Strategy and TAP do not include details of whether it is intended for this data to be captured. DLV confirmed that Services Australia does not collect demographic data on people who register a donation decision.²¹²

The Committee notes that the enhanced integration of Medicare and AODR data (see Sections 3.3.6 and 3.4.1) could allow for better demographic data reporting.

3.6 Trust in systems and use of data

Public services are becoming increasingly digitised (such as digital driver licences) as recognised in DGS’s *Corporate Plan 2023–2027*:

Digital services are the face of modern government, and great digital services can build trust with citizens. Citizens and businesses now expect government information and services to be readily available online, easy to find and understand, and at low or no cost.²¹³

Some inquiry participants raised trust and privacy in relation to the health sector and management of data as relevant to efforts to increase registrations.²¹⁴ For example, Lifeblood identified that as a donation agency, it ‘cannot risk being seen as untrustworthy in the way’ it handles donor information. The importance of trust in healthcare settings is discussed in Chapter 4.²¹⁵

²¹⁰ Philip Waters, *Transcript of evidence*, p. 37; Brendan Sullivan, *Transcript of evidence*, p. 46.

²¹¹ EY, *Review of the Australian organ donation, retrieval and transplantation system*, p. [105].

²¹² DonateLife Victoria, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 1 August 2023, p. 1.

²¹³ Department of Government Services, *Corporate Plan 2023–2027: Achieving our objectives*, 4 September 2023, <<https://www.vic.gov.au/dgs-corporate-plan-2023-2027/achieving-our-objectives>> accessed 28 November 2023.

²¹⁴ Catholic Archdiocese of Melbourne, *Submission 19*, p. 2; Jocelyn Harte, *Submission 7*, received 5 April 2023, p. 1; Donor Families Australia, *Submission 21*, p. 3; Austin Health, Transplant Infectious Diseases Clinical Service, *Submission 22*, received 18 May 2023, p. 6; Graham Harrison, *Submission 25*, p. 2.

²¹⁵ Stuart Chesneau, *Transcript of evidence*, p. 48.

DGS advised Service Victoria builds public trust through its privacy-by-design approach, by only collecting necessary data. DGS is undertaking a range of initiatives to improve ethical and safe data storage across the Victorian Public Sector.²¹⁶

DGS's *Corporate Plan 2023–2027* emphasises the importance of cyber security and states it 'will transform the way government delivers services, establishing a strong technology backbone'.²¹⁷ This is especially important in the context of donation because registration data is sensitive, private health information and there were past difficulties transitioning data to the AODR. DLV observed a 'sense that communities may have difficulty trusting in the safe storage and checking of their private personal information.'²¹⁸ DLV stated this presents challenges due to 'perceived or actual pressures on governments and systems that we have not seen before.'²¹⁹

Privacy and cybersecurity measures are important for any change to donor registration processes, particularly where state and federal data systems interact. For example, a change to driver licence registrations would require privacy and information security impact assessments²²⁰ and potentially informed consent for information to be shared between government bodies.²²¹ The security of AODR, Medicare and Victorian Government database interactions are also important (see Sections 3.3.6 and 3.4.1). Austin Health noted the sensitive implementation of any reforms will help maintain public trust.²²²

FINDING 20: As organ and tissue donation registration data is sensitive, private health information, any digital enhancements implemented by the Victorian Government to encourage people to record a donation decision on the Australian Organ Donor Register needs to be accompanied by appropriate confidentiality and security measures to maintain public trust.

²¹⁶ Department of Government Services, response to questions on notice, p. 2. For example, by 'uplifting response capabilities' through a new Cyber Defence Centre.

²¹⁷ Department of Government Services, *Corporate Plan 2023–2027*; Department of Government Services, *Corporate Plan 2023–2027: Message from the Secretary*, 4 September 2023, <<https://www.vic.gov.au/dgs-corporate-plan-2023-2027/message-secretary>> accessed 28 November 2023.

²¹⁸ DonateLife Victoria, *Submission 27*, pp. 1–2.

²¹⁹ Ibid.

²²⁰ Jacqui Sampson, *Transcript of evidence*, p. 6.

²²¹ Alfred Health, *Submission 38*, p. 8.

²²² Austin Health, *Submission 34*, p. 6.

Chapter 4

Donation conversations and family consent

Next of kin are always asked to consent when a potential organ and tissue donor is identified. This means that while registering to be a donor on the Australian Organ Donor Register (AODR) is important and significantly increases the likelihood consent will be given for donation to proceed, rates of deceased donation are ‘primarily limited by rates of consent by family members’.¹

How donation conversations between medical staff and next of kin unfold influences families’ decision making about consent. Dr Rohit D’Costa, State Medical Director of DonateLife Victoria (DLV) explained the four grades of donation conversations:

1. When the potential donor has registered and discussed their donation wishes with their family—87% consent rate.
2. When the potential donor has registered but has not discussed their donation wishes with their family—87% consent rate.
3. When the potential donor has not registered but the family knows their donation wishes—75% consent rate.
4. When the potential donor has not registered and the family does not know their donation wishes—44% consent rate.²

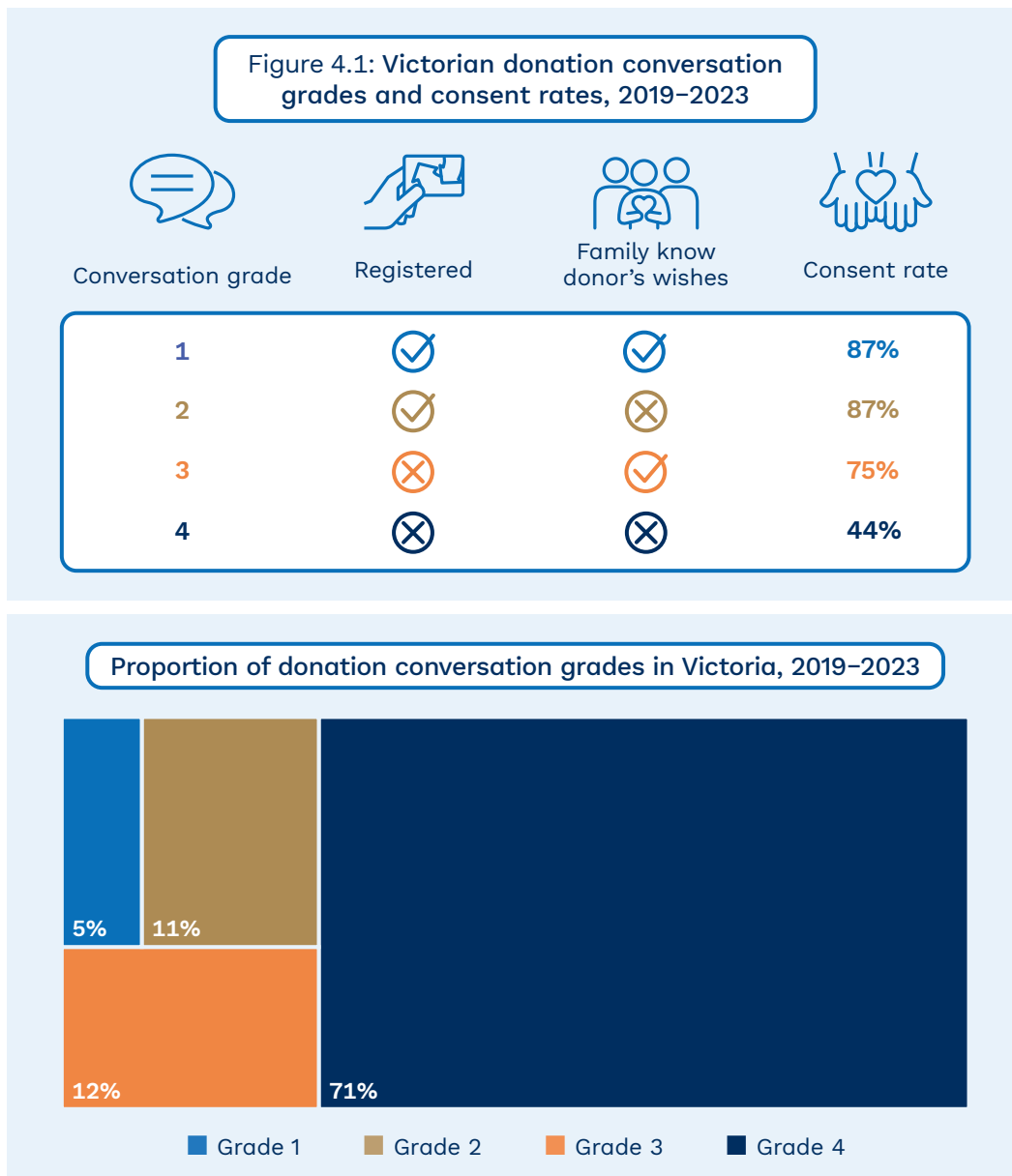
These statistics demonstrate the impact of donor registration and family discussion on consent rates. However, while DLV encourages both registration and family discussion, currently most donation conversations in Victoria are grade 4. This means most families are being asked to consent to donation when their loved one is not registered on the AODR and they cannot recall having a discussion with them about donation.³

The Committee uses the term *family discussion* to describe discussion between an individual and their family to communicate their donation wishes; and the term *donation conversation* to describe conversation between next of kin and medical professionals at end of life.

1 S. L. Neate et al., ‘Understanding Australian families’ organ donation decisions’, *Anaesthesia and Intensive Care*, vol. 43, no. 1, 2015, p. 48.

2 Dr Rohit D’Costa, State Medical Director, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 14; DonateLife Victoria, *Supplementary information*, supplementary evidence received 19 June 2023, p. 2.

3 Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 2.



Source: Donatelife Victoria, *Supplementary information*, supplementary evidence received 19 June 2023, p 2. The consent rate statistic is an average of 2019 to June 2023.

While not legally required, family consent when a potential donor is registered is critical. The consent process respects families and maximises information sharing to help determine donor suitability.⁴

Increasing registrations and family discussions lead to better donation conversations and in turn, higher consent rates. This is critical to grow donation rates. The Organ and Tissue Authority (OTA) acknowledged this in its *Annual report 2022–23*, noting that in 2022 achieving a national consent rate of 56% was the only performance measure not met, with the yearly rate falling by 2% to 54%.⁵

⁴ See Chapter 3, Section 3.2.1.

⁵ Organ and Tissue Authority, *Annual report 2022–23*, 2023, pp. 2, 29.

This chapter examines research into understanding families' experiences of donation conversations. It then considers factors that are known to influence decision making around consent: a potential donor's registration status; prior family discussion about donation; involvement of donation specialists; health literacy and knowledge of donation processes; trust and support of donor families; and different community perspectives.

4.1 Understanding experiences of donation conversations

Consent rates in Australia have decreased over the past approximately ten years, a trend that was amplified by the impacts of the COVID-19 pandemic. While similar decreases were experienced internationally, the factors influencing the longstanding decline in consent rates in Australia are not well understood.⁶ For example, OTA suggested they 'could be attributable to pressures on the health system, workforce and community by the COVID-19 pandemic.'⁷ However, this does not explain the longer-term downward trend (see Chapter 1, Figure 1.10).

St Vincent's Hospital Melbourne's Organ and Tissue Donation Team (St Vincent's OTD) submitted that '[a]t the moment we don't understand why consent rates have remained below 2019 levels.'⁸ Noting research undertaken by St Vincent's Hospital Melbourne ten years ago to determine the reversible factors affecting organ donation consent rates in Victorian hospitals, St Vincent's OTD suggested:

It would be beneficial to relook at factors that influence family responses to consent for organ and tissues donation in 2023. This would allow the effect of issues created by COVID such as visitor limitations, mask mandates and distrust of health systems to be evaluated and provide an informed launch into programs targeted at improving consent rates.⁹

The two most recent studies into family experiences of donation conversations and providing consent in Victoria and Australia are discussed below.

4.1.1 Victorian qualitative study of potential donor families' experiences (2012–2013)

Between April 2012 and September 2013, St Vincent's Hospital funded a qualitative family interview study across four Melbourne metropolitan hospitals.¹⁰ After interviewing families who consented and declined donation, the study made several

6 St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, received 19 May 2023, p. 1; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022, 2023*, p. 19; Dr Rohit D'Costa, DonateLife Victoria *Transcript of evidence*, p. 3.

7 Organ and Tissue Authority, *Annual report 2022–23*, p. 19.

8 St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 1.

9 Ibid.

10 Neate et al., 'Understanding Australian families' organ donation decisions', pp. 42–43.

findings on what influences families' donation decisions and their experiences of donation-related communication, processes and outcomes.¹¹ These findings included:

- Almost all families commented that the DonateLife staff who 'conducted the formal consent process were supportive, sensitive and knowledgeable.'¹²
- 'Families reported that little or no prior knowledge or understanding of [the complexities of] donation made having discussions and understanding processes difficult.'¹³
- 'The formal consent process, which involves exploring the potential donor's medical history and a list of all organs and tissues to be donated, was experienced as difficult by most participants'.¹⁴
- Families expressed similar reasons for consenting to those described internationally, like altruism and wish fulfilment. Pragmatism was more commonly noted by families that participated in the St Vincent's study than in similar United States (US) and United Kingdom studies.¹⁵
- In international literature, themes such as fairness of organ allocation and not enough being done to save the potential donor were reasons identified by families for declining consent. Families who participated in the St Vincent's study did not identify these reasons.¹⁶

The study found that 'clear and compassionate conversations and explanations that enabled time for discussion and reflection assisted families' and that the skills of the person leading donation conversations 'are of great importance'.¹⁷

Non-English-speaking donor families were excluded from the study due to insufficient funding to hire interpreters. The Committee supports the study's suggestion that assessing non-English-speaking donor families' experiences is 'urgently needed' to 'further improve services and provide everyone the opportunity to donate'.¹⁸

4.1.2 National study of family experiences of donation, Wave 5 (2018–2019)

Commissioned by OTA, this ongoing research project collects feedback about donor families' experiences to improve the care and support leading up to, during and after donation. OTA publishes two-year 'wave' research reports, with the fifth most

¹¹ Ibid.; C. H. Marck et al., 'Potential donor families' experiences of organ and tissue donation-related communication, processes and outcomes', *Anaesthesia and Intensive Care*, vol. 44, no. 1, 2016.

¹² Marck et al., 'Potential donor families' experiences of organ and tissue donation-related communication, processes and outcomes', p. 102.

¹³ Ibid.

¹⁴ Ibid., p. 104.

¹⁵ Neate et al., 'Understanding Australian families' organ donation decisions', pp. 44–45, 48–49.

¹⁶ Ibid., p. 49.

¹⁷ Ibid.

¹⁸ Marck et al., 'Potential donor families' experiences of organ and tissue donation-related communication, processes and outcomes', p. 105.

recent wave report published in late 2023 covering family experiences in 2018–19.¹⁹ The findings included:

- ‘Families who know what their family member wanted find it easier to make a decision about donation ... When decisions align with a family member’s wishes, families feel comfortable with their decision.’
- Motivators to provide consent include donation being ‘a chance for something positive to come out of a personal tragedy’ and families feeling ‘their loved one would have wanted to help others.’
- Barriers to providing consent include families knowing or believing ‘their family member would not want to donate’ and believing that ‘their family member has been through enough.’
- ‘Consistent with previous waves, 88% of family members surveyed who consented to donation’ would donate themselves.²⁰

The findings across the five waves covering families’ experiences of donation from 2010–11 to 2018–19 do not vary greatly.²¹ However, the lapse of time between families consenting or declining donation and the publication of the wave reports may diminish their value to the sector. Understanding potential donor families’ current experiences in Victoria would assist in informing strategies to improve donation conversations and ultimately consent rates. For example, during the COVID-19 pandemic (which started in Australia in 2020), OTA did not meet its target of involving a donation specialist nurse in family discussions 80% of the time.²² Wave reports covering this period are not yet available.

FINDING 21: The delay between family experiences of organ and tissue donation processes and the publication of the Organ and Tissue Authority’s wave research reports into these experiences, may diminish their usefulness to inform and improve donation-related communication and processes. No studies have been undertaken on this in a Victorian setting since the COVID-19 pandemic.

¹⁹ Organ and Tissue Authority, *Feedback from families*, n.d., <<https://www.donatelife.gov.au/about-us/data-and-research/national-study-family-experiences-organ-and-tissue-donation>> accessed 3 November 2023.

²⁰ Proof Research, *National study of family experiences of organ and tissue donation, Wave 5: experiences in 2018 and 2019—research report*, report for Organ and Tissue Authority, 2023, pp. 1, 4.

²¹ *Ibid.*, pp. 117–122.

²² Organ and Tissue Authority, *Annual report 2021–22*, 2022, p. 29. Involvement of a donation specialist nurse in family conversations about donation was reported at 74% in 2020, 77% in 2021 and 80% in 2022, see Organ and Tissue Authority, *Annual report 2022–23*, p. 5.

RECOMMENDATION 7: The Victorian Department of Health work with the Organ and Tissue Authority (OTA) and DonateLife Victoria to explore ways to:

- maximise the usefulness of OTA’s wave research reports into family experiences of donation to inform and improve donation-related communication and processes in Victoria
- ensure non-English-speaking Victorian families’ recent experiences of organ and tissue donation-related communication and processes are being captured in OTA’s research.

4.2 Factors influencing family decision making about consent

There are several factors known to significantly influence family decision making about consent. This section considers these factors and how they may assist or influence donor families and inform best practice for donation conversations.

4.2.1 Registration on the Australian Organ Donor Register

In 2022, 82% of the time families consented to donation where a potential donor was registered on the AODR.²³ However, currently most people who die in hospital who are eligible to donate are not registered on the AODR.²⁴

The AODR is accessed by authorised medical professionals when a potential donor is identified in hospital, enabling them to verify a person’s decision about donation.²⁵ Alfred Health outlined that typically the AODR is checked online by a donation specialist while on the phone receiving the referral and before approaching the family.²⁶

OTA’s *Best practice guidelines for offering organ and tissue donation in Australia* and funding agreements with hospitals promote routine checking of patients’ AODR status when approaching end of life.²⁷ OTA’s *Annual report 2021–22* advised that in 2021, this routine checking remained stable at 91% of the time.²⁸ However, no details are

²³ Organ and Tissue Authority, *Annual report 2022–23*, p. 21.

²⁴ Mark McDonald, National Manager, Analytics and Technology, Organ and Tissue Authority, Parliament of Western Australia, Public Administration Committee, Public hearing, Perth, 17 May 2023, *Transcript of evidence*, p. 9; Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, Parliament of Western Australia, Public Administration Committee, Public hearing, Perth, 17 May 2023, *Transcript of evidence*, p. 9.

²⁵ Services Australia, *Annual report 2021–22*, 2022, p. 74. Authorised medical professionals include donation specialist nurses in the tissue sector, see Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 41.

²⁶ Laura Fleckner, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 29.

²⁷ Organ and Tissue Authority, *Best practice guidelines for offering organ and tissue donation in Australia*, April 2021, p. 7; Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, Parliament of Western Australia, Public Administration Committee, Public hearing, Perth, 17 May 2023, *Transcript of evidence*, p. 10.

²⁸ Organ and Tissue Authority, *Annual report 2021–22*, p. 18.

provided to understand the reasons or situations where the AODR was not checked the remaining 9% of the time. OTA does not appear to have set a target for routine checking of the AODR²⁹ but its *Annual report 2022–23* identifies it as a key internal hospital practice metric.³⁰ Transplant Australia identified checking of the AODR 100% of the time as an opportunity for improvement.³¹

When someone is registered on the AODR families are more comfortable making donation decisions.³² It makes families' consent decisions more about affirming the potential donor's choice, and donation conversations about fulfilling wishes.³³ Laura Fleckner, Donation Specialist Nursing Coordinator (DSNC) at Alfred Health told the Committee, '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."' ³⁴

Georgina Callaghan, also a DSNC at Alfred Health explained 'knowing whether someone has registered their intention or consent to help others through [donation] ... definitely does steer the nature of the conversation, particularly in those cases where people are registered'.³⁵ Dr Aadhil Aziz, General Practitioner (GP) and Co-Deputy Chair Victoria Faculty of the Royal Australian College of General Practitioners (RACGP) suggested that registration 'takes out that guessing game' for families by providing tangible evidence of a choice made in life and that most people respect their loved ones' wishes and provide consent.³⁶

FINDING 22: Registering an organ and tissue donation decision on the Australian Organ Donor Register provides clear direction to donor families and donation staff on a potential donor's wishes and substantially increases the likelihood that a family will consent to donation. Registration changes the nature of donation conversations by making it easier for families to honour and respect their deceased loved ones' wishes.

29 Ibid., pp. 27–30; Organ and Tissue Authority, *Annual report 2022–23*, p. 41. While a target is not specifically mentioned in OTA annual reports, DonateLife Western Australia's submission to the *Inquiry into organ and tissue donation in Western Australia* states this target is 100%, see DonateLife Western Australia, submission to Parliament of Western Australia, Legislative Council Standing Committee on Public Administration, *Inquiry into organ and tissue donation in Western Australia, 2023*, p. 1.

30 Organ and Tissue Authority, *Annual report 2022–23*, p. 41.

31 Chris Thomas, Chief Executive Officer, Transplant Australia, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 21.

32 Proof Research, *National study of family experiences of organ and tissue donation, Wave 5*, p. 24; Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 21.

33 Georgina Callaghan, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, pp. 29–30.

34 Laura Fleckner, *Transcript of evidence*, p. 30.

35 Georgina Callaghan, *Transcript of evidence*, pp. 29–30.

36 Dr Aadhil Aziz, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 29.

4.2.2 Prior family discussion about and/or knowledge of donation wishes

In 2022, 63% of the time families consented to donation if they knew a potential donor's wishes, regardless of the donor's registration status.³⁷ OTA's wave reports published as part of the ongoing national study of family experiences of donation consistently highlight how prior knowledge of loved ones' donation wishes helps guide families when they are asked to consent to donation.³⁸ If a family is unaware of a potential donor's wishes or they were not registered on the AODR, this makes the decision about consent more difficult. Families placed in these situations 'can grow to doubt the decision they made in hospital, irrespective of whether that decision was to consent to or decline donation.'³⁹

The wave reports stress the importance of clear, prior discussion with family about an individual's willingness to become a donor.⁴⁰ OTA's website includes information about talking with family about donation and steps to start the discussion.⁴¹

Prior family discussion benefits both a potential donor's family and donation staff. Georgina Callaghan explained that when a donor's wishes are not known it makes the donation conversation more difficult, especially for 'families who are already in the throes of quite intense grief, and that burden of decision-making is quite a lot for them during that time in their life.'⁴²

Leanne Campbell shared with the Committee how even a brief discussion with her son about his donation wishes put her family in a position to honour his wishes and consent to deceased organ donation.

³⁷ Organ and Tissue Authority, *Annual report 2022–23*, p. 21.

³⁸ Proof Research, *National study of family experiences of organ and tissue donation, Wave 5*, pp. 24–26, 117.

³⁹ *Ibid.*, p. 26.

⁴⁰ *Ibid.*, p. 25.

⁴¹ Organ and Tissue Authority, *Talk to your family about donation*, n.d., <<https://www.donatelife.gov.au/all-about-donation/talk-your-family-about-donation>> accessed 7 December 2023.

⁴² Georgina Callaghan, *Transcript of evidence*, pp. 29–30.

Brett, organ donor

In 2009 while holidaying with mates on the Murray River, 21-year-old Brett was in an accident. His mother, Leanne, told the Committee that ‘one of his mates decided it would be fun to ride a pushbike down a boat ramp and knocked him over at the bottom.’ Brett hit his head. Leanne explained:

We received a wake-up call at 1:30 in the morning to say that there had been an incident but everything would be fine and that we would hear from the hospital. At about 3:30 we got a call from them saying no, it was not good at all.

Brett had not registered as an organ and tissue donor on the AODR, but his family knew his wishes and consented to donation. Leanne shared with the Committee:

... [the family] had only very recently, only two weeks prior—which is just freaky—had the discussion about organ donation with Brett ... he said, ‘Well, if I am dead, they’re no good to me,’ shut the fridge door and walked out of the house.

While acknowledging that processes and support for families making donation decisions have improved since Brett’s accident, Leanne noted ‘the importance of having really well trained nurse donation specialists and clinicians that are good on the floor’. After driving from Melbourne to Echuca in the early hours and back again (while Brett was transferred by air), the family were sleep deprived and felt ill-prepared for the questions they were being asked ahead of donation. Leanne described feeling as if she was in a fog with everything that was happening:

... while we knew his wishes, that in no way prepared us for what we were about to be thrown into ... Why do we have to wait until we are in this critical point before we educate people ...

Speaking more generally about organ and tissue donation awareness, Leanne emphasised the overriding significance of family consent for donation to proceed and the value of people sharing their donation wishes with their family, especially given people can become donors without being registered on the AODR:

I think the thing I find hardest with the campaign to register, register, register and the anecdotal stuff that ‘It is only a minute—it’s really easy,’ is there is no context that you have to have talked or the importance of talking to your family. It is not enough to say, ‘I want to be an organ donor.’

Source: Leanne Campbell, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*.

FINDING 23: 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. Family discussion about donation changes the nature of donation conversations by making it easier for families to honour and respect their deceased loved ones' wishes.

RECOMMENDATION 8: The Victorian Department of Health work with the Australian Department of Health and Aged Care and Services Australia to explore opportunities following registration on the Australian Organ Donor Register (AODR) to:

- automatically contact people, encouraging them to share their donation wishes with family and provide links to steps to help start family discussion about donation
- provide an option to allow people to automatically share their donation decision with family members via an email sent by the AODR.

4.2.3 Involvement of trained donation specialists

Throughout the Inquiry the Committee consistently heard about the significance of trained donation specialists being involved in donation conversations.⁴³ St Vincent's OTD described this as 'the backbone of the donation process'⁴⁴ and Melbourne Lions Eye Donation Service (LEDS) stated:

We need to make sure that donor specialist nursing coordinators ... are in place in as many facilities as possible ... Without those donation specialists or suitably trained health professionals to guide that decision to donate, having a large registration base is essentially ineffectual.⁴⁵

DLV dedicates a lot of work toward conversation training for donation specialists so that 'families are in the best possible position to make a decision that would support what their loved one would have wanted.'⁴⁶

OTA reported that in 2022 a donation specialist nurse was involved in 80% of donation conversations and 6 in 10 families provided consent for donation when they were supported by a donation specialist nurse (compared to 2 in 10 when they were not).⁴⁷

⁴³ St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2; Robert Manning, *Submission 15*, received 6 May 2023, p. 15; Transplant Australia, *Submission 23*, received 18 May 2023, p. 5; Organ and Tissue Authority, *Submission 31*, received 19 May 2023, p. 6; Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 32.

⁴⁴ St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2.

⁴⁵ Bronwyn Cohen, *Transcript of evidence*, p. 32.

⁴⁶ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 2; Tony Holland, General Manager, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 14.

⁴⁷ Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, p. 20.

Anna and David Gillard shared with the Committee their experience providing consent for their son Rhys to become a deceased tissue donor following a donation conversation with a Tissue Donation Nurse Specialist.

Rhys, tissue donor

Rhys died in 2021 aged 17 from a sudden cardiac arrest. His parents, Anna and David, shared with the Committee their experience making the decision to consent to Rhys becoming a tissue donor.

As Rhys was a ‘fit and healthy athlete’ and the cause of his cardiac arrest was unclear, he was transported to the Coroner. Anna and David then received a phone call from Janine, a Tissue Donation Nurse Specialist. Janine advised that while organ donation was not an option for Rhys, he was a prime candidate for tissue donation. Anna and David described their conversation with Janine as ‘amazing’, reflecting:

We did not know anything about tissue donation, and most people we speak to do not.

Anna and David explained how Janine, a highly trained individual, talked them through the options for Rhys’s donation and how the tissue donation process gave them something to focus on. Rhys had not registered as an organ and tissue donor on the AODR and they had not discussed donation as a family. However, Anna and David believed that Rhys was always sharing and giving during his life and that deciding to consent to Rhys becoming a tissue donor was in line with that. Rhys helped seven people by donating his corneas and skin and Anna and David said ‘it gave [them] a lot of comfort knowing he had helped other people.’

Anna and David described the ongoing communication with the Donor Tissue Bank of Victoria (DTBV) and DLV about donation outcomes as ‘really special’. Anna spoke about their experience with DTBV’s Tree of Life and a DLV donor families event. The Tree of Life mural has green, yellow and red leaves, reflecting the cycles of seasons and grief responses, and the leaves bear the first names of tissue donors:

... the tissue bank does the leaf ceremony ... But in 2021 it was COVID, so it was not going to happen. But we went in for a meeting ... with the forensic pathologist, which was in the next building, so we called Janine to see if we could actually go and have a look at the *Tree of Life*, and we got some leaves with Rhys’s name on it and chatted to Janine about it all. That was a really special experience, as well as going to the DonateLife Victoria event, which was in December last year. That is wider than just the tissue bank, but it was such a safe space to be with lots of people ... [all grieving for a loved one]. I think I just cried the whole 2 hours we were there. But it was just beautiful [and powerful] to hear the stories, and it was just a safe space to share that emotion. So to be provided with that as well by the organisation was really lovely.

Source: Anna and David Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*.

FINDING 24: Involving a trained organ and tissue donation specialist in end of life communication and donation conversations with families significantly increases the likelihood that a family will consent to donation.

Regarding the retention of DSNCs, Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist at St Vincent's OTD explained that 'every time an experienced nurse donor coordinator is lost to the sector, you lose a very large amount of investment and skill.'⁴⁸ St Vincent's OTD described 'the model of on call and recall' to duty for DSNCs as 'onerous', suggesting it 'can be a barrier to both recruitment and retention' of donation specialists.⁴⁹ St Vincent's OTD considered that expanding the pool of donation specialists, supporting flexible work and reducing on call practices would help.⁵⁰

Previously DLV struggled to maintain a full roster of DSNCs, an issue that predates the COVID-19 pandemic.⁵¹ DLV advised they currently have an improved roster of 34 nurses responding to donation cases across Victoria, representing an increase in total staffing.⁵² Anna McNamara, DSNC at Alfred Health said she 'would love to do [the job] ... forever' and that burnout has reduced with the improved roster.⁵³

FINDING 25: DonateLife Victoria has recently implemented an improved roster of donation specialists to respond to organ and tissue donation cases in Victoria, with most donation specialists located in metropolitan Melbourne and travelling to regional areas as required. Maintaining a cohort of appropriately qualified staff and actively managing the roster to avoid burnout remains important.

RECOMMENDATION 9: The Victorian Government build capacity for DonateLife Victoria and the Donor Tissue Bank of Victoria to continually improve recruitment and retention strategies for organ and tissue donation specialists and report annually on the outcomes achieved.

Professional education package

OTA has trained donation specialists since 2011.⁵⁴ OTA's current professional education package includes a two day core and a half day practical Family Donation

⁴⁸ Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 47.

⁴⁹ St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2.

⁵⁰ Ibid.

⁵¹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 5; Dr Bernadette Hickey, *Transcript of evidence*, p. 47.

⁵² Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 5.

⁵³ Anna McNamara, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 22.

⁵⁴ Organ and Tissue Authority, *Annual report 2021-22*, p. 23.

Conversation (FDC) workshop attended by donation specialists every two years.⁵⁵ Collaborating with several leading intensive care-related bodies, OTA has revised the training to incorporate learnings from engagement with First Nations peoples.⁵⁶ Dr D’Costa of DLV explained that the FDC workshop discusses ‘communication skills in general and then how to support families at times of intense grief’ and:

The particular focus of the conversation training is getting people to make an informed and enduring decision, recognising that these are some of the times when people have experienced a position where they feel they have lost their autonomy, they have not been able to make any decisions and their loved one is dying. Really it is an unfair thing to happen to people that their loved one is dying in an intensive care unit [ICU], typically, and there is nothing that can save them.⁵⁷

Noting concerns raised in the Inquiry about knowledge of tissue donation in the sector, the Committee confirmed with OTA that the core and practical FDC workshops provide skills relevant for conversations about both organ and tissue donation.⁵⁸ All DonateLife staff are enrolled in an Eye and Tissue Donation eLearning module providing ‘information on what eye and tissue donation and transplantation is and the role of health professionals in the process.’⁵⁹ The content of this module has been distributed to OTA’s Education Coordinators Network so that it is accessible to general hospital staff.⁶⁰ OTA also offers Introductory Donation Awareness Training, a one day interdisciplinary workshop attended by a broad range of health professionals.⁶¹ This training has a ‘sizable allocation to information around eye and tissue donation.’⁶² Increasing knowledge about tissue donation in the medical community is discussed in Chapter 7.

An example of how the knowledge and skills from OTA’s workshops inform donation processes was provided by DSNCs from Alfred Health, who explained that following their training, their role is to embed that practice in the hospital. Alfred Health advised that in 2023 its practice is to raise donation with every family as part of end of life decision making, regardless of a patient’s registration status or suitability to be a donor. This means donation staff can be clear that they raise donation without exception early to inform families future decision making. Where a patient is not suitable to be a donor but registered to be a donor, this also allows staff to acknowledge this by ‘thank[ing] the family for their loved one’s generosity in thinking of others’.⁶³

55 Ibid.; Organ and Tissue Authority, *Information about training for Victorian Legislative Assembly’s Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, September and October 2023.

56 Organ and Tissue Authority, *Annual report 2021–22*, p. 23. OTA collaborated with bodies, including the College of Intensive Medicine, Australian and New Zealand Intensive Care Society and the Australian College of Critical Care Nurses.

57 Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 14.

58 Organ and Tissue Authority, *Information about training*, p. 4.

59 Ibid.

60 Ibid.

61 Organ and Tissue Authority, *Introductory Donation Awareness Training (IDAT) workshop*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/professional-training/introductory-donation-awareness-training-idat-workshop>> accessed 3 November 2023.

62 Organ and Tissue Authority, *Information about training*, p. 4.

63 Laura Fleckner, *Transcript of evidence*, pp. 18–19, 20.

While OTA provided the Committee with national attendance numbers for these workshops, it was 'unable to provide a breakdown by jurisdiction', advising this would require further investigation because of 'complexities in this data as attendees sometimes travel interstate to attend these workshops.'⁶⁴ OTA's *Annual report 2022–23* provided high-level, national information about FDC workshops, such as attendance numbers and select locations where workshops ran.⁶⁵ However, OTA does not publicly report on the effectiveness of FDC workshops.

FINDING 26: The Organ and Tissue Authority (OTA) is responsible for training donation specialists. However, jurisdictional data about the number of attendees and the effectiveness of OTA's family donation conversation workshops is not publicly available.

RECOMMENDATION 10: The Victorian Department of Health support DonateLife Victoria to work with the Organ and Tissue Authority to improve public reporting on donation specialist training, including by publishing jurisdictional level data about attendance and effectiveness of family donation conversation workshops.

4.2.4 Health literacy and knowledge of donation processes

... just because we are surrounded with information does not mean that we have the ability to know it or to understand it.⁶⁶

Representatives from RACGP suggested that poor health literacy in Australia is a primary barrier to donation. Associate Professor Christopher Hogan, GP and Member of the Victoria Faculty of RACGP advised that poor health literacy impacts donation because it 'leads to multilevel ignorance, misperception and conspiracy theories about death, health and organ transplantation.'⁶⁷ Dr Bindiya Sethi, GP and Co-Deputy Chair Victoria Faculty of RACGP also highlighted the need to increase health literacy in culturally and linguistically diverse (CALD) communities to help minimise cultural barriers to donation.⁶⁸

Health literacy 'relates to how people access, understand and use health information in ways that benefit their health.'⁶⁹ In 2006, only 41% of Australians aged 15 to 74 had a

⁶⁴ Organ and Tissue Authority, *Information about training*, pp. 2–3.

⁶⁵ Organ and Tissue Authority, *Annual report 2022–23*, p. 34.

⁶⁶ Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 31.

⁶⁷ *Ibid.*, p. 22.

⁶⁸ Dr Bindiya Sethi, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 23.

⁶⁹ Australian Institute of Health and Welfare, *Health literacy*, 2022, <<https://www.aihw.gov.au/reports/australias-health/health-literacy>> accessed 9 October 2023; Australian Commission on Safety and Quality in Health Care, *Health literacy*, n.d., <<https://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/health-literacy>> accessed 9 October 2023. Health literacy consists of two parts: individual—the ability to understand health information and use it to make informed decisions and take actions for personal health; and environmental—the policies, processes and health infrastructure people navigate, which impacts their experiences and understanding of healthcare.

'level of health literacy that allow[ed] them to meet the complex demands of everyday life.'⁷⁰ While more recent data is not available,⁷¹ the Australian Institute of Health and Welfare observed in 2018 that there is little information available to help people navigate health policies and systems and health literacy is influenced by a person's 'cultural beliefs, language, disability, education, income and health status'.⁷²

Improving health literacy is one way to help donor families during the donation and consent process.

The consent process involves families providing information on a potential donor's medical history and organs and tissues for donation. This can be difficult for families even when they understand the requirement.⁷³ For example, Leanne Campbell shared with the Committee how learning about the consent and donation process while dealing with the imminent death of her child was 'not ideal' and 'very confronting':⁷⁴

We did not know the different types of death. We did not know how that would impact on us. We were not aware that by law they have to get consent for each organ ... There is also a whole list of questions that are asked of you, obviously very pertinent to what is going on in terms of medical things, but you are asked about their sex life—had he been with a sex worker? Was he a drug taker? ... why don't we divulge these questions to the public? Why is this a hidden thing? Why do we have to wait until we are in this critical point before we educate people that this is what happens?⁷⁵

Prior knowledge or personal experience with donation improves a person's health literacy and inherently prepares them to be involved in a donation conversation.⁷⁶

Cynthia Caruna has familiarity with organ donation as a result of close family experiences and shared with the Committee how this better prepared her to make the decision to consent for her son, Myles, becoming a deceased tissue donor.

70 Australian Institute of Health and Welfare, *Australia's health 2018: Australia's health series no. 16*, Canberra, 2018, p. 164. In 2018 the Australian Bureau of Statistics conducted a national health survey on health literacy in Australia. The survey did not provide an overall score for health literacy, nor did it evaluate whether health literacy is good or poor, see Australian Institute of Health and Welfare, *Health literacy*; Australian Bureau of Statistics, *National Health Survey: Health literacy*, 2019, <<https://www.abs.gov.au/statistics/health/health-conditions-and-risks/national-health-survey-health-literacy/2018#about-the-health-literacy-survey>> accessed 9 October 2023.

71 The Australian Institute of Health and Welfare's *Australia's health 2018* and 2022 publications do not include health literacy data, see Australian Institute of Health and Welfare, *Australia's health 2018*; Australian Institute of Health and Welfare, *Australia's health 2022 data insights: Australia's health series no. 18*, Canberra, 2022.

72 Australian Institute of Health and Welfare, *Australia's health 2018*, p. 183, with sources.

73 Marck et al., 'Potential donor families' experiences of organ and tissue donation-related communication, processes and outcomes', p. 104.

74 Leanne Campbell, *Submission 16*, received 7 May 2023, p. 3.

75 Leanne Campbell, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 14. Death must occur before a donation can take place but brain death and circulatory death (the two definitions of death in Victoria's legislation) are not well understood or accepted, see Neate et al., 'Understanding Australian families' organ donation decisions', p. 49; Leanne Campbell, *Submission 16*, p. 2.

76 Samantha Francis-Pester, *Submission 28*, received 19 May 2023, p. 3; Cynthia Caruna, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 22; Professor Robert Jones, Liver Transplant Unit Director, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 7; Dr Brooke Huuskes, Senior Lecturer, Centre for Cardiovascular Biology and Disease Research, La Trobe University, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 57.

Myles, tissue donor

Family history of polycystic kidney disease helped form Myles's view on donation at a very early age. Five of Myles's great aunts and uncles suffered from the genetic disease, managing their condition with medication, dialysis and eventually successful kidney transplants. Myles's mother, Cynthia, shared with the Committee the impact the transplants had on her aunts' and uncles' quality of life and on Myles:

When my uncle was not on dialysis, Myles would spend time with him, asking questions about the procedure and the outcomes. Like most children, there was no conditioning about what may or may not have been improper questions. Many years later my uncle told me how much he appreciated the interest and how much in awe he was of this child, who seemingly had no fear of the process and his condition, as in his experience even most adults shied away from the topic. I believe that it was this experience that made Myles aware and shaped his outlook on organ donations.

Myles was born with severe eczema and developed life-threatening food allergies and asthma. The family attended hospitals and specialist appointments regularly to manage these conditions. Long-term medication use impacted Myles's childhood but he was happy, earning the nickname 'Myles and miles of smiles.'

In 2006 when Myles was 15 years old, he suffered a cardiorespiratory arrest and was admitted to hospital. After a prolonged stay in an ICU and an adolescent ward, he never woke up and passed away. When it became apparent that Myles was deteriorating on the ward and organ donation was not viable, Cynthia decided to contact the DTBV to organise tissue donation.

Myles was not old enough to register as an organ and tissue donor on the AODR. However, prior family conversations meant his family was fully aware of Myles's wish to be a donor. Cynthia noted that if the next of kin are unaware of a loved ones' wishes, making a donation decision at a time of great grief and sadness can be overwhelming.

The impact of Myles's donation extended beyond the recipients:

Apart from [donating] his tissue of skin ... [heart] valves and corneas, Myles has made a difference. After his passing many of his school friends had the conversations [about organ and tissue donation] with their parents, and one has even become a paramedic.

Source: Cynthia Caruana, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*.

FINDING 27: Poor health literacy and lack of knowledge about organ and tissue donation makes family donation conversations harder. Families with good health literacy and prior experience with organ and tissue donation are better equipped to handle donation conversations and decision making about consent.

4.2.5 Trust and support of families

The hospital environment can increase families' stress during donation conversations. This means 'effective communication' with families by trained, sensitive, compassionate and caring specialists 'at the appropriate time, in a supportive environment' puts families in the best position to make donation decisions.⁷⁷ Inquiry participants suggested practices that optimise the donation process for families include:

- using face-to-face communication where possible⁷⁸
- using interpretation services to overcome language barriers to ensure effective communication⁷⁹
- 'creating a supportive environment ... such as allowing sufficient time with the patient'⁸⁰
- providing appropriate support during and after the decision making process⁸¹
- establishing rapport and trust.⁸²

Building rapport, particularly after the COVID-19 pandemic

Safety measures implemented in response to the COVID-19 pandemic like reduced visitor numbers and the wearing of face masks limited opportunities for face-to-face communication in hospitals. This reinforced the importance of interpersonal communication to build rapport and trust when having donation conversations. Associate Professor Helen Opdam, National Medical Director of OTA suggested that consent rates during the pandemic were impacted as:

... families could not attend the hospitals and go through the end-of-life journey with their family member because of visitor restrictions ... [meaning there was not] a chance to build rapport with families, explain that survival of their family member is not possible and then at an appropriate time move on to raising the possibility of donation—without that direct relationship and trying to raise it over the telephone or a video teleconference, or if people were able to visit in person it was one or two family members and everyone was decked out in masks and PPE [personal protective equipment] ...⁸³

77 Laura Siminoff, Amma Agyemang and Heather Traino, 'Consent to organ donation: a review', *Progress in Transplantation*, vol. 23, no. 1, 2013, p. 1.

78 Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 26; Associate Professor William Silvester, Chair, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 38; Leanne Campbell, *Transcript of evidence*, p. 14.

79 ANZICS Death and Organ Donation Committee, *Submission 41a*, received 18 August 2023, p. 1; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, received 2 November 2023, p. 5.

80 Siminoff, Agyemang and Traino, 'Consent to organ donation: a review', p. 6; Leanne Campbell, *Submission 16*, p. 4.

81 Leanne Campbell, *Transcript of evidence*, p. 4; Donor Families Australia, *Submission 21*, received 17 May 2023, p. 3; Transplant Australia, *Submission 23*, p. 13; Graham Harrison, *Submission 25*, received 18 May 2023, p. 3.

82 Dr Bernadette Hickey, *Transcript of evidence*, p. 45; Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 21–22; Donor Families Australia, *Submission 21*, p. 2; Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 22.

83 Associate Professor Helen Opdam, *Transcript of evidence*, p. 26.

Associate Professor William Silvester, Chair of the Australian and New Zealand Intensive Care Society Death and Organ Donation Committee (ANZICS DODC) supported this view and informed the Committee that '[n]ow even if we are face to face [with families], we are doing it behind masks' and families are not always permitted to visit patients together.⁸⁴ Emphasising the value of face-to-face donation conversations with family, Associate Professor Silvester stated:

... if you are trying to have a carefully nuanced, emotional discussion where you are going to be asking this family to put aside their grief in the midst of what is happening and consider and then agree to donation based on what their loved one's views would have been, that is a very hard discussion to have over the phone, particularly if they are already feeling aggrieved that not as many of them could come in when they wanted to and the hours have been restricted.⁸⁵

Associate Professor Opdam of OTA suggested that during the COVID-19 pandemic 'families didn't get to come along [the donation] journey in the same way'. Associate Professor Opdam noted that the donation and transplantation process has many steps and interdependencies, stating:

... it's no surprise, with the healthcare system continuing to recover from the [COVID-19] pandemic ... that the donation and transplantation programs are impacted. But one of the biggest impacts has been a reduction in the consent rate, so that's the percentage of times there's family saying yes to donation when donation is possible in a hospital.⁸⁶

Donation consent rates have decreased in Australia over the past approximately ten years, a trend accelerated by the COVID-19 pandemic⁸⁷ (see Section 4.1), with the consent rate decreasing from 64% in 2019 to 54% in 2022 (see Chapter 1, Figure 1.10).⁸⁸ Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation at Alfred Health also described the 'huge impact' of the COVID-19 pandemic:

We had challenges in being able to establish a rapport with family members, and that therefore influenced the way in which we could have a conversation around end of life and donation. I think families were exhausted about the logistical challenges by simply coming into hospital to see their loved one die, and so the idea of continuing another conversation around organ donation ... you have heard previously that the consent rates just dropped off drastically and we have not been able to get them back [and]... [i]t is a bit unclear as to why we have not been able to regain those consent rates ...⁸⁹

Leanne Campbell reflected on her own experience of being asked about donating her child's organs over the phone, noting this 'is not the ideal situation' especially in circumstances where you do not have clarity about their medical situation.⁹⁰

⁸⁴ Associate Professor William Silvester, *Transcript of evidence*, p. 38.

⁸⁵ *Ibid.*

⁸⁶ ABC Listen, *The pandemic's impact on organ donation*, 6 March 2023, <<https://www.abc.net.au/listen/programs/healthreport/the-pandemic-s-impact-on-organ-donation/102050594>> accessed 16 February 2024.

⁸⁷ Organ and Tissue Authority, *Annual report 2021-22*, pp. 2-3.

⁸⁸ See also ABC Listen, *The pandemic's impact on organ donation*.

⁸⁹ Dr Joshua Ihle, *Transcript of evidence*, p. 22.

⁹⁰ Leanne Campbell, *Transcript of evidence*, p. 14.

Anna McNamara, DSNC at Alfred Health explained that when donation specialists cannot get to regional areas to have donation conversations they will encourage the intensivist or registrar to have the donation conversation and ‘often say they can have us on FaceTime to meet the family, but they are really hard barriers to get through.’⁹¹

Donor Families Australia submitted that part of the reason families decline consent is because they ‘are not being approached by medical staff in a way that would help them say yes.’⁹² It was also suggested that hospital clinicians receive training in empathy and next of kin communications.⁹³

Overcoming language barriers

Overcoming language barriers to ensure all families can engage in donation conversations and reach an informed decision about consent is equally important. Of the families who declined donation that participated in OTA’s most recent wave report for 2018–19, 19% spoke another language (Burmese, Italian, Filipino, Thai, German, Hindi).⁹⁴

The Ethnic Communities’ Council of Victoria Policy Advisory Committee on Health and Wellbeing observed that donation conversations in hospitals can happen very quickly, adding a layer of difficulty for families impacted by language barriers.⁹⁵ DLV and DTBV engage interpretation services to overcome these barriers.⁹⁶ DTBV practice is to hold donation conversations face-to-face to ‘ensure an accurate and honest translation.’⁹⁷ However, ANZICS DODC advised that phone translation services are used in other states and in Victorian hospitals more broadly, including to assist ‘organ donation staff in communications with families’.⁹⁸ DTBV noted that it will review its practice.⁹⁹

Philip Waters, General Manager of Deaf Victoria explained how the communication challenges deaf and hard of hearing people often have with their family mean it is unlikely they will share their donation wishes:

There are often people who are deaf or hard of hearing who do not really have discussions with their family about vital things to do with their lives ... [meaning] hard-of-hearing people will often miss out on [donation] discussions in the family because of the communication barriers.¹⁰⁰

⁹¹ Anna McNamara, *Transcript of evidence*, p. 29. When a family consents to donation, the donation specialist then travels to the regional centre to coordinate the case. Rural and regional donation is discussed in Chapter 7.

⁹² Donor Families Australia, *Submission 21*, p. 2.

⁹³ Robert Manning, *Submission 15*, p. 17.

⁹⁴ Proof Research, *National study of family experiences of organ and tissue donation, Wave 5*, pp. 17, 22.

⁹⁵ Notes from Chair and Deputy Chair meeting with Ethnic Communities’ Council of Victoria Policy Advisory Committee on Health and Wellbeing, 23 August 2023, p. 2.

⁹⁶ ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, p. 5.

⁹⁷ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, p. 5.

⁹⁸ ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1.

⁹⁹ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, p. 5.

¹⁰⁰ Philip Waters, General Manager, Deaf Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 32.

Philip Waters suggested an Auslan interpreter or other conversation tools (for example, writing things down or visual aids like videos) may help when donor coordinators have donation conversations with deaf and hard of hearing people.¹⁰¹

Before, during and after donation

Effective communication and family support during the donation process includes:

... developing and maintaining a supportive, trust-based relationship with the family that includes addressing concerns and questions with sensitivity and providing information underscoring the benefits of donation; and ... providing closure by summarizing the family's position regarding donation, outlining the next steps in the process, and expressing gratitude for the family's time and consideration of donation.¹⁰²

Several inquiry participants raised the importance of providing support to families before, during and after donation,¹⁰³ with Transplant Australia suggesting there was an opportunity for continued improvement in this area.¹⁰⁴ Graham Harrison also raised the need to provide 'consistent aftercare' to donor families.¹⁰⁵ Robert Manning suggested that one way the State could ease the burden on donor families is to make a capped contribution to a donor's funeral expenses.¹⁰⁶ Monash Bioethics Centre (MBC), who undertake research into biomedicine, technology and healthcare ethics, noted the need to be careful implementing initiatives like this to ensure they do not incentivise donation.¹⁰⁷ Dr Julian Koplin, Lecturer at MBC emphasised any 'rewards' to honour donors needs to be considered and implemented carefully to avoid inducing donation (discussed in Chapter 6).¹⁰⁸

Donor Families Australia suggested that a 'lack of trust in the system' may impact a family's decision to consent to donation.¹⁰⁹ Lucinda Barry, CEO of OTA stated its ongoing wave study with donor families indicates that trust in the health system can be compromised if it is not working efficiently.¹¹⁰ This emphasises the need to better understand families' recent experiences of donation as identified in Recommendation 7.

Dr Hickey referred the Committee to a study undertaken in the US in the early 2000s which 'suggested that it was people's whole hospital experience that contributed to their trust, distrust or their desire to donate, not just the care they received in that last period of time around a crisis.'¹¹¹ Dr Hickey also surmised that families' and patients'

¹⁰¹ Ibid., p. 35.

¹⁰² Siminoff, Agyemang and Traino, 'Consent to organ donation: a review', p. 5.

¹⁰³ Leanne Campbell, *Submission 16*, p. 3; Donor Families Australia, *Submission 21*, p. 3.

¹⁰⁴ Transplant Australia, *Submission 23*, p. 13.

¹⁰⁵ Graham Harrison, *Submission 25*, p. 3.

¹⁰⁶ Robert Manning, *Submission 15*, p. 18.

¹⁰⁷ Monash Bioethics Centre, *Submission 37*, received 1 June 2023, p. 4; Monash University, *Monash Bioethics Centre: About*, n.d., <<https://www.monash.edu/arts/bioethics/about>> accessed 8 January 2024. See also Dr Bernadette Hickey, *Transcript of evidence*, p. 54.

¹⁰⁸ Dr Julian Koplin, Lecturer, Monash Bioethics Centre, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, pp. 14, 18.

¹⁰⁹ Donor Families Australia, *Submission 21*, p. 3.

¹¹⁰ Lucinda Barry, *Transcript of evidence*, p. 21.

¹¹¹ Dr Bernadette Hickey, *Transcript of evidence*, p. 51.

experience of the donation sector ‘influences the community’s respect, understanding and trust of the system, and ... therefore also influences registration rates.’¹¹²

FINDING 28: If clinicians and donation staff can meet with families face-to-face (using translators if required) this assists in establishing rapport and trust with families which positively impacts donation conversations and consent rates.

FINDING 29: Continuously improving support for donor families before, during and after the decision making process for organ and tissue donation consent is important and has the capacity to positively influence the community’s respect, understanding and trust of the donation system, which in turn could positively affect registration and consent rates.

Donor families and recipients meeting

Several inquiry participants discussed whether transplant recipients and families should be able to meet.¹¹³ This is currently prohibited under the respective Human Tissue Acts in Australia, but recipients and families can communicate through de-identified letters.¹¹⁴ LEDS described recipients and families writing to each other as ‘a powerful, powerful tool’ to recognise donors.¹¹⁵

Leanne Campbell suggested many people already think it is possible for donor families and recipients to meet and that allowing it would be healing: it could help families in the grieving process and assist recipients to ‘come to terms with the gift they have received.’¹¹⁶ Anna and David Gillard discussed that for them, it is enough to know that their son’s tissue was donated. It could be hard for recipients to be placed in the position of meeting donor families.¹¹⁷ Cynthia Caruana expanded on this, stating:

I would dearly love to be able to meet with those people, if they were up to it. I take on board ... that sometimes it is very, very difficult. You are so grateful for that opportunity, but your quality of life has come at great cost to somebody else, whether it was expected or sudden, and I do understand that person not wanting to put more pain on the donor family. But I certainly think that if both sides were open, there should be some active encouragement, because as I said, for me personally, I would just love to know and I would just love to meet them. I do not want to have a relationship with them, but I would just love to meet with them that one time, just to see with my own eyes the difference that my son made. As a mother—and my husband is a little bit different about that—I know there is [a] piece of him somewhere out there, I know his legacy lives on.¹¹⁸

¹¹² Ibid., p. 44.

¹¹³ Georgina Callaghan, *Transcript of evidence*, p. 26; Leanne Campbell, *Transcript of evidence*, p. 17; Leanne Campbell, *Submission 16*, p. 4; Graham Harrison, *Submission 25*, p. 3.

¹¹⁴ EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, p. [106].

¹¹⁵ Bronwyn Cohen, *Transcript of evidence*, p. 32.

¹¹⁶ Leanne Campbell, *Submission 16*, pp. 4–5; Leanne Campbell, *Transcript of evidence*, p. 17.

¹¹⁷ Anna Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 25; David Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 25.

¹¹⁸ Cynthia Caruana, *Transcript of evidence*, p. 25.

Inquiry participants who discussed the issue thought that it should be up to donor families and recipients, as consenting adults, to choose to meet.¹¹⁹ The decision of those who do not want to meet should be equally respected.¹²⁰

Some inquiry participants noted a ‘fear’ in the medical sector that contact between recipients and donor families would result in negative consequences, but it has occurred many times over the past several years with positive outcomes.¹²¹

FINDING 30: Transplant recipients and donor families can communicate through de-identified letters but respective Human Tissue Acts in Australia prevent them from meeting. Donor families and healthcare professionals have diverse views about the opportunity for transplant recipients and donor families to meet.

RECOMMENDATION 11: The Victorian Government discuss at a national level the opportunity for all jurisdictions to seek to amend respective Human Tissue Acts to allow consenting, adult transplant recipients and donor families to choose to meet.

Recognising donors on death certificates

The *Births, Deaths and Marriages Registration Act 1996* (Vic) allows the Registrar of Births Deaths and Marriages (BDM) to include additional information about a person on their death certificate and the BDM register.¹²² However, section 45 of the HT Act prevents health professionals and hospital staff from disclosing information identifying a deceased donor without the deceased donor’s consent.¹²³ This means that a donor’s next of kin may ask the Registrar of BDM to recognise their loved one as a donor, but health professionals and hospital staff would not be in a position to verify that a donation occurred.

The Committee notes that the 2012 Victorian Legislative Council Legal and Social Issues References Committee’s *Inquiry into organ donation in Victoria* recommended ‘[t]hat the Victorian Government consider ways to acknowledge and recognise the altruistic act of organ donation including the possibility of suitable acknowledgement on the donor’s death certificate.’¹²⁴

¹¹⁹ Leanne Campbell, *Transcript of evidence*, p. 17; Cynthia Caruana, *Transcript of evidence*, p. 25; Graham Harrison, *Submission 25*, p. 3; Georgina Callaghan, *Transcript of evidence*, p. 26.

¹²⁰ Tony Holland, General Manager of DonatLife Victoria, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 49; Georgina Callaghan, *Transcript of evidence*, p. 26.

¹²¹ Graham Harrison, *Submission 25*, p. 3; Leanne Campbell, *Transcript of evidence*, p. 17.

¹²² *Births, Deaths and Marriages Registration Act 1996* (Vic) ss 41(42)(b), 50–51.

¹²³ *Human Tissue Act 1982* (Vic) s 45.

¹²⁴ Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*, p. 100.

Evidence from families of deceased donors suggested that recognising donation on death certificates is one appropriate way to acknowledge a donor's selfless contribution to improving or saving another's life and helps support families.

Anna Gillard suggested that this type of acknowledgment 'would be a really good way' to commemorate the donor's contribution on an 'official document'.¹²⁵ Leanne Campbell stressed that it would provide 'a permanent record of [the donor's] Gift of Life to others.'¹²⁶ Leanne Campbell has campaigned for ten years for donor death certificate recognition in Victoria, proposing that an exception to disclosing identifying information, similar to that provided in ACT, be included in the HT Act.¹²⁷ Donor Families Australia also suggested that Victoria emulate the ACT's 2021 legislative amendments to enable recognition of someone as a donor on their death certificate.¹²⁸

Case Study 4.1 Australian Capital Territory (ACT), donor acknowledgment in the death register and on death certificates

2021 amendments to the *Births, Deaths and Marriages Registration Act 1997* (ACT) (ACT BDMR Act) allow donation to be acknowledged in the death register and on a donor's death certificate in the ACT by the donor's next of kin applying to add the statement:

The deceased gave a gift of life, generously donating organs/tissue.

The amendments provided that the Registrar 'must include in the [death] register a statement that the person was a tissue donor' (section 38A(2)) if requested by the donor's next of kin. The request 'must be in writing and include information verifying that the deceased person was a tissue donor' (section 38A(3)).

The ACT also amended the *Transplantation and Anatomy Act 1978* (ACT) to provide an exception to the ACT's restriction on health professionals and hospital employees disclosing information identifying a deceased donor (section 49(4)(b)). This means disclosure is permitted to a donor's next of kin for the purposes of section 38A(3) in the ACT BDMR Act.

In the ACT next of kin can apply to acknowledge historical donations and both donor acknowledgments are free, including the printing of an amended death certificate.

Source: ACT Government, *Organ and tissue donor acknowledgment*, fact sheet, May 2021; *Births, Deaths and Marriages Registration Act 1997* (ACT); *Transplantation and Anatomy Act 1978* (ACT).

¹²⁵ Anna Gillard, *Transcript of evidence*, p. 25.

¹²⁶ Leanne Campbell, *Submission 16*, p. 4.

¹²⁷ *Ibid.*; Leanne Campbell, *Transcript of evidence*, pp. 16, 17.

¹²⁸ Donor Families Australia, *Submission 21*, p. 6.

The Committee notes that a Bill modelled on the ACT legislation recently passed South Australia's Legislative Council and is currently before the House of Assembly.¹²⁹

OTA stated families have different views about recognising donors on death certificates and the issue is not currently part of its national strategy.¹³⁰

FINDING 31: The *Human Tissue Act 1982* (Vic) prevents health professionals and hospital staff from verifying with Births, Deaths and Marriages Victoria (BDM) that a deceased donation occurred. This means BDM cannot acknowledge a donor in the death register or on a death certificate as is the case in the Australian Capital Territory.

RECOMMENDATION 12: The Victorian Government seek to amend the *Human Tissue Act 1982* (Vic) to allow health professionals and hospital staff to disclose information identifying a deceased donor for the purposes of including this information in the death register and on a death certificate with the consent of a donor's next of kin or authorised family member.

RECOMMENDATION 13: The Victorian Government seek to amend the *Births, Deaths and Marriages Registration Act 1996* (Vic) to provide a clear process to recognise a deceased donor (including a past donor) in the death register and on a death certificate.

4.2.6 Cultural, social and religious beliefs and perspectives

Families decline consent to donation for several reasons. Alfred Health advised these can include:

- donation is not aligned with the patient's wishes
- the timeframe for donation is too protracted
- the potential donor should be buried whole
- religious objections to donation.¹³¹

The Committee received substantive evidence about how cultural, social and religious beliefs and perspectives influence the outcomes of donation conversations.¹³² Where

¹²⁹ Government of South Australia, South Australian Legislation, *Births, Deaths and Marriages Registration (Tissue Donation Statements) Amendment Bill 2022*, n.d., <[https://www.legislation.sa.gov.au/lz/path=/b/current/births%20deaths%20and%20marriages%20registration%20\(tissue%20donation%20statements\)%20amendment%20bill%202022_hon%20nicola%20centofanti%20mlc](https://www.legislation.sa.gov.au/lz/path=/b/current/births%20deaths%20and%20marriages%20registration%20(tissue%20donation%20statements)%20amendment%20bill%202022_hon%20nicola%20centofanti%20mlc)> accessed 12 December 2023.

¹³⁰ Lucinda Barry, *Transcript of evidence*, p. 31.

¹³¹ Alfred Health, *Submission 38*, received 1 June 2023, p. 6.

¹³² For example, Notes from Chair and Deputy Chair meeting with Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing, p. 2; Adel Salman, President, Islamic Council of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 62; Dai Nguyen, Bilingual and Bicultural Health Educator, Vietnamese, Multicultural Centre for Women's Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 66, 67.

possible, DLV accommodates cultural requirements to assist families with decision making.¹³³ Below is a quote from a family member who participated in OTA's most recent wave report and consented to donation in 2019:

When I went to visit him they said, 'the room is yours', so I really appreciated that. I created music and I danced around with him. I was quite loud, so I thought, 'okay, I'm being me with my husband' and they allowed it! They allowed me to grieve, however abnormal that was. And then after when we were going to turn him off, they let the whole family come in. They let groups of 10 people at a time come to sing to him, and it was beautiful. In our culture, this is how we grieve. In his dying bed we come in mass. And they allowed it. They just gave us so much accommodation to let that happen. It was kind of like a service because each culture or each family group who came was able to sing a song and say a prayer, in the ICU, and I really appreciated that. It was beautiful, it really was. It made me feel heaps better.¹³⁴

4

First Nations families

OTA has not publicly reported on First Nations family consent rates since 2016.¹³⁵ OTA's First Nations Engagement Group in conjunction with ABSTARR Consulting delivered cultural safety education sessions in March 2023 to around 40 staff from OTA and DonateLife agencies.¹³⁶ Georgina Callaghan, DSNC at Alfred Health told the Committee that when having donation conversations with First Nations families:

... we are very proactive in engaging with our Aboriginal liaison officers [ALOs] to be able to help support us to then be able to help support the patient and the families. Like any family, it is ... about having a good sense of cultural humility and really understanding what is important for that patient and family within their end-of-life care and making sure that we can help facilitate whatever is important to them and their beliefs.¹³⁷

Tony Holland advised that DLV has worked closely with ALOs in hospitals to accommodate smoking ceremonies for First Nations families.¹³⁸ DLV's specialised nursing workforce also participate in hospital cultural awareness and 'further ongoing education' in this space is in the Victorian Department of Health's (DH) current yearly workplan.¹³⁹ The Committee was unable to obtain evidence about the donation

¹³³ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 7.

¹³⁴ Proof Research, *National study of family experiences of organ and tissue donation, Wave 5*, p. 107.

¹³⁵ Organ and Tissue Authority, *Australian donation and transplantation activity report 2016, 2017*, p. 6. The 2016 *Activity report* noted Aboriginal consent rates were 40%. Subsequent OTA activity reports do not note these consent rates. However, the 2018 EY review noted Aboriginal and Torres Strait Islander consent rates were 20% in 2018, see EY, *Review of the Australian organ donation, retrieval and transplantation system*, report for Australian Department of Health and Aged Care, 2018, p. [20], with sources.

¹³⁶ Organ and Tissue Authority, *Annual report 2022–23*, p. 23.

¹³⁷ Georgina Callaghan, *Transcript of evidence*, p. 23.

¹³⁸ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 7.

¹³⁹ Department of Health, *Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 7 September 2023*, p. 4.

experiences of Victorian First Nations families or ALOs working in Victorian hospitals. However, DH advised:

Victoria has Aboriginal Hospital Liaison Officers (AHLOs) in hospitals to support Aboriginal patients, families, community members and hospital staff. There is no clear role expectation for an AHLO to be involved in discussions in relation to organ donation. However, the role of a AHLO could be a mechanism to better support tissue donation in the indigenous population.¹⁴⁰

The Central Australia Health Service shared with the Committee their recent experiences participating in a project with Alice Springs Hospital that engaged ALOs in focus groups to discuss donation. Learnings from this project can be applied in Victoria.

Case Study 4.2 Northern Territory (NT), views of First Nations people on donation

Alice Springs in the NT has the largest haemodialysis (blood dialysis) unit in the southern hemisphere. Dr Paul Secombe, Senior Specialist Clinician in the ICU at Central Australia Health Service advised that rates of dialysis-dependent kidney disease in the NT are ‘the highest in Australia and possibly the highest in the world’, with a kidney transplant the only cure.

First Nations peoples make up 30% of the NT population and are disproportionately represented in both renal failure and ICU. But the donation consent rate of First Nations peoples in the NT is around half to two-thirds that of non-First Nations consent rates. A grant from the Flinders Foundation enabled research with focus groups to consider why this may be the case. It aimed to understand First Nations peoples’ perspectives and knowledge about donation. Dr Secombe emphasised the focus groups were:

... the first time in the five or six years I had been working in this hospital to that point that I had sat down with this remarkable group of people and truly just listened to what they had to say about a whole host of issues, not just about organ donation but about the way that we Western-trained clinicians have perhaps been conducting our communications and also about the role of country and the role of family in the consenting process.

(Continued)

140 Ibid.

Case Study 4.2 Continued

The focus groups revealed that:

- donation is not discussed in the community and is considered culturally taboo
- the language used to conduct donation conversations about donation has not been culturally appropriate (for example, terms like ‘finishing up’ or ‘we have done all that we can do with the medicine that we have’ are better understood and more culturally appropriate than ‘dead’, ‘death’ or ‘dying’)
- cultural knowledge and education for clinicians and in the community is important
- there is mistrust in the healthcare system.

These often overlap. Because donation is not discussed in the community outside of clinical settings, there is a lack of understanding associated with it. Therefore, when donation is raised in a clinical setting, the language used to communicate with First Nations peoples is often not culturally appropriate. This extends to having the right family present for donation conversations based on kinship systems and allowing for an appropriate amount of time and space as part of the end of life process. A lack of cultural knowledge and sensitivity is linked to systemic racism and subsequent mistrust in the healthcare system. Dr Secombe observed:

... that most clinical teams do their rounds without having an embedded ALO or Aboriginal health practitioner as part of the ... team that is seen to be directly delivering care to the patient. And although it may be slightly different in Victoria, in our hospital, where 70 to 80% of our inpatients are Indigenous people, I would have thought that an Aboriginal person should be a core member of every clinical team when they see every patient.

Source: Dr Paul Secombe, Senior Specialist Clinician, Intensive Care Unit, Central Australia Health Service; Chrissie Davis, Donna Lemon, Linda Bray, Christine Spencer, Sally Sena, Jennifer Armstrong, Curtis Haines and Anthony Davis, Aboriginal Liaison Officers; Justine Swan-Castine, Acting Leader, Aboriginal Partnership and Strategy Unit, Alice Springs Hospital; and Dr Rosalind Beadle, Research Fellow, College of Medicine and Public Health, Flinders University, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*.

Raising awareness and increasing education about donation in First Nations communities is discussed in Chapter 5.

FINDING 32: Clinicians and donation specialists need sufficient cultural knowledge to sensitively raise donation with First Nations families in clinical settings. This includes ensuring the right family members are present for donation conversations based on kinship systems and that there is an appropriate amount of time and space as part of the end of life process.

RECOMMENDATION 14: The Victorian Department of Health review the current support arrangements for end of life care services for First Nations patients and families to ensure Victorian Aboriginal Liaison Officers are involved to help donation specialists lead culturally appropriate donation conversations and to assist families with decision making.

Culturally and linguistically diverse families

At the 2021 census, of Victoria's population:

- 49% were either born overseas or have a parent who was born overseas
- 28% spoke a language other than English at home, with Mandarin, Vietnamese, Greek and Punjabi being the most common
- 54% followed one of more than 130 different faiths, with Hinduism and Islam experiencing the largest increases from 2016 to 2021.¹⁴¹

DLV advised it tries to facilitate the involvement of spiritual leaders in the donation process for people from different faith backgrounds.¹⁴² For example, Muslims have a strong focus on honouring the body of the dead until they are buried, usually in a very short timeframe.¹⁴³ This means donation can be seen to disrupt that process, however, Adel Salman, President of the Islamic Council of Victoria advised:

Recently imams and scholars have come out very clearly and said it is absolutely permissible in Islam to donate one's organs to save the lives of other people and to improve the quality of life of other people. I think that is important because that means from a permissibility perspective there would be no major concern. Clearly some families would be concerned about what would happen to their loved one if organs are removed from the body of their loved one, but ... this is done in a very sensitive way and will not in any way compromise the process that Muslims undertake to honour their dead, which includes washing of the body and that praying over the body and that quite rapid burial that happens thereafter.¹⁴⁴

OTA's most recent wave report found that sometimes families decide not to donate 'due to a cultural or religious belief' despite knowing their loved one would have wanted to be a donor.¹⁴⁵ Encouraging sensitive discussions in CALD families can help dispel concerns about cultural or religious beliefs precluding the giving of consent for donation.¹⁴⁶ This is especially important because '[m]ost religions support organ and

¹⁴¹ Victorian Government, *Discover Victoria's diverse population*, 13 December 2022, <<https://www.vic.gov.au/discover-victorias-diverse-population>> accessed 4 November 2023.

¹⁴² Tony Holland, DonatLife Victoria, *Transcript of evidence*, p. 7.

¹⁴³ Adel Salman, *Transcript of evidence*, p. 60.

¹⁴⁴ Ibid.

¹⁴⁵ Proof Research, *National study of family experiences of organ and tissue donation*, Wave 5, p. 31.

¹⁴⁶ Adel Salman, *Transcript of evidence*, p. 61; Notes from Chair and Deputy Chair meeting with Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing, p. 2.

tissue donation as an act of charity and goodwill.¹⁴⁷ As with First Nations consent rates discussed above, OTA has not publicly reported on culturally diverse family consent rates since 2016.¹⁴⁸

Different perspectives across generations and the need for intergenerational conversations was also raised by Dai Nguyen, a Vietnamese-English bilingual and bicultural health educator at the Multicultural Centre for Women's Health:

For my children, it was easy for me to ask them to consent for me because they were born in Australia, but it was not easy for me to ask my parents from overseas, because they [are] still affect[ed] from Asian cultures. They do not want [to donate]—they believe when you pass away, they want the full body, and if you donate something, a part of your body, in the next life your body will be missing some part. It was not easy for most Asian people.¹⁴⁹

The impact language barriers can have on CALD families' experiences of donation conversations is discussed at Section 4.2.5. Encouraging family discussion, including in CALD families, is considered in Chapter 5.

FINDING 33: DonateLife Victoria should continue to facilitate the involvement of spiritual leaders in the organ and tissue donation process and accommodate cultural requirements to assist families involved in donation conversations where possible.

LEDS suggested that more families would feel comfortable discussing donation with DSNs who are 'of a similar ethnicity to the patient population' explaining:

We have lost donors from the south-east of Melbourne, and we firmly believe that it is because the person having the conversation does not look like you—they are feeling a little more uncomfortable having that conversation. Without those donation specialists or suitably trained health professionals to guide that decision to donate, having a large registration base is essentially ineffectual.¹⁵⁰

RACGP also shared with the Committee their experience engaging with multicultural communities, suggesting that better outcomes are usually achieved when health information is conveyed by a medical professional to a person with a shared or similar cultural background.¹⁵¹ A 2022 Victorian committee *Inquiry into support for older Victorians from migrant and refugee backgrounds* similarly found that a diverse workforce with healthcare staff that share the languages and cultural backgrounds of patients can build trust, understanding and communication.¹⁵²

¹⁴⁷ Organ and Tissue Authority, *Organ donation and religion*, (n.d.), <https://www.donatelife.gov.au/sites/default/files/2021-05/religion_facts.pdf> accessed 4 November 2023, p. 1.

¹⁴⁸ Organ and Tissue Authority, *Australian donation and transplantation activity report 2016*, p. 6.

¹⁴⁹ Dai Nguyen, *Transcript of evidence*, p. 66.

¹⁵⁰ Melbourne Lions Eye Donation Service, *Submission 18*, received 12 May 2023, p. 2; Bronwyn Cohen, *Transcript of evidence*, p. 32.

¹⁵¹ Dr Aadhil Aziz, *Transcript of evidence*, pp. 26–27.

¹⁵² Parliament of Victoria, Legislative Assembly Legal and Social Issues Committee, *Inquiry into support for older Victorians from migrant and refugee backgrounds*, August 2022, p. 69.

FINDING 34: Families may feel more comfortable when organ and tissue donation conversations occur between medical staff and families with a shared or similar cultural background. Clinicians and donation specialists need sufficient knowledge to sensitively raise donation with culturally and linguistically diverse families in clinical settings.

RECOMMENDATION 15: The Victorian Department of Health build capacity for DonateLife Victoria to ensure recruitment strategies will grow the cultural and ethnic diversity of the donation specialist workforce to reflect the State's multicultural population, and further the ability of donation specialists to lead culturally appropriate donation conversations and assist with family decision making.

Chapter 5

Awareness and education

Each donation is a unique gift from one human being to another, and we cannot afford to lose [donation] opportunities due to a lack of awareness ...¹

A key way to increase the number of Victorians registered on the Australian Organ Donor Register (AODR) is to promote awareness and increase education about organ and tissue donation. This chapter summarises the Organ and Tissue Authority's (OTA) and DonateLife Victoria's (DLV) shared awareness and education responsibilities. It then considers the use of mass media campaigns and their effectiveness, before looking at ideas to increase and improve community engagement, education and knowledge about donation to encourage Victorians to register. Improved data collection and reporting at a national level can help identify what motivates people to register and assist in creating targeted community awareness campaigns.

5.1 Victoria's operating environment

OTA leads the national donation communication and engagement program in collaboration with the DonateLife Network.² To raise awareness about donation, OTA produces resources,³ awards grants⁴ and partners with organisations to deliver events and local activities.⁵

OTA's *Communications and Engagement Framework 2022-27* aims to provide a 'work program and delivery model' to 'increase the number of Australians on the AODR, increase awareness about donation and encourage family discussion.'⁶ To inform future activities OTA has also engaged a market researcher to better understand 'the drivers and barriers that influence the intention-action gap between support for organ and tissue donation, registration and family discussion.'⁷ It is unclear when the findings of this research will be available.

OTA's Community Awareness Grants program renews yearly and funds 'community-based awareness and education activities to build support' for donation,

1 Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 39.

2 Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 16. The DonateLife Network is discussed in Chapter 2.

3 Organ and Tissue Authority, *Strategy 2022-2027*, 2022, p. 5; Organ and Tissue Authority, *Community resource library*, n.d., <<https://www.donatelife.gov.au/get-involved/community-resource-library>> accessed 5 October 2023.

4 Organ and Tissue Authority, *Annual report 2022-23*, 2023, p. 23.

5 Organ and Tissue Authority, *Our partners*, n.d., <<https://www.donatelife.gov.au/our-partners>> accessed 5 October 2023.

6 Organ and Tissue Authority, *Annual report 2022-23*, p. 25.

7 Ibid.

particularly among those not registered on the AODR.⁸ In 2023 the program focused on encouraging young people to register.⁹ Suggested grant applicants included not-for-profit, community and digital content organisations, education providers, media and public relations agencies and organisations working with young people.¹⁰

OTA's Partnerships program funds organisations in the sport, media and health sectors to increase OTA's reach and engagement.¹¹ A 2020–21 Federal Budget allocation of \$4 million over four years saw OTA award partnerships to seven organisations, including Victorian sports teams the Western Bulldogs and Melbourne Storm.¹²

As part of the DonateLife Network, DLV receives funding from OTA for education and community awareness in Victoria.¹³ DLV works under the direction of OTA and the Victorian Department of Health (DH). OTA provides strategic and creative direction to ensure messaging and graphic design is consistent across the country.¹⁴ DLV is responsible for raising awareness about donation among Victorians, and encouraging them to register on the AODR and talk to their families about their decision.¹⁵

DLV has 2.6 full time equivalent staff working in communications and since these positions were established in 2015, registration rates have 'steadily climbed ... with more than 400,000 additional Victorians registering on the AODR.'¹⁶

In recent years, DLV has allocated \$80,000 to \$160,000 per year to advertising for all community engagement in Victoria, including 'billboards, regional buses [sic], street posters, digital out-of-home screens, and some regional TV advertising'.¹⁷

5.1.1 Legislative framework for awareness activities relating to donation

Amendments taking effect from 21 February 2024 to the *Australian Organ and Tissue Donation Authority Act 2008* (Cth) outline when information identifying deceased donors can be disclosed by OTA, DonateLife agencies and grant recipients for educational, commemorative, promotional or community awareness activities.¹⁸ The amendments also provide that the donor or 'authorised family member' must

⁸ Organ and Tissue Authority, *Community awareness grants program: Grant opportunity guidelines 2023*, 2022, p. 5.

⁹ Ibid.

¹⁰ Ibid., p. 8.

¹¹ Organ and Tissue Authority, *Grants and tenders*, n.d., <<https://www.donatelife.gov.au/about-us/grants-and-tenders>> accessed 5 October 2023.

¹² Ibid.; Organ and Tissue Authority, *Our partners*; DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 4; Tony Holland, General Manager, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 16.

¹³ Lucinda Barry, *Transcript of evidence*, p. 17; DonateLife Victoria, *Submission 27*, p. 1.

¹⁴ DonateLife Victoria, *Submission 27*, p. 4.

¹⁵ Ibid., p. 1.

¹⁶ Ibid., p. 4.

¹⁷ Ibid.

¹⁸ *Australian Organ and Tissue Donation Authority Amendment (Disclosure of Information) Act 2023* (Cth). Grant recipients are recipients of financial assistance from OTA in relation to organ or tissue donation and transplantation matters, see *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth) s 11(11)(g).

consent to such disclosures.¹⁹ Donor Families Australia emphasised how it is important for families to be able to legally share their child's donation story and refer to their name as part of the grieving process.²⁰

In Victoria under section 40 of the *Human Tissue Act 1982 (Vic)* (HT Act) any 'advertising' relating to donation must be approved by the Minister for Health.²¹ While OTA advertising bypasses this requirement, DLV advised the current legislative framework is unclear,²² including the definition of 'advertising'.²³ DLV explained this requirement can be a challenge and a barrier because it is not pragmatic to obtain ministerial approval for every piece of advertising. DLV suggests the 'additional layer of approval' is 'restrictive' and 'prevents year round campaigning'.²⁴ As a result, DLV recommended simplifying the HT Act to allow more flexibility to raise awareness. Delegating the authority to approve DLV advertising to the DLV General Manager or OTA CEO would streamline processes and enable more awareness activities to occur.²⁵

FINDING 35: The requirement under the *Human Tissue Act 1982 (Vic)* for organ and tissue donation advertising in Victoria to be approved by the Minister for Health restricts DonateLife Victoria's ability to conduct awareness activities.

RECOMMENDATION 16: The Victorian Government seek to amend the *Human Tissue Act 1982 (Vic)* to remove the requirement for DonateLife Victoria (DLV) to obtain the Minister for Health's approval for awareness activities or narrow the definition of advertising to exclude certain DLV awareness activities.

5.2 Mass awareness and education campaigns

OTA and DLV advised that significant investment in a mass awareness campaign could educate the community about donation and result in behavioural change to encourage registrations at scale.²⁶ Inquiry participants also emphasised that any mass awareness campaign should convey the importance of starting a family discussion about donation preferences.²⁷ Campaigns of this nature would contribute to sustained community support and improve registration and consent rates.²⁸

¹⁹ *Australian Organ and Tissue Donation Authority Amendment (Disclosure of Information) Act 2023 (Cth)*, ss 58, 58A. Authorised family member is defined in s 5 and includes the donor's partner, parent, legal guardian, child, sibling, grandparent, grandchild or person related to the donor under traditional Aboriginal or Torres Strait Islander kinship rules.

²⁰ Donor Families Australia, *Submission 21*, received 17 May 2023, pp. 4–5.

²¹ *Human Tissue Act 1982 (Vic)* s 40.

²² Dr Rohit D'Costa, State Medical Director, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 16.

²³ DonateLife Victoria, *Submission 27*, p. 6.

²⁴ *Ibid.*, p. 8.

²⁵ *Ibid.*

²⁶ Organ and Tissue Authority, *Submission 31*, received 19 May 2023, p. 5.

²⁷ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, received 16 June 2023, pp. 13, 17; Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 2; DonateLife Victoria, *Submission 27*, p. 6.

²⁸ Organ and Tissue Authority, *Submission 31*, p. 6.

OTA confirmed it has not made a big investment in mass media in the past ten years, so growth in new AODR registrations has been slow (about 2 or 3%) outside of 2021 (about 5%).²⁹ DLV advised that its 'communications strategies cannot create the impact required'.³⁰ DLV suggested at least \$10 million would be needed to reach the approximately 3.3 million Victorians who support donation but have not taken the time to register.³¹ This mass increase is especially important as modelling 'shows registration needs to occur on a mass scale to make a difference, with one million registrations converting to approximately 11 donors'.³²

FINDING 36: While investing in mass awareness campaigns that educate Australians about organ and tissue donation would encourage registration at scale, the Organ and Tissue Authority has not made any big investments in mass media over the last ten years.

DonateLife Week, held yearly in June, is OTA's biggest national awareness initiative to encourage Australians to register and tell their family they want to be a donor:

DonateLife Week is delivered within a small budget and includes digital marketing activities, community events, [public relations] and media promotion. DonateLife Week accounts for around 30% of new registrations on the AODR annually, and last year we saw around 210,000 Australians registering, of which 48,000 were Victorians.³³

To maximise their effectiveness, any mass media campaigns should use postcode data to target localities with low registration rates and tailor messaging based on demographic data (including age, cultural and language diversity and religious affiliation).³⁴

Figure 5.1 below is a map showing the estimated percentage of people registered on the AODR by Victorian local government area (LGA) in 2022. Below this is a table of the ten Victorian LGAs with the lowest percentage of people registered on the AODR in 2022, with the percentage increase in population from 2021 to 2036 and the number of language communities with low English proficiency in 2022.

As part of the Inquiry the Committee has published on its webpage an interactive heatmap to show the estimated percentage of Victorians registered on the AODR by LGA.³⁵

²⁹ Brianna Elms, National Manager, Communications and Engagement, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 25. OTA attributed the 2021 anomaly to the number of people interacting with the Medicare app to obtain vaccination certificates (see Chapter 3, Section 3.4.1), as well as a digital campaign for young people and 30-minute documentary on WIN TV that aired leading up to DonateLife Week.

³⁰ DonateLife Victoria, *Submission 27*, p. 7.

³¹ Ibid.

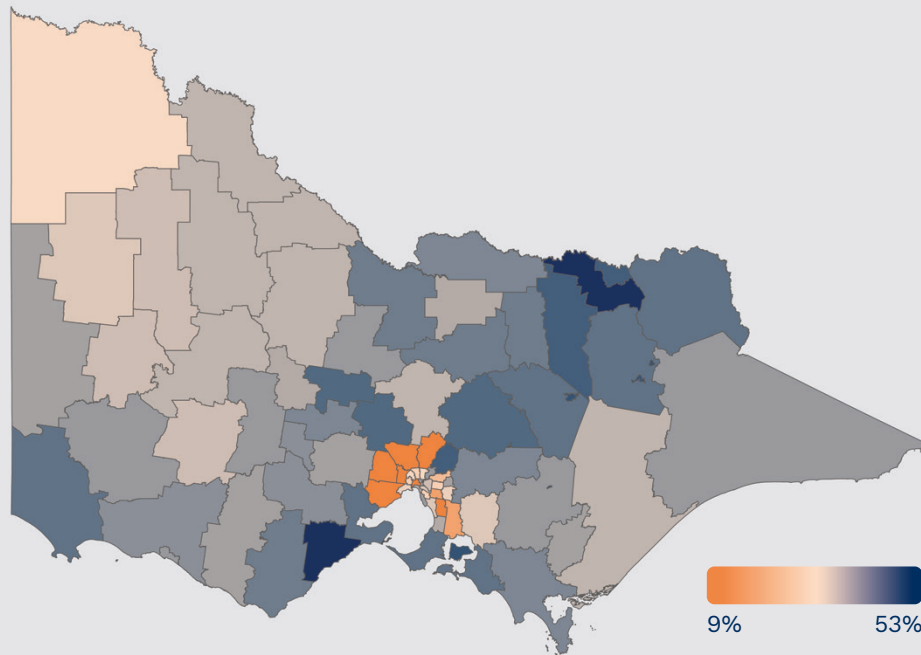
³² Organ and Tissue Authority, *Submission 31*, p. 5.

³³ Lucinda Barry, *Transcript of evidence*, p. 16.

³⁴ DonateLife Victoria, *Submission 27*, p. 7.

³⁵ See the Committee's website for an interactive heatmap that shows the estimated percentage of Victorians registered on the AODR by LGA that can be filtered by metropolitan and regional areas <parliament.vic.gov.au/organtissuedonor-reports>.

Figure 5.1: Percentage of Victorians registered on the Australian Organ Donor Register (AODR) by local government area (LGA), 2022



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

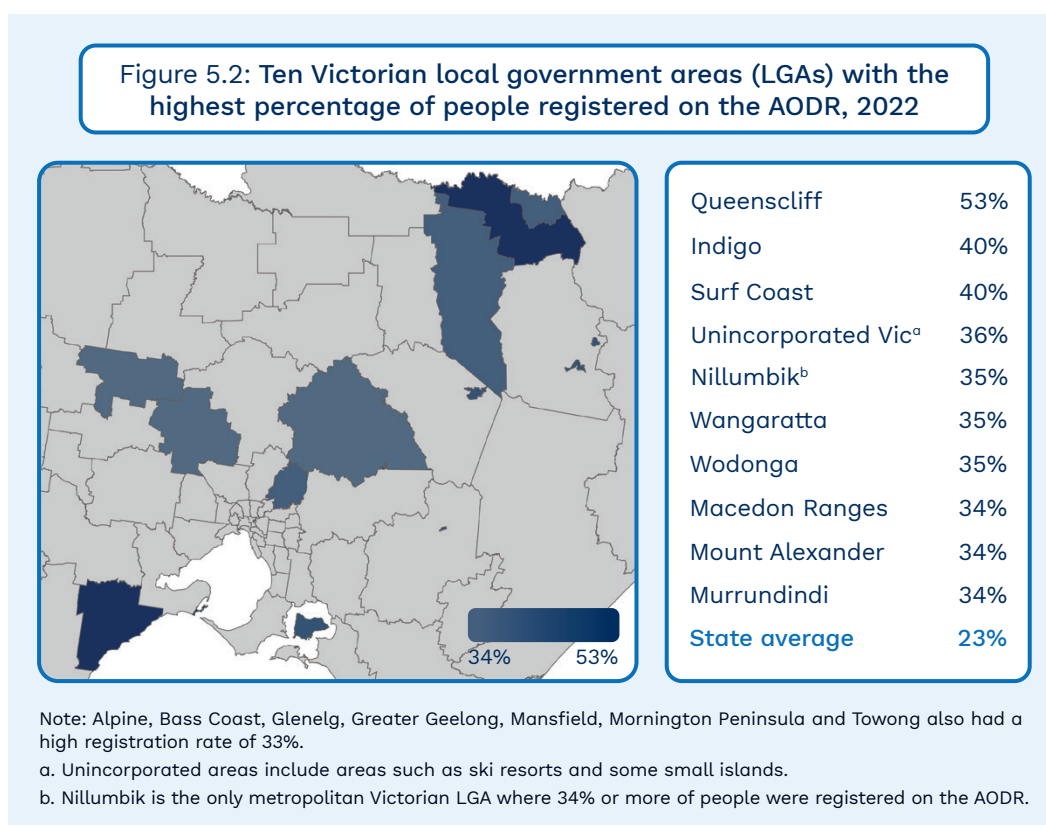
a. 50 is the metro average and the lowest throughout Victoria is 20 in Nillumbik and Warrnambool.

Source: Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to additional written questions on notice received 13 September 2023, pp. 5-7; Department of Transport and Planning, *Victoria in future: The official Victorian state government projection of population and households*, 3 October 2023, <<https://www.planning.vic.gov.au/guides-and-resources/data-and-insights/victoria-in-future>> accessed 5 December 2023 (Committee calculation); Department of Families, Fairness and Housing, *Mapping languages spoken in Victoria: Metropolitan Melbourne, 2023*, pp. 21-22 (based on 2022 census data). Number of language communities with low English proficiency per LGA relates to communities with 50 or more speakers.

In 2022, less than 20% of people were registered on the AODR in ten Victorian LGAs,³⁶ six of which (Wyndham, Hume, Melbourne, Melton, Whittlesea, Casey) are expected to see the largest population growth in metropolitan Melbourne from 2021 to 2036.³⁷ These LGAs also have a high number of language communities with low English proficiency, meaning they need resources in many different languages.³⁸

FINDING 37: In 2022, less than 20% of people were registered on the Australian Organ Donor Register in ten Victorian local government areas (LGAs), six of which (Wyndham, Hume, Melbourne, Melton, Whittlesea, Casey) are expected to see the largest population growth in metropolitan Melbourne from 2021 to 2036. These areas also have a high number of language communities with diverse language needs and low English proficiency.

Figure 5.2 shows the ten Victorian LGAs with the highest percentage of people registered on the AODR in 2022.



Source: Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to additional written questions on notice received 13 September 2023, pp. 5-7; Regional Development Victoria, Victoria's Regions, 20 October 2023, <<https://www.rdv.vic.gov.au/victorias-regions#region-listing>> accessed 21 February 2024; Department of Environment, Land, Water and Planning, *Vicmap: Product data specification*, 2021, Version 3.4, p. [21].

³⁶ Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 13 September 2023, pp. 5-7.

³⁷ Department of Transport and Planning, *Victoria in future: The official Victorian state government projection of population and households*, 3 October 2023, <<https://www.planning.vic.gov.au/guides-and-resources/data-and-insights/victoria-in-future>> accessed 5 December 2023.

³⁸ Department of Families, Fairness and Housing, *Mapping languages spoken in Victoria: Metropolitan Melbourne, 2023*, pp. 21-22.

In 2022, 34% or more of people were registered on the AODR in ten Victorian LGAs—over 10% higher than the State average. Nine of these LGAs are located in regional Victoria with Nillumbik being the only metropolitan area³⁹—and one with a small number of language communities with low English proficiency.⁴⁰

FINDING 38: In 2022, 34% or more of people were registered on the Australian Organ Donor Register in ten Victorian local government areas, nine of which are regional. This compares to a state average of 23%.

FINDING 39: Mass awareness campaigns about organ and tissue donation should use postcode data to target localities with low donor registration rates and tailor messaging based on demographic data (including age, cultural and language diversity and religious affiliation).

RECOMMENDATION 17: The Victorian Government advocate to the Australian Government for additional Organ and Tissue Authority funding to increase awareness campaigns about organ and tissue donation that use postcode data to target localities with low registration rates and tailor messaging based on demographic data.

RECOMMENDATION 18: The Victorian Government consult with and support DonateLife Victoria to undertake targeted awareness campaigns about organ and tissue donation, using Victorian registration and demographic data, and publicly report on the effectiveness of the activities undertaken.

5.2.1 Events to raise mass awareness, celebrate donors and support their families

National events, often arranged by volunteers, also help to raise mass awareness about donation. These events generally focus on telling personal stories about donation, and celebrate donors and support donor families.

Donor Families Australia organises Donor Heroes' Night yearly on 18 May which attracts a mass online response nationally and internationally.⁴¹ Since 2020 (the inaugural year) the event has experienced consistent growth through social media.⁴² Other countries like Canada and the United Kingdom (UK) are also 'really keen to

³⁹ See Figure 5.2.

⁴⁰ Department of Families, Fairness and Housing, *Mapping languages spoken in Victoria: Metropolitan Melbourne, 2023*, pp. 21–22 (based on 2022 census data). Nillumbik had 20 language communities with low English proficiency, the lowest of all metropolitan LGAs. Number of language communities with low English proficiency per LGA relates to communities with 50 or more speakers.

⁴¹ Donor Families Australia, *Submission 21*, p. 6.

⁴² Leanne Campbell, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 17; Donor Families Australia, *Donor Heroes' Night*, n.d., <<https://www.donorfamiliesaustralia.org/donor-heroes-night>> accessed 13 December 2023.

get on board, which is a wonderful message about not only recognising donors but also promoting [donation].⁴³ Donor Families Australia suggested DLV promote Donor Heroes' Night to honour donors in the community 'whilst shining a light on the importance of' donation.⁴⁴

The World Transplant Games can also 'leave a legacy of increased awareness' about donation and increase AODR registrations.⁴⁵ Most recently held in Perth in 2023, Transplant Australia explained transplant recipients contribute to the public promotion of donation by providing 'a lived experience of being a transplant recipient' and 'speak[ing] first-hand as the living proof that donation provides a second chance at life.'⁴⁶ Participants in the Games from a donor background (involved in living donation or representing the family of a donor) attend 'to better understand and validate their family's decision' and 'see recipients honouring their gift living their lives to the fullest.'⁴⁷

Publicly recognising donors and their families is important and helps raise awareness about donation.⁴⁸ The Melbourne Lions Eye Donation Service (LEDS) stated:

We also need to recognise and honour those who have donated. This can include highlighting their stories and the impact they have had on others as well as recognising their families for their generosity and support.⁴⁹

OTA explained it has a national donor recognition program and works directly with donor families to support them: 'We have a Thank You Day once a year for donors. We acknowledge publicly donation, and their many donor family stories are told through our community education and awareness program.'⁵⁰ State DonateLife agencies, including DLV, often hold a Service of Remembrance event around Thank You Day.⁵¹

DTBV's Tree of Life mural also recognises and promotes awareness of tissue donors:

The mural is a stylised tree to which leaves of different colours are attached. The tree has a range of green, yellow and red leaves reflecting the cycle of seasons and grief responses. The leaves bear the first name of each tissue donor and are placed on the Tree at the

⁴³ Leanne Campbell, *Transcript of evidence*, p. 17. See also Donor Families Australia, *Submission 21*, p. 6.

⁴⁴ Donor Families Australia, *Submission 21*, p. 6.

⁴⁵ Transplant Australia, *Submission 23*, received 18 May 2023, pp. 3-4.

⁴⁶ *Ibid.*, p. 4.

⁴⁷ *Ibid.*, pp. 3-4.

⁴⁸ Noting the importance of careful implementation of any initiatives so as to avoid being an inducement to donation, see Monash Bioethics Centre, *Submission 37*, received 1 June 2023, pp. 4-5. See also Chapters 4 and 6.

⁴⁹ Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 32. See also Robert Manning, *Submission 15*, received 6 May 2023, p. 2.

⁵⁰ Lucinda Barry, *Transcript of evidence*, p. 31.

⁵¹ Organ and Tissue Authority, *News and events*, n.d., <<https://www.donatelife.gov.au/news-events>> accessed 12 December 2023; Organ and Tissue Authority, *Victorian Service of Remembrance 2023*, n.d., <<https://www.donatelife.gov.au/news-events/events/2023/victorian-service-remembrance-2023>> accessed 12 December 2023.

end of each month. Twelve months later the Tree is full of donor leaves, reflecting the vast contribution donors and their families have made over the previous year.⁵²

Each year DTBV hosts afternoon tea to mark the ‘Annual Leaf Day’,⁵³ which Anna Gillard, whose son was a deceased tissue donor, described as a ‘really special experience’.⁵⁴

Figure 5.3: Donor Tissue Bank of Victoria’s Tree of Life mural



Source: image provided by Donor Tissue Bank of Victoria, 16 February 2024. ©Victorian Institute of Forensic Medicine 2024, reproduced with permission.

52 Donor Tissue Bank of Victoria, *Tree of Life*, n.d., <<https://dtbv.org.au/discover/tree-of-life>> accessed 12 December 2023.

53 Ibid.

54 Anna Gillard, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 21.

Leanne Campbell, a mother who consented to her son becoming a deceased donor, raised the idea of a memorial in a public garden as a ‘special place for all people involved in transplantation to come and reflect’⁵⁵ to recognise donors and their families and promote awareness and family discussion about donation.

5.3 Content of awareness and education campaigns

Inquiry participants shared ideas with the Committee about the content that could work best in awareness and education campaigns to promote donation and registrations.

5.3.1 Using personal stories

When you hear the stories and you can see the direct result of the generosity of other people it is hard not to be moved to action.⁵⁶

Several participants suggested using personal stories,⁵⁷ noting the power of lived experience of donor recipients⁵⁸ and donor families⁵⁹ who can talk about the positive impact donation can have. This includes donor families’ reflections about ‘knowing that they have done something for the good of others in a really difficult and tragic time’.⁶⁰

Young people want ‘to hear firsthand experiences of organ and tissue donation from people who are a similar age to them.’⁶¹ Brianna Elms, National Manager, Communications and Engagement at OTA emphasised that personal stories about donation and the life-saving gift of transplantation is what resonates with people:

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.⁶²

5.3.2 Overcoming myths and misconceptions

Overcoming myths and misconceptions about donation could help to stop deter potential donors from registering on the AODR and assist families to discuss and share

55 Leanne Campbell, *Submission 16*, received 7 May 2023, p. 5.

56 Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 47.

57 Zaidee’s Rainbow Foundation, *Submission 13*, received 5 May 2023, p. 4; Tony Holland, General Manager of DonateLife Victoria, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 47; Dr Brooke Huuskes, Senior Lecturer, Centre for Cardiovascular Biology and Disease Research, La Trobe University, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 57; Brianna Elms, *Transcript of evidence*, p. 22; Dr Yvette O’Brien, Intensivist, Medical Donation Specialist and Deputy Director, Intensive Care Unit, St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 53.

58 Stuart Chesneau, *Transcript of evidence*, p. 47.

59 Zaidee’s Rainbow Foundation, *Submission 13*, p. 5.

60 Dr Yvette O’Brien, *Transcript of evidence*, p. 53.

61 Dr Brooke Huuskes, *Transcript of evidence*, p. 57.

62 Brianna Elms, *Transcript of evidence*, p. 22.

their donation wishes as well as participate in donation conversations.⁶³ Awareness and education campaigns can help reduce these myths by sharing and promoting correct information about donation.

The Committee heard that many people think they are unsuitable to be a donor because they are too old or unfit, they smoke or drink too much, or they have HIV, Hepatitis B or Hepatitis C.⁶⁴ But, this is not necessarily true⁶⁵ and is a misconception that can be addressed through education or advertising. Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation at Alfred Health described to the Committee an effective advertisement run by the United States (US) equivalent of OTA that helped overcome these misconceptions:

It was an advertisement of a very crass gentleman who was a bit of a social misfit: he smoked, he drank, he abused people and then he died. Everyone was surprised that he was registered, and the campaign changed to say, 'No-one expected this, but actually he was a very giving gentleman. He gave his organs: his heart to this person, his lungs [to another] ...'⁶⁶

Inquiry participants advised that people also have misconceptions about what a body will look like after organs and tissues have been removed, suggesting people are unaware that:

- 'the body is respectfully sewed up' and 'handed back to the family' after organs and tissues have been removed⁶⁷
- '[y]ou would never know' an eye or cornea had been removed from a donor and it just 'looks like they are asleep'⁶⁸
- 'the body could still be used in an open-casket funeral'.⁶⁹

⁶³ Anna McNamara, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 19; Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 27; Department of Health, *Submission 42*, received 25 July 2023, p. 3; Stuart Chesneau, *Transcript of evidence*, p. 51; Dr Aadhil Aziz, General Practitioner, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, pp. 29–30; Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 45. Specifically for culturally diverse communities: Adel Salman, President, Islamic Council of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 31; Maryaan Essa, Bilingual and Bicultural Health Educator, Arabic, Multicultural Centre for Women's Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 65–66; Dai Nguyen, Bilingual and Bicultural Health Educator, Vietnamese, Multicultural Centre for Women's Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 67.

⁶⁴ Anna McNamara, *Transcript of evidence*, p. 19; Department of Health, *Submission 42*, p. 3.

⁶⁵ Anna McNamara, *Transcript of evidence*, p. 19.

⁶⁶ Dr Joshua Ihle, *Transcript of evidence*, p. 27. The advertisement is available at: WHATEVER, *Donate Life America Commercial about Coleman Sweeney—The World's Biggest Asshole*, video, 8 August 2016, <<https://www.youtube.com/watch?v=DVMtObX2MhM>> accessed 5 December 2023.

⁶⁷ Dr Aadhil Aziz, *Transcript of evidence*, pp. 29–30.

⁶⁸ Dr Heather Machin, Senior Project Manager, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 35; Bronwyn Cohen, *Transcript of evidence*, p. 35.

⁶⁹ Maryaan Essa, *Transcript of evidence*, p. 65.

Inquiry participants also suggested some people believe their religion does not support donation,⁷⁰ even though ‘the vast majority of religions actually support donation’.⁷¹ Ideas to help overcome this are discussed in Section 5.4.3.

5.3.3 Providing more detailed and clear information

The Committee heard about the need for awareness and education about donation to provide more detailed and clear information to:

- ensure people are making an informed decision to register
- explain the entire pathway to becoming a donor
- encourage people to talk about their donation wishes.⁷²

The 2008 National Clinical Taskforce on Organ and Tissue Donation suggested AODR registrations be sought sensitively ‘with comprehensive information available’ to enable people to ‘examine the issue and make a decision in their own time.’⁷³ It recommended ‘that possible avenues of AODR registration that would require an instantaneous decision in isolation from information about donation should not be pursued.’⁷⁴

Several inquiry participants emphasised that the donation process is not as simple as ‘just sign[ing] up and that will fix everything’.⁷⁵ In a recent La Trobe University study, young people who wanted to make an informed decision about registration advised they found it difficult to locate information and many were unaware of the importance of sharing their donation wishes with family.⁷⁶ Young people’s awareness and the La Trobe University study are discussed in Section 5.5.

Inquiry participants suggested that more detailed and clear information is needed ahead of time so that the details of donation are not a surprise when families need to make a consent decision in hospital.⁷⁷ Alfred Health advised that families, when making the decision to consent to donation, may perceive their loved one’s

⁷⁰ Adel Salman, *Transcript of evidence*, p. 31.

⁷¹ Chris Thomas, Chief Executive Officer, Transplant Australia, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 28; Organ and Tissue Authority, *Myths about donation*, n.d., <<https://www.donatelife.gov.au/all-about-donation/myths-about-donation>> accessed 8 December 2023.

⁷² Leanne Campbell, *Submission 16*, p. 2; Alfred Health, *Submission 38*, received 1 June 2023, p. 4; Stuart Chesneau, *Transcript of evidence*, p. 51; Kon Kakris, State Manager, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 23; Catholic Archdiocese of Melbourne, *Submission 19*, received 16 May 2023, p. 2 cover letter; Dr Brooke Huuskes, *Transcript of evidence*, p. 57; Graham Harrison, *Submission 25*, received 18 May 2023, p. 2; Allan Turner, Managing Director, Zaidee’s Rainbow Foundation, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 32.

⁷³ National Clinical Taskforce on Organ and Tissue Donation, *Final report: think nationally, act locally: volume 1*, Australian Government Department of Health and Ageing, 2008, p. 156.

⁷⁴ Ibid.

⁷⁵ Allan Turner, *Transcript of evidence*, p. 32.

⁷⁶ Dr Brooke Huuskes, *Transcript of evidence*, p. 57.

⁷⁷ Leanne Campbell, *Submission 16*, p. 2; Alfred Health, *Submission 38*, p. 4; Stuart Chesneau, *Transcript of evidence*, p. 51; Kon Kakris, *Transcript of evidence*, p. 23; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2 cover letter; Dr Brooke Huuskes, *Transcript of evidence*, p. 57; Graham Harrison, *Submission 25*, p. 2; Allan Turner, *Transcript of evidence*, p. 32.

‘registration as ... abstract, ill-informed, disconnected, and possibly even [a] selfish issue’. This means increasing registrations is only one part of the puzzle and ensuring donor ‘families understand and are comfortable complying with the donation pathway’ is the other.⁷⁸

Allan Turner, Managing Director of Zaidee’s Rainbow Foundation and a father who consented to his daughter becoming a deceased donor, suggested that mass education should spell out the total pathway to becoming a donor and the donation process once a person is in the intensive care unit (ICU).⁷⁹ Leanne Campbell explained:

Within our community there is a lack of knowledge and information about the organ [and tissue] donation process to be able to draw on. At the time of registering, it should be compulsory to have read some relevant information PRIOR to signing the registration form ... I wish we had this information prior, so we had some knowledge to draw on and did not feel ambushed at the time of our son’s accident.⁸⁰

The Catholic Archdiocese of Melbourne emphasised that education and awareness should put families in a position where they know what to expect and can make ‘donation decisions in an informed way prior to the pressured circumstances’ of the ICU.⁸¹ Kon Kakris, State Manager of the Royal Australian College of General Practitioners (RACGP) explained that the highly emotional and charged environment of the ICU:

... is not the right time to be having those conversations for the first time with grieving loved ones ... these conversations need to be had much, much earlier, and they need to be clear so that everybody knows and it takes the emotion away from the situation.⁸²

Opportunities following registration on the AODR to remind people to share their donation wishes with their family and link them to steps to help start family discussion about donation are discussed in Chapter 4, Section 4.2.2.

FINDING 40: People have a strong desire to make an informed decision about registering on the Australian Organ Donor Register and to understand the donation process. Awareness and education campaigns about donation should seek to include personal stories from donor recipients and donor families, as well as content to dispel myths and misconceptions about donation and encourage people to discuss donation with their family.

RECOMMENDATION 19: The Victorian Government ensure that all avenues it uses to promote organ and tissue donor registration include, wherever possible, personal stories from donor recipients and donor families, as well as content to dispel myths and misconceptions about donation and encourage people to discuss donation with their family.

⁷⁸ Alfred Health, *Submission 38*, p. 4.

⁷⁹ Allan Turner, *Transcript of evidence*, p. 32.

⁸⁰ Leanne Campbell, *Submission 16*, p. 2. Emphasis in original.

⁸¹ Catholic Archdiocese of Melbourne, *Submission 19*, p. 2 cover letter.

⁸² Kon Kakris, *Transcript of evidence*, p. 23.

5.3.4 Increasing awareness of tissue donation

While acknowledging the successes of DonateLife Week, the Donor Tissue Bank of Victoria (DTBV) raised concerns about the campaign's impact on increasing 'awareness across the board, particularly of tissue donation.'⁸³ LEDS also noted that social media can be a powerful tool to raise awareness about eye donations and their positive impact.⁸⁴ Use of social media to promote awareness and education is discussed in Section 5.6.1

While OTA's week-long digital campaign focused on tissue and eye donation ran for the second time in May 2023,⁸⁵ DTBV advocated for the messaging of all community awareness campaigns to highlight the benefits of and potential for tissue donation.⁸⁶

DTBV also drew attention to the AODR 'missing a 'T' for Tissue',⁸⁷ suggesting the register requires a name change to include the word tissue.⁸⁸ LEDS noted that when campaigning:

anytime the word 'organ' is mentioned the word 'tissue' needs to follow. There is a real misconception in just general dialogue that it is all about organs, and it is not. The fact that we do more transplants for eyes than organ[s] speaks to that, and yet we get zero attention, and that makes it very difficult in trying to then get funding to support things or even make sure donors are provided with the correct information. That narrative around organs versus organs and tissues really needs to change.⁸⁹

In this context, the Committee notes consideration should be given to campaign material, AODR registration avenues, and physical and digital cards that evidence a person's donation decision including reference to tissue wherever the word organ is used. For example, if a donor's decision is to be recorded on a driver licence it should read 'organ and tissue donor' and the Medicare app should read 'organ and tissue donation', not simply 'organ donation'.⁹⁰

FINDING 41: While many people know it is possible to become an organ donor, many are unaware they can also become a tissue donor. Donation campaign materials, Australian Organ Donor Registration avenues, and physical and digital cards (including driver licences) that evidence a person's donation decision should include reference to tissue wherever the word organ is used.

⁸³ Brendan Sullivan, *Transcript of evidence*, pp. 44–45.

⁸⁴ Melbourne Lions Eye Donation Service, *Submission 18*, received 12 May 2023, p. 2.

⁸⁵ Organ and Tissue Authority, *Annual report 2022–23*, p. 37; Organ and Tissue Authority, *We're talking eye and tissue donation*, 8 May 2023, <<https://www.donatelife.gov.au/news-events/news/2023/were-talking-eye-and-tissue-donation>> accessed 4 December 2023. The campaign's reach increased from 2022 to 2023 by 83.3% on Facebook (to reach 30,436 views) and by 58% on Instagram (to reach 20,796 views).

⁸⁶ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 13, 17.

⁸⁷ Brendan Sullivan, *Transcript of evidence*, p. 39.

⁸⁸ *Ibid.*, p. 44.

⁸⁹ Dr Heather Machin, *Transcript of evidence*, p. 42.

⁹⁰ See Chapter 3, Figures 3.1 to 3.5 for example images that reference 'organ' not 'tissue'.

RECOMMENDATION 20: The Victorian Government consult with and support DonateLife Victoria to:

- include information about tissue donation and its importance in all donation awareness and campaign materials
- advocate to the Organ and Tissue Authority to increase its focus on tissue donation awareness, including by scoping the potential to add tissue to the name of the Australian Organ Donor Register.

5.4 Engaging different communities

The Committee heard from a variety of inquiry participants that respectful engagement with different communities about donation requires tailored approaches based on specific factors, such as culture or religion.

5.4.1 Multicultural and religious communities

Adel Salman, President of the Islamic Council of Victoria (ICV) explained there was a general perception that donating or registering to donate means the body of the deceased will somehow be disrespected. On matters like this, Adel Salman advised that most Muslims (practising or cultural) will seek the opinion of scholars or imams who have ‘very clearly’ stated it is ‘permissible in Islam to donate’ organs and tissue to save and improve lives.⁹¹

The Catholic Archdiocese of Melbourne also expressed strong support for donation ‘as an act of charity and solidarity’,⁹² emphasising that ‘[c]onsent to donation is an essential part of respecting the person who has died’.⁹³

The Multicultural Centre for Women’s Health (MCWH) received OTA grant funding to produce in-language videos and conduct face-to-face in-language education sessions on donation in 2018 (Case Study 5.1).⁹⁴ Three bilingual and bicultural educators who helped deliver the in-language education sessions for people from culturally and linguistically diverse (CALD) backgrounds provided evidence to the Committee.

They identified some barriers to donation in multicultural communities include:

- in some Asian cultures intergenerational conversations can be hard because older generations may believe that by donating, a part of the body will be missing in the next life
- there is a concept in Buddhism that ‘the organs need to stay there overnight, they cannot be removed, otherwise the soul will be damaged’

⁹¹ Adel Salman, *Transcript of evidence*, p. 60.

⁹² Catholic Archdiocese of Melbourne, *Submission 19*, p. 1 cover letter.

⁹³ *Ibid.*, p. 3 cover letter.

⁹⁴ Maryaan Essa, *Transcript of evidence*, p. 65.

- language barriers may prevent registration because people do not understand the process
- donation is not common in Arab countries so there may be little understanding about donation and misconceptions remain.⁹⁵

Case Study 5.1 Multicultural Centre for Women's Health, *Your contribution saves other lives* project, 2018

Your contribution saves other lives aimed to help people from CALD backgrounds and their families make informed decisions on donation and transplantation. The project produced one-page information fact sheets and short videos in Arabic, Chinese and Vietnamese, featuring bilingual health educators talking about:

- why it is important to become a donor and to discuss this with your family
- how to register.

These were publicly accessible on MCWH's website, social media and YouTube.

Nine in-language education sessions were also delivered to 171 women from Arabic, Chinese and Vietnamese backgrounds. The sessions were evaluated and:

Overall, there was a lot of expressed interest in the topic, with participants having little previous knowledge about organ and tissue donation. They were reassured that the body could still be used in an open-casket funeral and that so many people could potentially benefit from one donation. There were concerns about whether money changed hands in the process, and many did not realise that the family was consulted, after death, about their wishes. People would consider organ donation after the sessions and ... [having] the facts and the information about the process. Many women also said they would now go back to their families and discuss the issue.

Not knowing how to register as a donor was a barrier and hearing real-life stories was considered an enabler. At least 13 people committed to register as donors from the sessions. MCWH shared the following quotes from women who attended:

After attending this session, I will consider organ donation as it could save many lives.

I will register to be a donor as long as my organs are still useful for other people as I understand it's important after today's session.

In this session, I have received valuable information about tissue and organ donation, its effect on other people[s] live[s], the urgent need of it, and way to register online as an organ donor.

(Continued)

⁹⁵ Dai Nguyen, *Transcript of evidence*, pp. 66–67; Maryaana Essa, *Transcript of evidence*, p. 67.

Case Study 5.1 Continued

This session has changed my attitude regarding organ donation. Giving lives to people who need organ transplant is a very humanitarian action and a noble thing to do.

MCWH suggested that the outcomes of the sessions could be improved by including younger family members. Ensuring all family members have the same, correct information about donation will assist families to have effective conversations about their donation wishes.

Source: Maryaan Essa, Bilingual and Bicultural Health Educator, Arabic; Dai Nguyen, Bilingual and Bicultural Health Educator, Vietnamese; Hanh Thi Pham, Bilingual and Bicultural Health Educator, Vietnamese, Multicultural Centre for Women's Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*.

Addressing these challenges requires a targeted approach. The Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing (ECCV Committee) stressed that '[n]ot all cultures are comfortable talking about death, dying and donation ... There are many differences between multicultural communities. One approach will not fit all communities.'⁹⁶

FINDING 42: There are many differences between Victoria's multicultural and religious communities. One approach to raising awareness and education about organ and tissue donation and how to register on the Australian Organ Donor Register will not fit all communities.

FINDING 43: Awareness and education about organ and tissue donation should target and include all generations of families from multicultural and faith-based communities to assist them to have effective discussion about donation.

5.4.2 First Nations communities

As noted in Chapter 4, the Committee did not obtain evidence about donation experiences from Victorian First Nations families. However, several Central Australia Health Service staff spoke about a recent project in the Northern Territory that engaged Aboriginal Liaison Officers (ALOs) in focus groups to discuss donation. The ALOs involved in the focus groups stressed the importance of listening to First Nations peoples and understanding that their path to donation will be different. For example, the Committee was advised that a far northern Western Australia

⁹⁶ Notes from Chair and Deputy Chair meeting with Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing, 23 August 2023, p. 1.

research project found that the idea of returning to country and being buried whole is an important concept for those First Nations communities.⁹⁷

Dr Paul Secombe, Senior Specialist Clinician with the Central Australia Health Service observed that ‘education forms the cornerstone of everything that needs to happen going forward.’⁹⁸ It needs to ‘occur at a community level ... be led by community members and ... be culturally and linguistically appropriate.’⁹⁹ Dr Secombe identified a strength of the recent project was that it truly inserted ‘an Aboriginal voice into the process of improving health care’ and this framework could be ‘reimplemented or re-used almost anywhere else if the right people are there.’¹⁰⁰

Since conducting the focus groups, Alice Springs Hospital received funding from OTA to produce a local education resource: an animated video project driven and scripted by ALOs, featuring their voices. The video is for use in the community to explain donation so it is not raised for the first time ‘at the bedside of a loved family member who is at or past end of life.’¹⁰¹ Justine Swan-Castine, Acting Leader of the Aboriginal Partnership and Strategy Unit at Alice Springs Hospital explained:

... a lot of the time having that conversation in the hospital setting ... just makes it really uncomfortable. But if we can get that done prior and they come into the hospital, having those education sessions or even that conversation at home, at the clinic, at community centres, out bush, it just makes it a lot easier by the time they get to that point where you want to be asking, ‘Have you heard about this, being an organ donor?’ And then they are like, ‘Oh, yes, actually I’ve seen something on TV at home about that.’ It makes [it] a lot easier, I think ...¹⁰²

OTA established a DonatLife First Nations Engagement Group in 2021 to raise awareness, knowledge and support for organ and tissue donation across First Nations populations on an ongoing basis.¹⁰³ Brianna Elms of OTA stated ‘First Nations are an integral part of our strategy and an identified target audience group’, administering grants to partners who deliver messaging around registration and donation to First Nations audiences.¹⁰⁴ Brianna Elms stated it uses a ‘partnership approach’ by working ‘with organisations who are much better placed or much more local’ than OTA to achieve outcomes.¹⁰⁵

97 Dr Paul Secombe, Senior Specialist Clinician, Intensive Care Unit, Central Australia Health Service, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 4.

98 *Ibid.*, p. 3.

99 *Ibid.*, p. 5.

100 *Ibid.*

101 *Ibid.*

102 Justine Swan-Castine, Acting Leader, Aboriginal Partnership and Strategy Unit, Alice Springs Hospital, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 11.

103 Organ and Tissue Authority, *Annual report 2022–23*, pp. 23–24.

104 Brianna Elms, *Transcript of evidence*, p. 18.

105 *Ibid.*

OTA has a partnership with Tonic Health Media,¹⁰⁶ which in 2022 ‘delivered TV broadcast messaging in more than 200 Aboriginal Community Controlled Health Centres.’¹⁰⁷ OTA advised mass media activities are ineffective at promoting AODR registration for First Nations audiences, and effective messaging requires an explanation of ‘that end-to-end story’ about healthcare and donation, ‘all the way through to the benefits of transplantation’.¹⁰⁸

In Victoria, DLV has two representatives on OTA’s First Nations Engagement Group.¹⁰⁹ OTA has also engaged ABSTARR Consulting ‘to perform a cultural needs assessment and gap analysis of OTA and the DonateLife Network and provide advice on how to improve cultural safety.’¹¹⁰ Tony Holland, General Manager of DLV advised:

One of the things that Abstarr is going to do with us is try and find the best collaborations that we can, because we need to do this in partnership. We need to bring the right people to the table and have the right conversations. It is certainly not through lack of trying; it is just about understanding the right approach to take and the right groups to approach. So it is not that nothing has been done, it is just it is a respectful and slow process.¹¹¹

DLV recognised the importance of building collaborative and consultative relationships with the right community groups. But DLV noted current resourcing limitations and a lack of staff or volunteers in regional areas have prevented the formation of these relationships with First Nations health groups in regional Victoria.¹¹²

FINDING 44: Building collaborative and consultative relationships with Victorian First Nations communities and Elders about organ and tissue donation is essential to ensure that community awareness about registration on the Australian Organ Donor Register and donation processes increases and is culturally appropriate.

5.4.3 Ways to address the challenges of engaging with different communities

Inquiry participants shared ideas to improve engagement with different communities in Victoria about donation. Adel Salman from ICV described that by learning from the COVID-19 pandemic model for sharing public health information, communications

¹⁰⁶ Ibid.

¹⁰⁷ Organ and Tissue Authority, *Annual report 2022–23*, p. 23. Tonic Health Media was ‘[f]ounded by doctors with the goal of minimising time pressure placed on General Practice and improving health literacy for all Australians’, see Tonic Media Network, *Our network*, n.d., <<https://www.tonicmedianetwork.com.au/our-network>> accessed 11 December 2023. The Tonic Media Network ‘is the largest national digital OOH [out of home] health network, broadcasting carefully curated video, audio, and captioned content that engages viewers with health, wellbeing, and lifestyle information’, see Tonic Media Network, *What we do*, n.d., <<https://www.tonicmedianetwork.com.au/what-we-do>> accessed 11 December 2023.

¹⁰⁸ Brianna Elms, *Transcript of evidence*, p. 18.

¹⁰⁹ Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 6.

¹¹⁰ Organ and Tissue Authority, *Annual report 2022–23*, p. 23.

¹¹¹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 7.

¹¹² Ibid.; Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 7.

about donation should involve respected cultural or religious leaders, highlight the importance of donation and share accurate information. Providing a forum to recognise concerns or misinformation and discuss them openly and sensitively is also important.¹¹³

The ECCV Committee stressed the importance of building trusted, reciprocal relationships in multicultural communities by ‘spending time, being genuine, having a presence and building personal connection’ before sharing information about donation.¹¹⁴ Community leaders are a starting point to build these relationships, as well as:

- in-person attendance at community events, visits to local groups or partnerships with local councils, with the involvement of bicultural health workers or translators to assist with communication if needed
- talking directly with people and sharing facts or stories, noting this often has a greater impact than one-way sharing of translated resources.¹¹⁵

These principles should apply to any culturally diverse engagement about donation. DH identified the following as key opportunities to improve donation rates in Victoria:

- ‘providing culturally/religiously appropriate education and awareness-raising campaigns to targeted cultural/religious groups’¹¹⁶
- ‘targeted engagement with ... houses of worship and various segments of the community to encourage individuals to register’.¹¹⁷

For example, the Catholic Archdiocese of Melbourne’s submission indicated a preparedness ‘to co-operate with Government on any public education program’ that seeks to improve donor registration rates in Victoria.¹¹⁸

In a submission, Transplant Australia recommended undertaking a three-year Indigenous Ambassador project to:

enable Indigenous Australians with lived experience of transplantation and donation to share their stories with their own communities while advocating for transplant navigators to help those waiting for a transplant.¹¹⁹

DH acknowledged the benefits of having cultural ambassadors to champion donation but indicated they do not exist.¹²⁰

¹¹³ Adel Salman, *Transcript of evidence*, p. 61.

¹¹⁴ Notes from Chair and Deputy Chair meeting with Ethnic Communities’ Council of Victoria Policy Advisory Committee on Health and Wellbeing, p. 2.

¹¹⁵ Ibid.

¹¹⁶ Department of Health, *Submission 42*, p. 3.

¹¹⁷ Ibid., p. 2.

¹¹⁸ Catholic Archdiocese of Melbourne, *Submission 19*, p. 2.

¹¹⁹ Transplant Australia, *Submission 23*, p. 13.

¹²⁰ Louise McKinlay, Acting Deputy Secretary, Commissioning and System Improvement, Department of Health, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, p. 3.

Inquiry participants also suggested that young people in multicultural communities have a particular role in talking about donation and sharing donation stories.¹²¹ The ECCV Committee noted the power of young people to influence change and be leaders in their communities. While talking to older generations about donation may be challenging, young people can ‘encourage multigenerational discussions with family and community.’¹²² The ECCV Committee referred to a March 2023 report by the Centre for Multicultural Youth that observed that during the COVID-19 pandemic multicultural young people were ‘invisible leaders’ who ‘served as bridges to information and support, playing proactive brokering and support roles to ensure that their families and communities had access to help and resources.’¹²³

Representatives from the UK’s National Health Service (NHS) Blood and Transplant emphasised the importance for education campaigns to engage with digitally disadvantaged and diverse groups, for example, through mail drops and easy-read and translated resources.¹²⁴ Many of OTA’s resources, including videos, are available in different languages online. But Deaf Victoria advised that OTA’s Auslan videos are difficult to find.¹²⁵ To ensure easy access to the videos, Philip Waters, General Manager of Deaf Victoria suggested OTA include a link on the landing page to show that resources are available in other languages, including Auslan. This is important to encourage registrations and provide education about donation.¹²⁶

DLV’s volunteers also play an ‘integral’ role in Victoria to help raise awareness of donation at activities and events in different communities.¹²⁷ DLV identified a need for more volunteers, particularly from non-English-speaking backgrounds, to work in their communities.¹²⁸

FINDING 45: Co-designed and tailored community engagement projects between diverse community leaders and organisations and the Victorian Government, modelled on those established during the COVID-19 pandemic to share public health information, would provide ideal opportunities to share information and talk about organ and tissue donation with diverse communities.

121 Chris Thomas, *Transcript of evidence*, p. 28. Notes from Chair and Deputy Chair meeting with Ethnic Communities’ Council of Victoria Policy Advisory Committee on Health and Wellbeing, p. 2.

122 Notes from Chair and Deputy Chair meeting with Ethnic Communities’ Council of Victoria Policy Advisory Committee on Health and Wellbeing, p. 2.

123 Ibid.; Centre for Multicultural Youth, *Invisible leaders: How multicultural young people served as bridges and brokers during the COVID-19 pandemic in Victoria*, 23 March 2023, <<https://www.cmy.net.au/resource/invisible-leaders>> accessed 9 November 2023.

124 Phil Walton, Project Lead, Deemed Consent Legislation, National Health Service, Blood and Transplant, United Kingdom, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 45.

125 Philip Waters, General Manager, Deaf Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 3. See also Organ and Tissue Authority, Education resources, n.d., <<https://www.donatelife.gov.au/education-resources>> accessed 11 December 2023.

126 Philip Waters, *Transcript of evidence*, p. 32.

127 Organ and Tissue Authority, *DonateLife Victoria*, n.d., <<https://www.donatelife.gov.au/find-your-local-donatelife-agency/donatelife-victoria>> accessed 13 December 2023.

128 Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 7.

RECOMMENDATION 21: The Victorian Government consult with community leaders, Elders and organisations to co-design and tailor engagement projects to provide opportunities to share information and talk about organ and tissue donation, including:

- the production of resources to engage with digitally disadvantaged Victorians through mail drops as well as easy-read and translated resources
- the provision of translated resources in different formats to promote registration and family discussion when Victorians engage with government touchpoints, including through driver licence applications and renewals
- programs to support intergenerational discussion in families from multicultural and faith-based communities
- a First Nations organ and tissue donation ambassador program.

5.5 Engaging young people

Enhancing young people's motivation to register and share their donation wishes with family was a recurring theme in the Inquiry.¹²⁹

Young people are under-represented on the AODR (10% registration rate for people aged 16 to 25 in 2022) despite most supporting donation.¹³⁰ In 2022, the Australian Government's Behavioural Economics Team (BETA) investigated the motivations and barriers for young adults to register on the AODR.¹³¹ BETA's focus group and survey results suggested 'many young adults want to donate but just haven't gotten around to it'.¹³² This is called the intention-action gap. The BETA report advised that OTA has used the results of the project to inform its national community engagement program and campaign work.¹³³

Researchers Dr Brooke Huuskes and Dr Stacey Hokke of La Trobe University received grant funding from OTA in 2022 to better understand what young people think and feel about donation.¹³⁴ Their findings indicate the main issues affecting registrations among young people are a lack of awareness and understanding of donation:

Young people expressed a strong desire to make an informed decision [about registering on the AODR] yet felt there was a lack of information available to them which was the main barrier to them signing up.¹³⁵

¹²⁹ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 13; Name withheld, *Submission 9*, received 7 April 2023, p. 7; Victorian and Tasmanian Transplantation Committee, *Submission 39*, received 2 June 2023, p. 2; Alfred Health, *Submission 38*, p. 9; Donor Mate, *Submission 36*, received 31 May 2023, pp. 2–3.

¹³⁰ Dr Brooke Huuskes, *Transcript of evidence*, p. 57.

¹³¹ Department of Prime Minister and Cabinet, *Improving organ donor registration among young adults*, 23 February 2023, <<https://www.pmc.gov.au/news/improving-organ-donor-registration-among-young-adults>> accessed 6 December 2023.

¹³² Ibid.

¹³³ Department of Prime Minister and Cabinet, *Improving organ donor registration among young adults*, report prepared by Behavioural Economics Team of the Australian Government, 2022, pp. 4, 14.

¹³⁴ Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, received 19 May 2023, p. 1.

¹³⁵ Ibid.

Cool Australia, an organisation developing educational resources for schools, also received OTA grant funding in 2021 to help educate young people on the topic of donation and encourage them to join the AODR.¹³⁶ Cool Australia used the funding to consult a child and adolescent psychologist and ‘create nine lessons covering years 9 and 10—English, health and physical education, civics, science and work studies.’¹³⁷ Representatives from Cool Australia explained the importance of co-designing education resources on sensitive topics with experts to ensure they are ‘really trusted and high quality for teachers.’¹³⁸ Cool Australia suggested that educators should:

Use a broad range of activities that will meet young people where they are at around [donation] ... some will be ready to register and others will never have considered this. Use a mix of awareness-building, education, opportunities for discussion and consideration of the issues, encouragement, empowering and prompting young people to act on their intention and facilitating registration.¹³⁹

When it comes to promoting family discussion about donation, DLV suggested ‘incorporating it into some sort of transition from teenage to adulthood’ stating ‘if there was going to be money spent ... [targeting young people] would probably be where the best bang for buck would be.’¹⁴⁰ Dr Bernadette Hickey from St Vincent’s Hospital Melbourne’s Organ and Tissue Donation Team shared her insights regarding family consent decisions where a potential young donor is identified:

... one of the difficulties is that young people often are quite altruistic and they register to be a donor, but they do not carry their family with them. And although the registered decision to donate is often the thing that is most influential in the family discussion, if the family have substantial objections, then that can lead to a registered donor but the family not providing consent.¹⁴¹

OTA advised that South Australia’s (SA) registration rate among young people is higher than other states.¹⁴² OTA spoke of SA’s P.A.R.T.Y Program for 15- and 16-year-old school students which it believes leads to younger South Australians making an informed decision about donation when they get their driver licence.¹⁴³ Students in SA are provided scenario-based education over two days on things like driving, drugs and alcohol. One scenario involves the mother of a boy who became a donor talking about donation, along with a presentation from the state medical director of DonateLife SA. It means young people are educated about donation prior to getting a driver licence.¹⁴⁴

¹³⁶ Thea Stinear, Chief Executive Officer, Cool Australia, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 54.

¹³⁷ Naomi Nicholas, Head of Community Engagement, Cool Australia, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 54; Cool Australia, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 12 July 2023, Appendix 1, p. 1.

¹³⁸ Thea Stinear, *Transcript of evidence*, p. 53; Naomi Nicholas, *Transcript of evidence*, p. 54.

¹³⁹ Cool Australia, response to questions on notice, Appendix 1, p. 2.

¹⁴⁰ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 10.

¹⁴¹ Dr Bernadette Hickey, *Transcript of evidence*, p. 48.

¹⁴² Brianna Elms, *Transcript of evidence*, p. 20.

¹⁴³ Ibid.

¹⁴⁴ Lucinda Barry, *Transcript of evidence*, p. 20.

In 2023, SA's P.A.R.T.Y Program was offered at three metropolitan and three regional locations.¹⁴⁵ DLV described how the program provides a base level of education and encourages 'those kids [to] go home and talk to their parents about it.'¹⁴⁶ Transplant Australia also recommended introducing 'a national education program for year 10–12 students as they move into the driving licence age.'¹⁴⁷

OTA advised that DonateLife Queensland (DLQ) 'runs their own in-schools education', attending assemblies, and health or other classes. DLQ 'use their nursing cohort' to run the sessions and often 'take recipients with them to share that kind of personal story.'¹⁴⁸ OTA's *Annual report 2018–19* references a Queensland 'Community Champions program' that ran in 2017 involving champions 'assisting with talks at schools, workplaces and various clubs' as well as 'manning stalls and speaking with media outlets'.¹⁴⁹ The *Annual report 2018–19* advised DLQ had trained about 70 champions and that their assistance 'contributed to a 20% increase in [AODR] numbers in Queensland across 2018.'¹⁵⁰

FINDING 46: Many young people support the idea of organ and tissue donation but across Australia only 10% of people aged 16 to 25 have registered a donation decision on the Australian Organ Donor Register. Providing donation-related awareness-building, education and discussion opportunities for younger Victorians will help them to make an informed decision about donation and share this with their family.

RECOMMENDATION 22: The Victorian Government develop and deliver a program in conjunction with DonateLife Victoria and the Donor Tissue Bank of Victoria targeted at 15- and 16-year-olds to increase knowledge about organ and tissue donation to enable informed decision making and promote effective family discussions ahead of becoming eligible for driver licences, and publicly report on the outcomes achieved by the program.

5.5.1 Incorporating donation into formal education channels

Several inquiry participants suggested donation be included in the Victorian school curriculum,¹⁵¹ noting this could:

- normalise discussion about donation for young people and encourage them to discuss donation with family¹⁵²

¹⁴⁵ P.A.R.T.Y Program SA, *Register*, n.d., <<https://partyprograms.org/register>> accessed 8 December 2023.

¹⁴⁶ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 10.

¹⁴⁷ Transplant Australia, *Submission 23*, p. 13.

¹⁴⁸ Brianna Elms, *Transcript of evidence*, p. 20.

¹⁴⁹ Organ and Tissue Authority, *Annual report 2018–19*, 2019, p. 50.

¹⁵⁰ *Ibid.*

¹⁵¹ See, for example, Melbourne Lions Eye Donation Service, *Submission 18*, p. 2; DonateLife Victoria, *Submission 27*, p. 7; Dr Stacey Hokke, Research Fellow, Judith Lumley Centre, School of Nursing and Midwifery, La Trobe University, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 57.

¹⁵² Philip Waters, *Transcript of evidence*, p. 36.

- increase familiarity with donation from a young age¹⁵³
- increase awareness and understanding about donation and the likelihood of registering (reducing the intention-action gap)¹⁵⁴
- drive cultural change and the acceptance of donation¹⁵⁵
- help raise awareness about donation for school students and young people from diverse backgrounds, for example, deaf and hard of hearing¹⁵⁶ or First Nations.¹⁵⁷

DH advised that it connects with the Victorian Department of Education (DET) in relation to donation awareness in schools but has not gone as far as changing the curriculum. DH expressed a commitment to do more given ‘educating young people around the opportunities and raising that awareness with families is really important’¹⁵⁸ and noting its ‘whole-of-government approach’ to ‘maximise donation opportunities.’¹⁵⁹

While DET helps with how to teach, the Victorian Curriculum and Assessment Authority sets the curriculum for the State. Victoria’s curriculum includes ‘Discussing ethical issues that arise from organ transplantation’ as a non-mandated elaboration for Science Understanding.¹⁶⁰ This means it is as an advisory example ‘to provide guidance on how the curriculum may be transformed into a classroom activity or learning opportunity’ and schools have autonomy to choose which examples they use.¹⁶¹ Thea Stinear, CEO of Cool Australia explained:

schools and teachers have autonomy to teach topics that they deem appropriate for their children. The [Australian] government sets the syllabus and the state interprets that syllabus for the teachers to then use, so our resources are not mandated by any government, necessarily, but teachers are out there googling every day, looking for fresh ways to reinvigorate their classrooms and connect with their kids with interesting topics.¹⁶²

NHS Blood and Transplant advised when England moved to an opt-out system it was able to incorporate donation into more education, but that some schools ‘take to it

¹⁵³ DonateLife Victoria, *Submission 27*, p. 7.

¹⁵⁴ Dr Brooke Huuskes, *Transcript of evidence*, p. 58.

¹⁵⁵ Bronwyn Cohen, *Transcript of evidence*, p. 31.

¹⁵⁶ Philip Waters, *Transcript of evidence*, p. 36.

¹⁵⁷ Christine Spencer, Aboriginal Liaison Officer, Central Australia Health Service, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 8; Dr Rosalind Beadle, Research Fellow, College of Medicine and Public Health, Flinders University, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, pp. 9, 11.

¹⁵⁸ Louise McKinlay, *Transcript of evidence*, p. 7.

¹⁵⁹ *Ibid.*, p. 3.

¹⁶⁰ Victorian Curriculum and Assessment Authority, Science, n.d., <<https://victoriancurriculum.vcaa.vic.edu.au/science/curriculum/f-10#level=7-8>> accessed 14 November 2023, see levels 7 and 8; Victorian Curriculum and Assessment Authority, *Overview: Navigation and terminology*, n.d. <<https://victoriancurriculum.vcaa.vic.edu.au/overview/navigation-and-terminology>> accessed 14 November 2023, see Content Descriptions, VCSU090.

¹⁶¹ Victorian Curriculum and Assessment Authority, *Science*; Victorian Curriculum and Assessment Authority, *Overview*.

¹⁶² Thea Stinear, *Transcript of evidence*, p. 55.

really well' and others do not.¹⁶³ Even though registration is not required under the opt-out system, NHS Blood and Transplant highlighted education campaigns about donation generally in schools is important:

... 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 organ donors. We also are aware that actually decision-makers in an organ donation situation are not necessarily the peers of a young person, they are the older people in the room—their parents and others—so it is important to have, we think, that mindset of what we are trying to achieve with our education.¹⁶⁴

Cool Australia suggested that opportunities exist for whole-school engagement around the topic during DonateLife Week. Thea Stinear shared that teachers and schools love to support campaigns, such as R U OK? Day or Tree Day—proposing that focusing marketing efforts towards schools around DonateLife Week may present an opportunity to increase awareness.¹⁶⁵ Allan Turner discussed the impact that Zaidee's rainbow school days have spreading awareness about donation in kindergartens and primary schools, stating 'these kids ... trot off home in all the excitement about the rainbow day' and they say to their parents 'we had a great day today, we all got dressed up in rainbow gear, we had rainbow cake and we spoke about Zaidee's story.'¹⁶⁶

Dr Hokke and LEDS considered donation information could be included in TAFEs, university and student associations or unions.¹⁶⁷ Philip Waters from Deaf Victoria, for example, registered as a donor at university when he signed up to the student union.¹⁶⁸ Dr Huuskes and Dr Hokke also spoke about La Trobe University's interest in disseminating information about blood donation from Lifeblood through their social media platforms as a positive social good. They suggested that universities could potentially collaborate with OTA and DLV in a similar way to share information about organ and tissue donation.¹⁶⁹

¹⁶³ Dr Dale Gardiner, Associate Medical Director, Deceased Organ Donation, National Health Service, Blood and Transplant, United Kingdom, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 47; Professor Derek Manas, Medical Director, Organ and Tissue Donation and Transplantation, National Health Service, Blood and Transplant, United Kingdom, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 48. NHS is currently evaluating the 'take-up' and outcomes of donation education in schools and whether children then discuss donation with their families.

¹⁶⁴ Dr Dale Gardiner, *Transcript of evidence*, p. 47.

¹⁶⁵ Thea Stinear, *Transcript of evidence*, p. 54.

¹⁶⁶ Allan Turner, *Transcript of evidence*, p. 34. Zaidee's rainbow shoelaces are symbols to promote awareness of donation. Zaidee's Rainbow Foundation invites schools to support a 'Zaidee's day' where everyone can wear a pair of rainbow shoelaces and the Foundation shares Zaidee's story to promote awareness and conversation about donation, see Zaidee's Rainbow Foundation, *Zaidee's Rainbow Foundation*, n.d., <<https://www.zaidee.org>> accessed 8 December 2023.

¹⁶⁷ Dr Stacey Hokke, *Transcript of evidence*, p. 63; Melbourne Lions Eye Donation Service, *Submission 18*, pp. 1–2.

¹⁶⁸ Philip Waters, *Transcript of evidence*, p. 34.

¹⁶⁹ Dr Stacey Hokke, *Transcript of evidence*, p. 65.

FINDING 47: Incorporating organ and tissue donation into formal education channels would help raise young people’s awareness and understanding about donation (including those from diverse backgrounds) and could encourage, empower and prompt young people to act on their intention and register on the Australian Organ Donor Register and share this with their family.

RECOMMENDATION 23: The Victorian Government include information about organ and tissue donation in the primary and secondary school curriculum.

RECOMMENDATION 24: The Victorian Department of Education promote awareness and family discussion about organ and tissue donation to Victorian schools during DonateLife Week, as well as consider how schools can use other touchpoints to share information about donation, such as via social media.

5.6 Other strategies to increase and improve awareness and education

Other strategies that were raised by inquiry participants to increase and improve organ and tissue donation awareness and promote registration are discussed below.

5.6.1 Media and social media

A 2018 federal review of the organ donation, retrieval and transplantation system recommended: ‘The strategies to improve the AODR registrations should be broadened to include links to social media and other entry portals’ to ‘enable greater visibility and accessibility of the AODR.’¹⁷⁰ While improvements have been made since 2018, inquiry participants, including the Victorian DH, identified media and advertising (on TV and radio) and social media as opportunities to improve donation rates.¹⁷¹ For example, donation and registration could be promoted through posters, billboards and pamphlets comprising a brief message, engaging headlines and QR codes to access further information and start the registration process, similar to image-based posts on social media.¹⁷²

The ‘power of video-based communication strategies in influencing public opinion and action’ was raised by pixel42, a video production business involved with projects to increase donation awareness and registration in Victoria (Case Study 5.2).¹⁷³

¹⁷⁰ EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, p. [105].

¹⁷¹ Department of Health, *Submission 42*, p. 3; ANZICS Death and Organ Donation Committee, *Submission 41*, received 19 June 2023, p. 6; Emma Buchanan, *Submission 3*, received 31 March 2023, p. 1; Leah Macey, *Submission 6*, received 5 April 2023, p. 1.

¹⁷² Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, pp. 15–18.

¹⁷³ pixel42, *Submission 48*, received 25 October 2023, p. 1.

As donation is ‘a profoundly human and deeply personal decision’, pixel42 suggested that a connection with stories, voices and faces will help people understand donation and encourage action. pixel42 suggested video is a powerful medium to convey this:

Leveraging the unique strengths of video in awareness and communication campaigns is a compelling approach. It empowers DonateLife to support Victorians more effectively, providing not just accurate and accessible information but also a deeper, more human understanding of organ and tissue donation. This blend of education, empathy, and action makes video a vital tool in increasing organ and tissue donor registrations, conversations and consent.¹⁷⁴

Case Study 5.2 pixel42, *The Call*, 2021

In 2021, pixel42 co-produced *The Call*—a documentary with DLV, OTA and WIN Network. It aimed to increase regional Victorians’ understanding of donation.

The Call brought together the experiences of donor families, organ recipients, those waiting for a life-saving transplant and the specialist teams who make donation possible. It included stories about the many sides of donation and transplantation and asked viewers to talk about donation with their family and register. *The Call* was broadcast in May 2021 and was supported by TV commercials before and after the broadcast. To support the cause, WIN Network also broadcast community service announcements in June 2021.

To assess the broadcast’s outcomes, AODR registrations in the target regional markets and metropolitan markets not exposed to the campaign were compared, showing:

that registrations increased in regional areas during the broadcast period, while they remained steady in metropolitan areas. Google Trends data also showed a significant increase in online activity relating to organ and tissue donation, and DonateLife, especially in the minutes following broadcast.

Source: pixel 42, *Submission 42*, received 25 October 2023, p. 13; OTA, *The Call brings organ and tissue donation to TV audiences*, 24 May 2021, <<https://www.donatelife.gov.au/news-events/news/2021/call-brings-organ-and-tissue-donation-tv-audiences>> accessed 20 November 2023.

Dr Hokke suggested that social media could be more effective by responding to the changing ways young people and families communicate. Young people could share screenshots of their registration or advertisements on social media with their networks and families to initiate conversations.¹⁷⁵ Proposals for promoting donation and registration raised in the La Trobe University study included using:

- YouTube, TikTok, Instagram, Twitter and Snapchat to disseminate video-based content as few young people use Facebook or access free-to-air TV

¹⁷⁴ Ibid., p. 2.

¹⁷⁵ Dr Stacey Hokke, *Transcript of evidence*, pp. 60–61.

- short videos with information-based content or emotive content, like personal stories from transplant recipients.¹⁷⁶

NHS Blood and Transplant informed the Committee about its marketing team in Scotland engaging young people through social media platforms, including a video game streaming service (Twitch). It reported ‘huge engagement on that platform’ and people having conversations about donation. Virtual engagement ‘in places where young people meet’ has benefited NHS Blood and Transplant’s donation campaigns.¹⁷⁷

Donor Mate raised challenges with donation advertising on social media platforms where algorithms disfavour posts that encourage users to leave to visit another website (for example, the DonateLife online registration webpage).¹⁷⁸ Donor Mate also suggested it is becoming harder to capture the attention of young people and convert micro-interactions (likes, smiley faces) in digital campaigns into registrations, particularly as young people move away from traditional media like TV, radio, newspapers and Facebook.¹⁷⁹ But evidence from other inquiry participants indicated these forms of media still have an important role in encouraging nuanced discussion about taboo topics. For example:

- Cynthia Caruna, who shared her family’s lived organ and tissue donation experience, proposed ‘TV programs which deal with difficult issues, for example, *Insight*, might be valuable in targeting’ people to sign up to the AODR.¹⁸⁰
- Dai Nguyen, Bilingual and Bicultural Health Educator at MCWH, suggested that in-language (Vietnamese) advertisements or news on SBS radio would probably work well.¹⁸¹

FINDING 48: Promotion, education and awareness of organ and tissue donation and registration in Victoria should use TV, radio, social media and online platforms as well as posters, billboards and pamphlets in public spaces to ensure broad reach across the community.

RECOMMENDATION 25: The Victorian Government enhance collaboration with DonateLife Victoria to increase the presence of promotional and educational material about organ and tissue donation through TV, radio, social media and online platforms as well as posters, billboards and pamphlets in public spaces, and publicly report on these initiatives and their effectiveness.

¹⁷⁶ Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, pp. 15–18.

¹⁷⁷ Phil Walton, *Transcript of evidence*, p. 47.

¹⁷⁸ Donor Mate, *Submission 36*, p. 3.

¹⁷⁹ *Ibid.*, pp. 2–3.

¹⁸⁰ Cynthia Caruana, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 23.

¹⁸¹ Dai Nguyen, *Transcript of evidence*, p. 68.

5.6.2 Partnerships and collaboration

Strategic partnerships and collaboration can improve knowledge about donation and awareness of the AODR.

Victorian DH listed ‘targeted engagement with businesses’ as a key opportunity to encourage people to register as donors.¹⁸² This could include working with local businesses in regional and rural farming communities.¹⁸³

Celebrity partnerships were raised as a potential way to increase awareness about donation and registration on a mass scale.¹⁸⁴ For example, LEDS drew attention to the work of Neale Daniher on motor neuron disease and Olivia Newton-John on breast cancer to demonstrate what can be achieved.¹⁸⁵ Allan Turner used the McGrath Foundation as an example of government and charity partnerships in the health sector that help improve community awareness, suggesting that partnering with foundations, such as Zaidee’s Rainbow Foundation, presents an opportunity for the Victorian Government to increase donation awareness.¹⁸⁶

5.6.3 Encouraging registrations at non-government touchpoints

Routine and widespread registration initiatives can provide more avenues to register,¹⁸⁷ encourage family discussion and normalise conversations, and increase education about donation.¹⁸⁸ Introducing regular registration options or prompts at government service touchpoints is discussed in Chapter 3. But inquiry participants also identified the following mechanisms could be used to promote the AODR:

- membership registrations and renewals, for example, professional (accountants, legal and medical professionals), union, university/student and sporting associations¹⁸⁹
- first aid programs¹⁹⁰
- income protection and life insurance applications, wills and by probate lawyers¹⁹¹
- encouragement to general practitioners to incorporate donation into discussions with patients about wills and powers of attorney (advance care planning is discussed in Chapter 7)¹⁹²

¹⁸² Department of Health, *Submission 42*, p. 2.

¹⁸³ Louise McKinlay, *Transcript of evidence*, p. 7.

¹⁸⁴ Bronwyn Cohen, *Transcript of evidence*, p. 32; Melbourne Lions Eye Donation Service, *Submission 18*, p. 2.

¹⁸⁵ Bronwyn Cohen, *Transcript of evidence*, p. 32.

¹⁸⁶ Allan Turner, *Transcript of evidence*, p. 33.

¹⁸⁷ Donor Mate, *Submission 36*, p. 2.

¹⁸⁸ Alfred Health, *Submission 38*, p. 9.

¹⁸⁹ Melbourne Lions Eye Donation Service, *Submission 18*, pp. 1–2; Donor Mate, *Submission 36*, p. 1; Catholic Archdiocese of Melbourne, *Submission 19*, p. 2.

¹⁹⁰ Dr Brooke Huuskes, *Transcript of evidence*, p. 63.

¹⁹¹ Alfred Health, *Submission 38*, p. 9; Adel Salman, *Transcript of evidence*, pp. 62–63.

¹⁹² Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, pp. 22, 24.

- a partnership with the National Bowel Screening Program—this is particularly relevant to eye donations, as donors are more likely to be older people¹⁹³
- partnerships with private health insurers and tech companies, an initiative already explored in the US.¹⁹⁴

Lifeblood

Several inquiry participants suggested better partnerships with Lifeblood could help promote organ and tissue donation, noting the altruistic nature of blood donors.¹⁹⁵

La Trobe University’s study recommended that OTA ‘[I]earn from and partner with Lifeblood’. Study participants ‘thought that blood donation was promoted well in Australia’ and that organ and tissue donation could draw upon Lifeblood’s marketing strategies.¹⁹⁶ Suggestions included to have:

- pamphlets or posters in blood donation centres to increase the visibility of organ and tissue donation to young people
- OTA contact people who have registered to thank them for reaching milestones (for example, after being registered for a certain number of years).¹⁹⁷

Lifeblood identified it could do more to promote organ and tissue donation on an ongoing basis, rather than on occasion throughout the year. This could include general awareness raising through Lifeblood’s app and marketing.¹⁹⁸ Promoting organ and tissue donation also fits with Lifeblood’s new strategic direction encouraging people to become donors for life: ‘it is not just about being a blood donor, [but] about being a general donor ... [organ and tissue] donation could be just as much a part of that’.¹⁹⁹

Lifeblood also noted some limitations to it raising awareness about organ and tissue donation. Federal funding to Lifeblood is subject to restrictions and current practices prevent Lifeblood from directly contacting registered blood donors about something they have not consented to (such as organ and tissue donation). Changing Lifeblood’s consent form and questionnaire, while potentially a promising idea, is a complex and multijurisdictional process.²⁰⁰

¹⁹³ Melbourne Lions Eye Donation Service, *Submission 18*, p. 2; Bronwyn Cohen, *Transcript of evidence*, pp. 32, 37.

¹⁹⁴ DonateLife Victoria, *Submission 27*, p. 8; Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, p. 3.

¹⁹⁵ Melbourne Lions Eye Donation Service, *Submission 18*, p. 2; Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, p. 1; Philip Waters, *Transcript of evidence*, p. 37; Louise McKinlay, *Transcript of evidence*, p. 15.

¹⁹⁶ Dr Brooke Huuskes and Dr Stacey Hokke, *Submission 32*, p. 23.

¹⁹⁷ *Ibid.*

¹⁹⁸ Stuart Chesneau, *Transcript of evidence*, pp. 47–48.

¹⁹⁹ *Ibid.*, p. 48. Lifeblood’s role in promoting types of donation other than blood is discussed in Chapter 6.

²⁰⁰ *Ibid.*, pp. 48, 50.

FINDING 49: Collaboration and partnerships with Victorian businesses, charities, not-for-profits, professional associations, unions and Lifeblood to encourage people to register on the Australian Organ Donor Register are key opportunities to increase registrations.

RECOMMENDATION 26: The Victorian Government assist DonateLife Victoria to collaborate and form partnerships to encourage people to register on the Australian Organ Donor Register with Victorian businesses, including farming and health insurers, charities, not-for-profits, professional and sporting associations, and unions.

RECOMMENDATION 27: The Victorian Department of Health support and encourage DonateLife Victoria and Lifeblood to work together to increase the promotion of organ and tissue donation through Lifeblood's network, and publicly report on the outcomes achieved by these initiatives.

5.6.4 Public reporting and sharing of outcomes

Ways to amend AODR registration processes to collect demographic and other information to better inform community awareness campaigns are discussed in Chapter 3, Section 3.5.

Monitoring and evaluating the outcomes achieved by awareness and education activities about organ and tissue donation increases understanding about what works best—this is especially important where the key outcome is to increase the number of donors registered on the AODR. It can also inform and improve future efforts to increase registrations and encourage family discussion about donation. Sharing the outcomes achieved through OTA-funded and DLV-run awareness activities is therefore important.

Organisations that receive OTA grants to conduct community-based awareness and education activities are required to provide final reports back to OTA. The reports 'identify if and how outcomes have been achieved using data and analytics where possible'.²⁰¹ However, these reports do not appear to be publicly available. This diminishes the ability for organisations to apply the learnings of past grant recipients to increase the effectiveness of future community-based activities. This is equally important to OTA's Partnerships program which does not appear to have any current outcomes reporting requirements.

²⁰¹ Organ and Tissue Authority, *Community awareness grants program*, p. 18.

Tony Holland of DLV advised that it is ‘very hard to measure the efficacy’ of some of DLV’s awareness activities ‘like bus advertising or billboards’.²⁰² But for events, such as the Melbourne Show, DLV can measure the effectiveness by a ‘count [of] how many people register or check the[ir] registration’ through the use of a QR code.²⁰³ While acknowledging the challenges of measuring the outcomes of some awareness activities, the Committee considers it important for DLV to maintain an open dialogue with its local community partners to understand what is working well for different groups to increase registration and family discussion about donation. This will ensure a focused approach to awareness activities in Victoria that maximise efficiency and effectiveness.

FINDING 50: Increasing public reporting on the outcomes achieved by awareness activities funded by the Organ and Tissue Authority about organ and tissue donation could help inform and improve future efforts, including those aimed to increase registration on the Australian Organ Donor Register and encourage family discussion about donation.

RECOMMENDATION 28: The Victorian Government advocate to the Organ and Tissue Authority (OTA) for increased transparency and accountability about OTA-funded donation awareness activities, especially those which aim to increase registrations and encourage family discussion.

²⁰² Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 8.

²⁰³ Ibid.

Chapter 6

Living donation

There is growing need for stem cell and kidney donors in Victoria and Australia. Through living donations people can contribute positively to help save lives.¹

This chapter is in three parts. The first discusses stem cell donation. The second considers living organ donation and the third outlines other types of living donation.²

Part 1: Stem cell donation

This part outlines what stem cell donation is and how to register and become a donor. It then considers the current stem cell donation landscape, including governance and funding arrangements, before looking at opportunities to increase the number of registered stem cell donors.

The Committee uses the term *stem cell* to describe both bone marrow and stem cell donations. Other phrases used in some sources are ‘haemopoietic stem cells’ (HSC) or ‘haemopoietic progenitor cells’ (HPC).

6.1 What is stem cell donation?

Stem cells are cells in the body that ‘can help with the growth or repair of body tissues.’³ As described in Chapter 1, stem cell transplants are important because they can treat blood cancers like leukaemia and lymphoma.

Most (9 in 10) stem cell donations are drawn from blood and there is minimal pain or side effects—it is similar to donating blood or plasma. Stem cell donations involve a matched donor completing a course of injections a few days in advance of a donation to stimulate the growth of more stem cells, before blood is withdrawn which the stem cells are then separated from in hospital over a few hours.⁴ Bone marrow donations are less common and involve a surgical procedure under anaesthesia. Bone marrow is collected from the pelvis and there is some pain.⁵

1 Professor Jeff Szer, Director, Australian Bone Marrow Donor Registry, public hearing, Melbourne, 5 August 2023, *Transcript of evidence*, p. 1.

2 Living tissue donation is considered in Chapter 7.

3 healthdirect, *Stem cells*, September 2020, <<https://www.healthdirect.gov.au/stem-cells>> accessed 10 January 2024.

4 Australian Bone Marrow Donor Registry, *Strength to Give, cheek swabs*, n.d., <<https://strengthtogive.org.au/cheek-swabs>> accessed 12 October 2023; Lifeblood, *Blood stem cell donation*, n.d., <<https://www.lifeblood.com.au/organ-and-tissue/blood-stem-cell>> accessed 12 October 2023; Lisa Smith, Chief Executive Officer, Australian Bone Marrow Donor Registry, public hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 8.

5 Professor Jeff Szer, *Transcript of evidence*, p. 7.

Stem cell transplants require a very precise match between donor and recipient—much more so than for organ donation. Patients requiring a stem cell transplant generally find a stem cell donor match with a sibling. Otherwise, a search for an unrelated donor in Australia or overseas is made through the Australian Bone Marrow Donor Registry (ABMDR).⁶ It is statistically impossible for the donors of one state or country to meet the needs of all their patients, so interstate and international donations will always be required.⁷

6.2 How do you register to become a stem cell donor?

Potential stem cell donors can register on the ABMDR through:

- Lifeblood—by booking a blood donation and asking about stem cell donation in the donor centre to join the ABMDR. A potential donor can then give a blood sample at the same time as a blood donation.⁸
- The Strength to Give campaign—by requesting a cheek swab kit be sent to them to complete at home and post back.⁹

The samples are tested for tissue and blood type and data is recorded on the ABMDR.¹⁰ Most people who join the ABMDR do not donate because they are not a match to a patient.¹¹

Ideal stem cell donors are aged 18 to 35, male and ethnically diverse.¹² Younger donors have fewer health complications and result in better clinical outcomes for patients. Donations from males result in more stem cells and avoid any complications from pregnancy in females.¹³ A patient is more likely to match with a donor of the same ethnicity.¹⁴ The need for more diverse donors is discussed in Section 6.3.4.

6 Leukaemia Foundation, *Allogeneic stem cell transplants*, n.d., <<https://www.leukaemia.org.au/blood-cancer/journey/active-treatment/treatment-options/stem-cell-transplants/allogeneic>> accessed 12 October 2023; Australian Bone Marrow Donor Registry, *Submission 43*, received 17 August 2023, p. 1.

7 Australian Bone Marrow Donor Registry, *Submission 43*, p. 1; Department of Health, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 7 September 2023, p. 3.

8 Lifeblood, *Blood stem cell donation*; Strength to Give, *Registering through a Lifeblood donor centre*, n.d., <<https://strengthtogive.org.au/lifeblood>> accessed 21 November 2023.

9 Australian Bone Marrow Donor Registry, *Strength to Give, cheek swabs*. Additionally, through the Bone Marrow Institute Cord Blood Bank at the Royal Children's Hospital, mothers can donate cord blood and this information is sent to the ABMDR, see The Royal Women's Hospital, *Cord blood collection*, n.d., <<https://www.thewomens.org.au/patients-visitors/clinics-and-services/pregnancy-birth/cord-blood-collection>> accessed 12 December 2023.

10 Australian Bone Marrow Donor Registry, *Submission 43*, p. 1; Australian Bone Marrow Donor Registry, *Strength to Give, cheek swabs*.

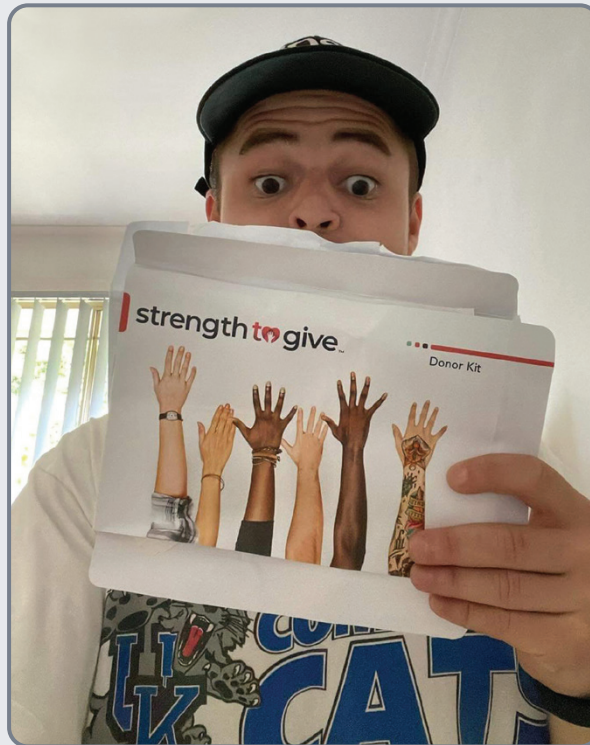
11 Australian Bone Marrow Donor Registry, *Strength to Give, cheek swabs*.

12 Department of Health and Aged Care, *National HPC Framework*, 2021, p. 9. Ideal donors are also known as optimal donors.

13 Strength to Give, *Frequently asked questions*, n.d., <<https://strengthtogive.org.au/faqs>> accessed 13 September 2023.

14 Australian Bone Marrow Donor Registry, *Submission 43*, pp. 4–5.

Figure 6.1: Receiving a Strength to Give cheek swab donation kit in the mail



Source: image provided by the Australian Bone Marrow Donor Registry, 14 February 2024.

6.3 Stem cell donation landscape

This section considers the national framework for stem cell donation and the roles of the Victorian Government and Lifeblood in donor recruitment. It then considers the ABMDR's governance and funding arrangements and the current need for more domestic donors from ethnically diverse backgrounds.

6.3.1 2018 review and national stem cell framework

Australia's *National HPC Framework* was developed in 2021 in response to a 2018 review of the stem cell sector commissioned by the Australian Government on behalf of all state and territory governments. Key findings of the review included:

- Governance and responsibilities in the sector were fragmented.
- Funding to the sector was costly, requiring multijurisdictional investment.
- Australia was increasingly reliant on overseas donors and demographic profiles of patients were becoming more diverse.

- The main way to recruit stem cell donors was to ask people who donated blood but this did not allow for the sufficient recruitment of ideal donors.
- Marketing to and communication with donors could be improved to promote engagement.¹⁵

As a first step, the review recommended developing ‘an intergovernmental position, which considers the strategic objectives for the HPC sector for the next five to ten years’—which saw the Commonwealth-led Jurisdictional HPC Committee agree to the *National HPC Framework*.¹⁶ All jurisdictions are represented on this Committee that ‘facilitates policy agreement and funding’ for unrelated stem cell donation services.¹⁷

The *National HPC Framework* has five long-term strategic objectives:

1. Facilitate safe, high-quality and standardised clinical stem cell services
2. Facilitate all patients’ equitable access to transplants, including vulnerable groups
3. Ensure stem cells are supplied through effective, efficient and appropriate service delivery and this supply addresses patient and clinical needs
4. Reduce reliance on overseas donations by improving tissue typing and donor recruitment
5. Enable the development and implementation of national, state and territory strategies to support governance that enhances sector coordination.¹⁸

The *National HPC Framework* recognises the need for greater self-sufficiency and sustainability, with a goal that demand for stem cells is largely met by local donors. While full self-sufficiency is unlikely because some reliance on the international donor pool is necessary, this reliance should be lower than current levels. Increased self-sufficiency means less ‘risk of exposure to global unplanned shifts in supply or demand’ for tissue products. Supply chain issues during the COVID-19 pandemic highlighted this risk.¹⁹

More targeted donor recruitment is also required to increase the diversity of Australia’s donor pool in the future and actively engage ideal donors. This will help meet the needs of Australian patients and reduce reliance on international donors.²⁰ In 2021, the Jurisdictional HPC Committee commissioned a review of international best practice in stem cell donor recruitment and retention.²¹ This was published in December 2023.²²

¹⁵ Department of Health and Aged Care, *National HPC Framework*, pp. 1–2.

¹⁶ *Ibid.*, p. 3.

¹⁷ Department of Health and Aged Care, *HPC Sector Clinical Advisory Group Governance*, August 2022, p. 1.

¹⁸ Department of Health and Aged Care, *National HPC Framework*, p. 12.

¹⁹ *Ibid.*, p. 15.

²⁰ *Ibid.*, p. 16.

²¹ *Ibid.*; Australian Bone Marrow Donor Registry, *Submission 43*, p. 2.

²² Department of Health and Aged Care, *Recommendations on adult haemopoietic progenitor cell donor recruitment reform*, 19 December 2023, <<https://www.health.gov.au/resources/publications/recommendations-on-adult-haemopoietic-progenitor-cell-donor-recruitment-reform>> accessed 22 February 2024.

6.3.2 Victorian Government and Lifeblood

State and territory governments ‘lead [stem cell donor] recruitment activities through agreements with [Lifeblood]’.²³ The 2018 stem cell review noted:

The activities of [Lifeblood], such as donor recruitment, tissue typing, and search and match coordination are covered by its agreements with state governments in NSW, Victoria, South Australia and Tasmania ... These agreements cover a number of other services provided by [Lifeblood], making it challenging to extract specific details, such as the cost of providing tissue typing services, and do not set out clear performance indicators or reporting requirements for items such as recruitment targets.²⁴

ABMDR advised ‘the Victorian government contracts Lifeblood to draw and test blood samples from eligible Victorian blood donors who also seek to be [stem cell] donors.’²⁵

Lifeblood stated at a hearing that it ‘is funded to recruit a set amount [of stem cell donors] through [its] fixed donor centre network nationally and then to do the follow-up testing to make sure that [it understands] all of the demographics.’²⁶

In 2022–23, Lifeblood recruited 5,934 donors to the ABMDR across Australia.²⁷

6.3.3 Australian Bone Marrow Donor Registry

ABMDR is a registered charity operating nationally and is part of an international network of bone marrow registries. The Jurisdictional HPC Committee provides policy and funding oversight to ABMDR.²⁸

ABMDR facilitates unrelated (that is, where a potential donor is not a blood relation of the patient) stem cell donor searches. ABMDR advised that in the past year it conducted 1,093 searches for new Australian patients (including 280 in Victoria) and facilitated stem cell delivery to 581 Australian patients.²⁹

Strength to Give is ABMDR’s donor-facing brand and campaign to communicate with potential donors with a focus on cheek swab recruitment.³⁰

²³ PwC, *Review of the HPC sector—final report*, report for Australian Department of Health and Aged Care, 2018, p. ii.

²⁴ Ibid.

²⁵ Australian Bone Marrow Donor Registry, *Submission 43*, p. 3.

²⁶ Stuart Chesneau, Executive Director, Strategy and Growth, Lifeblood, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 55.

²⁷ Lifeblood, *Annual report 2022–23*, 2023, p. 29.

²⁸ Australian Bone Marrow Donor Registry, *Submission 43*, p. 1.

²⁹ Ibid.

³⁰ Australian Bone Marrow Donor Registry, *Annual report 2020–21: connecting donors to patients*, 2021, pp. 3, 5.

In March 2023, ABMDR's Board committed \$3.3 million from the last of its discretionary reserves for Strength to Give, a large-scale awareness campaign and national recruitment plan to recruit 30,000 new donors.³¹ ABMDR advised that this \$3.3 million investment is not sustainable beyond 2023–24.³²

ABMDR receives income from international registries for exporting Australia-donated cells to subsidise its daily operations (approximately \$1.4 million in 2022–23).³³ Fees from exported umbilical cord cells are banked in a separate account (the current balance is around \$13 million). These funds cannot be used by ABMDR under the terms of its contract with the Australian Government unless agreed to by all jurisdictions.³⁴

At a Health Ministers' Meeting in February 2023, \$1 million of the exported umbilical cord cell funds were approved for immediate release for increased recruitment and provisional approval was given for further funding following clinical advice in April 2023. This \$1 million in funding and the clinical advice are yet to be released.³⁵

6.3.4 The need for more local and diverse stem cell donors

Chapter 1 outlined 600 Australians with blood cancer require donated stem cells for a transplant each year, but not enough Australians are registered.³⁶ This means Australia is increasingly dependent on overseas donors, particularly in comparison to other countries (see Figure 6.2).³⁷ Currently around 3 in 4 stem cell donations are sourced internationally.³⁸ International donations are more costly and slow, and travel time can affect the viability of donor stem cells.³⁹ Demand for unrelated donors is also rising as 'family sizes decrease, and the ageing population combined with clinical advances means that older patients are increasingly being treated through [stem cell] transplantation.'⁴⁰

31 Australian Bone Marrow Donor Registry, *Submission 43*, pp. 3–4.

32 *Ibid.*, p. 4.

33 *Ibid.*, p. 6.

34 Lisa Smith, *Transcript of evidence*, p. 3.

35 Australian Bone Marrow Donor Registry, *Submission 43*, p. 2; Leukaemia Foundation, *Submission 20*, received 17 May 2023, p. 5. The Health Ministers' Meeting consists of the health ministers of each jurisdiction and works to progress 'health issues of national importance which require cross-border collaboration', see Department of Health and Aged Care, *Health Ministers' Meeting (HMM)*, 14 November 2023, <<https://www.health.gov.au/committees-and-groups/health-ministers-meeting-hmm>> accessed 21 November 2023.

36 Leukaemia Foundation, *Submission 20*, p. 3.

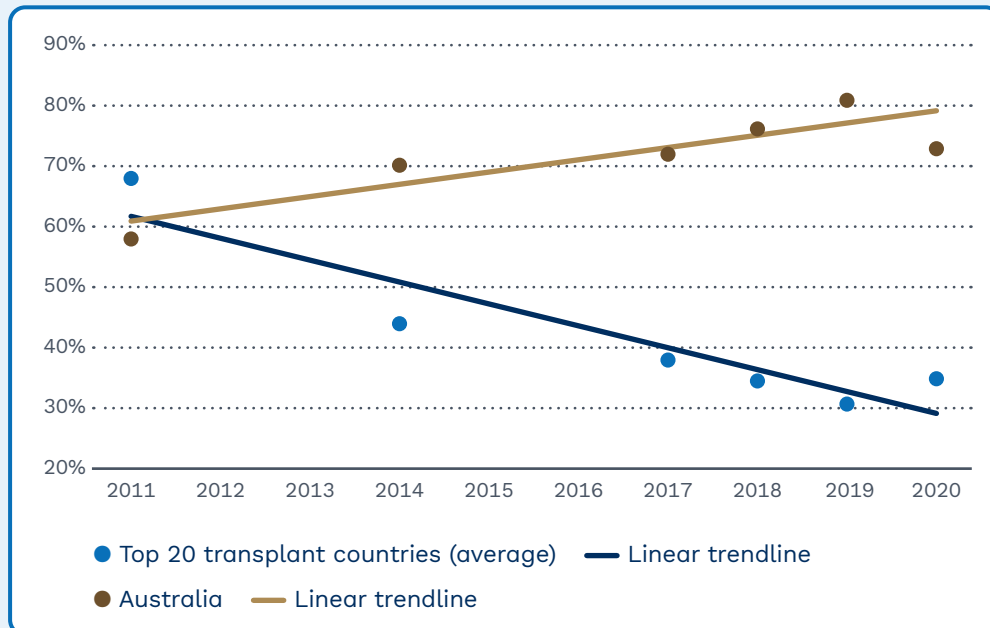
37 Australian Bone Marrow Donor Registry, *Submission 43*, p. 1; Australian Bone Marrow Donor Registry, *Annual report 2021–22: connecting donors to patients*, 2022, p. 5.

38 Chris Tanti, Chief Executive Officer, Leukaemia Foundation, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 2.

39 Leukaemia Foundation, *Submission 20*, p. 3; Australian Bone Marrow Donor Registry, *Submission 43*, p. 2.

40 Department of Health and Aged Care, *National HPC Framework*, p. 8.

Figure 6.2: Trend in the proportion of patients depending on overseas donors, Australia compared to transplant countries, 2011–2020



Source: Adapted from ABMDR, *Annual report 2021–22: connecting donors to patients*, 2022, p. 5.

Australia's cohort of registered ideal donors is not as large or growing to the same extent as other countries (see Figure 6.3). Australia has approximately 6 million people aged 18 to 35 and only 57,000 (less than 1%) are registered on the ABMDR.⁴¹ As of 2021–22, less than 5% of the 170,000 total donors on the ABMDR fit the ideal donor profile.⁴²

Australia's donor pool cannot meet the needs of diverse patients because it is small and current recruitment approaches fail to engage diverse audiences.⁴³ Relying on overseas donors means Australian patients from diverse ethnic backgrounds are less likely to find a match because international registries do not reflect Australia's diverse population. This particularly impacts Australians from First Nations, Pacific Islander and Southeast Asian communities.⁴⁴

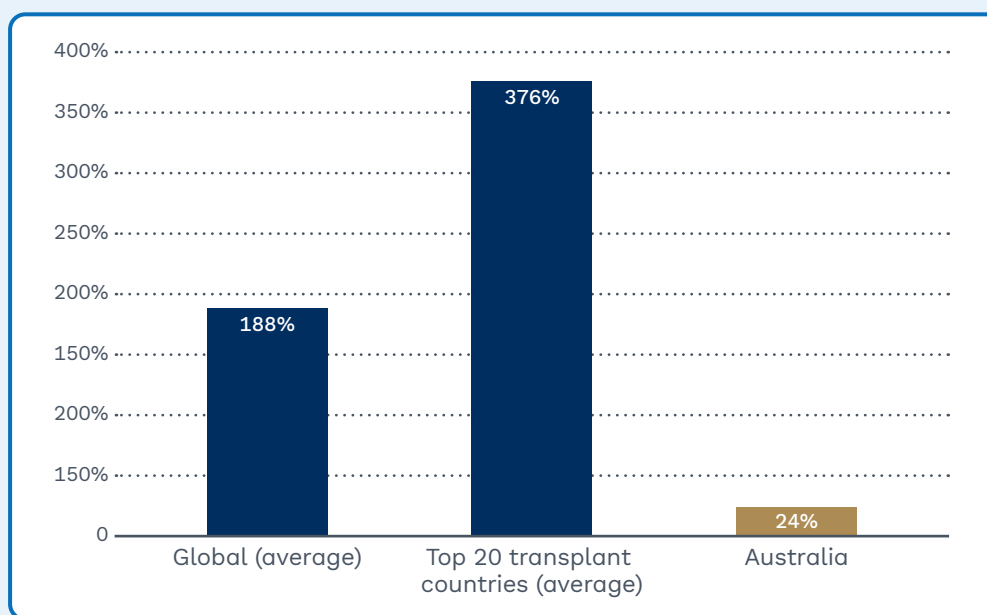
⁴¹ Australian Bone Marrow Donor Registry, *Submission 43*, p. 1.

⁴² Australian Bone Marrow Donor Registry, *Annual report 2021–22*, p. 9.

⁴³ Australian Bone Marrow Donor Registry, *Submission 43*, pp. 4–5.

⁴⁴ Ibid.; Leukaemia Foundation, *Submission 20*, pp. 3, 5; Australian Bone Marrow Donor Registry, *Annual report 2021–22*, p. 5.

Figure 6.3: Growth in stem cell donors aged 18 to 35, Australia compared to transplant countries, 2016–2020



Source: Adapted from ABMDR, *Annual report 2021–22: connecting donors to patients*, 2022, p. 5.

The cost to use international donors is increasing as they make up a rising proportion of stem cell transplants in Australia.⁴⁵ The Australian Government pays fees to import cells (approximately \$13.2 million in 2022–23).⁴⁶ ABMDR submitted the amount paid to Germany alone each year exceeds the amount of funding they receive for registry services. ABMDR advised it ‘is not currently funded for donor recruitment; and has no visibility of [stem cell] donor recruitment funding provided by states to Lifeblood’.⁴⁷ More local donors would reduce import expenditure and increase export income, which could then be used to fund increased stem cell donor recruitment in Australia.⁴⁸ Section 6.4.4 discusses funding arrangements in relation to donor recruitment in more detail.

FINDING 51: Minimising Australia’s reliance on international stem cell donors by increasing the number of domestic registered ideal donors would improve cost efficiency and produce more equitable outcomes for diverse patients, in particular for patients from First Nations, Pacific Islander and Southeast Asian communities.

⁴⁵ PwC, *Review of the HPC sector—final report*, p. vi.

⁴⁶ Australian Bone Marrow Donor Registry, *Submission 43*, pp. 5–6; Department of Health and Aged Care, *Haemopoietic progenitor cell framework and programs*, 2 June 2023, <<https://www.health.gov.au/our-work/haemopoietic-progenitor-cell-framework-and-programs>> accessed 21 November 2023.

⁴⁷ Australian Bone Marrow Donor Registry, *Submission 43*, p. 6.

⁴⁸ *Ibid.*

FINDING 52: The Australian Bone Marrow Donor Registry receives less funding for registry services than the Australian Government pays to Germany each year for imported stem cell donations.

RECOMMENDATION 29: The Victorian Department of Health advocate through the national Health Ministers' Meeting for increased Australian Government funding for the Australian Bone Marrow Donor Registry.

6.4 Opportunities to increase the number of registered stem cell donors

This section considers several opportunities identified by inquiry participants to increase stem cell donor recruitment, including increasing awareness of stem cell donation and overcoming myths, expanding Strength to Give, developing partnerships for targeted recruitment, and improving governance and funding arrangements for ABMDR and Lifeblood.

6.4.1 Increasing awareness and overcoming myths

Current awareness of the ABMDR and the importance and process of stem cell donations is low.⁴⁹ Myths and misconceptions about donation also prevail, including the method of donation (stem cell vs bone marrow) and eligibility to donate.⁵⁰ Many people still think donating stem cells is a painful process or requires an anaesthetic in hospital.⁵¹ While most donations historically involved bone marrow—a lengthy and complex process often involving an overnight stay in hospital and post-operative pain—clinical advancements mean most donations are now stem cell (see Section 6.1).⁵² ABMDR also highlighted that many people incorrectly think that by donating blood they have donated stem cells.⁵³

ABMDR observed that by drawing upon international best practice, the way to increase the number of registered donors is to engage with young target audiences beyond blood donors through online methods, publicise the need for donors, address myths about donation, develop community trust and expand cheek swab programs.⁵⁴

⁴⁹ Ibid., p. 4; Leukaemia Foundation, *Submission 20*, p. 5; UR the Cure, *Submission 44*, received 29 August 2023, p. 3.

⁵⁰ Australian Bone Marrow Donor Registry, *Submission 43*, p. 4.

⁵¹ UR the Cure, *Common questions*, n.d., <<https://www.urthecure.com.au/common-questions>> accessed 10 January 2024.

⁵² Ibid., Professor Jeff Szer, *Transcript of evidence*, pp. 7–8.

⁵³ Australian Bone Marrow Donor Registry, *Submission 43*, p. 4. See also Chris Tanti, *Transcript of evidence*, p. 7.

⁵⁴ Lisa Smith, *Transcript of evidence*, p. 2. Engaging with young people to increase awareness about donation is discussed in Chapter 5.

The recruitment of dedicated and informed donors is particularly important so registered donors know what a stem cell donation involves and are more likely to commit to a donation.⁵⁵

ABMDR's 2023 funding commitment for a large-scale awareness campaign aimed to create greater visibility and influence social norms about stem cell donation to increase people's motivation and commitment to register. However, as discussed in Section 6.3.3, ABMDR does not have funding to support these efforts beyond 2023–24.⁵⁶

Germany's national bone marrow registry shared its stem cell donor recruitment experiences with the Committee—demonstrating the benefits of marketing and education to promote the need for more stem cell donors.

Case Study 6.1 Germany, Zentralen Knochenmarkspender-Register Deutschland (ZKRD)

Germany is one of the most successful and efficient countries for stem cell donor recruitment. Almost 40% of all unrelated (non-family member) blood stem cell transplants globally involve German donors. Approximately 60% of Australia's stem cell donors are sourced from Germany.

ZKRD is the central coordination office for stem cell donor searches in Germany and the largest national registry worldwide. ZKRD receives over 3,500 search requests from German patients and 30,000 from overseas annually. Over 10 million people are registered donors in Germany with 7,000 stem cell collections made each year.

People can register with 26 independent donor centres and donor registration data is provided to ZKRD to conduct international and national searches. Donor centres manage their data through software provided by ZKRD. Local search units, for example in hospitals, use the ZKRD platform to find suitable donors. Most new registrations in Germany are through physical donor drives rather than online recruitment, although this dropped during the COVID-19 pandemic and is yet to rebound.

The registration of new donors at donor centres is privately funded and managed. Most of the donation fee (for example, when Australia or another country pays for a German donation) goes to the donor centre. In Germany, the government also provides a symbolic amount per registered donor on an annual basis to the donor centres. People who donate are reimbursed for lost income by individual donor centres.

(Continued)

⁵⁵ Ibid., p. 5.

⁵⁶ Australian Bone Marrow Donor Registry, *Submission 43*, p. 4.

Case Study 6.1 Continued

Dr Joannis Mytilineos, Chief Medical Officer at ZKRD explained the keys to success are marketing, education and easy registration processes. Often, social and traditional media marketing is centred on personal stories of people requiring a donation to drive more registrations and is targeted towards young people. Having numerous donor centres drives innovative approaches to recruiting donors. Donors sign a consent form allowing donor centres to use government authorities and contact them about donation if they move address.

Recruiting donors from culturally diverse backgrounds is an ongoing challenge. While the German population is more genetically homogenous than Australia, diversity is increasing. Donor centres only undertake some culturally diverse donor recruitment.

Source: ZKRD, *Annual report 2021, 2022*, pp. 5, 4; Dr Joannis Mytilineos, Chief Medical Officer, ZKRD, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, pp. 19–23.

FINDING 53: Awareness about stem cell donation and the need for more registered stem cell donors is low. Prevailing myths and misconceptions about the donation process can be a deterrent to registration on the Australian Bone Marrow Donor Registry, even though clinical advancements mean most donations are stem cell (not bone marrow) and have minimal pain or side effects.

6.4.2 Expanding Strength to Give and modernising recruitment practices

Modernising stem cell recruitment practices by expanding Strength to Give is a demonstrated means to increase awareness and overcome myths.⁵⁷

The Leukaemia Foundation and ABMDR advocated for less reliance on overseas donors and more people registered on the ABMDR.⁵⁸ ABMDR stated the solution is to:

sustainably invest in modern donor recruitment methods and significantly increase the number of donors recruited in Australia each year, not by 1,000 or 5,000 but by at least 30,000 donors a year over and above what is currently being delivered.⁵⁹

Currently, an average of 5,120 new Australian donors (representing 904 from Victoria) are added to the ABMDR each year. ABMDR advised that a home-delivered cheek swab program could result in an additional 25,000 new Australian donors each year that could meaningfully reduce Australia's reliance on overseas donations.⁶⁰

⁵⁷ Lisa Smith, *Transcript of evidence*, p. 2.

⁵⁸ Leukaemia Foundation, *Submission 20*, p. 4; Australian Bone Marrow Donor Registry, *Submission 43*, p. 3.

⁵⁹ Lisa Smith, *Transcript of evidence*, p. 2.

⁶⁰ Australian Bone Marrow Donor Registry, *Submission 43*, pp. 3–4.

ABMDR has run specific cheek swab recruitment programs twice on a small scale, resulting in over 11,000 additional registrations, with the proportion of young male donors registered doubling to 10% of the total donor pool.⁶¹ International evidence also points to the success of cheek swab campaigns, with many countries using these low-cost, high-volume programs.⁶²

ABMDR identified an opportunity for the Victorian Government to amplify ABMDR's awareness campaign through government channels and contribute to ABMDR's efforts to modernise recruitment practices by pivoting to home-delivered cheek swab campaigns.⁶³

FINDING 54: Strength to Give—the Australian Bone Marrow Donor Registry's donor-facing brand and campaign with a focus on recruiting stem cell donors through home-delivered cheek swabs—promotes evidence-based and modern recruitment practices to increase the number of registered stem cell donors. Expanding Strength to Give can help increase awareness of stem cell donations and encourage people to register to donate.

6.4.3 Developing partnerships for targeted donor recruitment

Targeted cheek swab collection at events with trained staff can increase the number of registered donors, particularly when facilitated by trusted partners in a community setting. ABMDR's recruitment partners include organisations (such as UR the Cure and Tackling Leukaemia) with demonstrated experience educating diverse communities, 'who have expressed interest in becoming accredited by ABMDR to facilitate swab collection events'.⁶⁴ These organisations help ABMDR to develop standards, training and infrastructure for community events and are guided by the national recruitment plan to ensure efforts are not duplicated and messaging is consistent or nuanced when required.⁶⁵

ABMDR advised it has 'recently sought' funding to process and test the cheek swabs collected at events. Some recruitment partners are seeking to raise money from private companies and the public in anticipation of an ongoing program.⁶⁶ ABMDR highlighted an opportunity for the Victorian Government to contribute funding to ABMDR's Victorian recruitment partners to conduct cheek swabs at targeted community events.⁶⁷

⁶¹ Ibid., p. 4; Australian Bone Marrow Donor Registry, *Annual report 2021–22*, p. 4.

⁶² Chris Tanti, *Transcript of evidence*, p. 2; Australian Bone Marrow Donor Registry, *Submission 43*, p. 3.

⁶³ Australian Bone Marrow Donor Registry, *Submission 43*, p. 6. See also Leukaemia Foundation, *Submission 20*, p. 5.

⁶⁴ Australian Bone Marrow Donor Registry, *Submission 43*, p. 5.

⁶⁵ Ibid.

⁶⁶ Ibid.

⁶⁷ Ibid., p. 6.

FINDING 55: Facilitated cheek swab collection at targeted community events with experienced and trusted partners would assist in increasing the number of ideal stem cell donors registered on the Australian Bone Marrow Donor Registry.

The Leukaemia Foundation identified the need for ‘proactive strategies’ to increase the ‘recruitment, education and retention of ideal donors ... to meet contemporary clinical trends and growing demand’.⁶⁸ The Foundation stated that ‘raising awareness in a way that is culturally appropriate for those communities in a language that they can understand is critical, and we do not do enough of that in Australia.’⁶⁹ This will ensure the needs of patients are better met and that the current blood cancer survival disparity for diverse patients and reliance on international donors is reduced.⁷⁰

ABMDR and the Leukaemia Foundation suggested education programs in schools and higher education institutions could increase awareness about stem cell donations and how to register, particularly because ideal donors are younger.⁷¹ ABMDR identified it could work with the Victorian Government to recruit donors through new opportunities like schools, TAFE and Victoria Police.⁷²

FINDING 56: Opportunities to increase awareness of stem cell donations and how to register on the Australian Bone Marrow Donor Registry include using culturally appropriate resources, and school and higher education-based programs.

RECOMMENDATION 30: The Victorian Government routinely use multiple government channels to promote awareness of stem cell donations and registration on the Australian Bone Marrow Donor Registry through the Strength to Give cheek swab campaign and blood donation.

RECOMMENDATION 31: The Victorian Government support Lifeblood, the Australian Bone Marrow Donor Registry and stem cell donor recruitment organisations to extend the reach of stem cell donor awareness and recruitment campaigns, including support to facilitate cheek swab collection at community events.

⁶⁸ Leukaemia Foundation, *Submission 20*, p. 5.

⁶⁹ Chris Tanti, *Transcript of evidence*, p. 7.

⁷⁰ *Ibid.*, p. 6; Leukaemia Foundation, *Submission 20*, pp. 3–4, 5.

⁷¹ Chris Tanti, *Transcript of evidence*, p. 5; Andrew Mosley, Head of Government Relations and Policy, Blood Cancer Partnerships, Leukaemia Foundation, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 5; Australian Bone Marrow Donor Registry, *Submission 43*, p. 6.

⁷² Australian Bone Marrow Donor Registry, *Submission 43*, p. 6.

6.4.4 Improving governance and funding arrangements

Lifeblood and ABMDR both recruit stem cell donors. This section discusses some opportunities that were identified by inquiry participants to enhance their governance and funding arrangements.

Lifeblood

Lifeblood's recruitment of stem cell donors through its 'fixed donor centre network'⁷³ means most donors are drawn from the blood donor pool despite stem cell donors having less restrictive eligibility requirements. ABMDR described this donation model as onerous, outdated and an impediment to large scale recruitment.⁷⁴

As noted in Section 6.3.2, Lifeblood's 2022–23 annual report stated it recruited 5,934 donors to the ABMDR across Australia. However, Lifeblood's annual report does not provide a recruitment target for this measure.⁷⁵ Stuart Chesneau, Executive Director, Strategy and Growth at Lifeblood advised:

... I think if Victoria wants to take the leadership in this space, there is a lot that we could do to increase. At the moment I think ... we have got a target of 1297 recruitments into the ABMDR in Victoria. As a target, that is not very many. I think we could do a lot more, again through awareness and again through the brand ...⁷⁶

In response to a written question on notice from the Committee, the Australian Department of Health and Aged Care stated '[i]n 2022–23, Lifeblood's funded recruitment target was 5,230 HPC donors. Lifeblood exceeded this target by approximately 80% and recruited 9,407 new donors to the registry.'⁷⁷

Lifeblood's existing consent process means it is unable to contact blood donors about other types of donation, including stem cell.⁷⁸ Lifeblood advised it is in 'active conversation' with the Australian Government about its role in stem cell donor recruitment and suggested:

... there is more that we can do. We have the network, we are good at the recruitment of donors and also the testing down the back. It needs to be at the right price, and we also need to figure out how to target people outside of just our donor panel [pool]. That is what we are in conversation with the Commonwealth about at the moment.⁷⁹

ABMDR observed donor recruitment activities have been under-resourced for about a decade.⁸⁰ Like Lifeblood, the Leukaemia Foundation identified an opportunity for the

⁷³ Stuart Chesneau, *Transcript of evidence*, p. 55.

⁷⁴ Australian Bone Marrow Donor Registry, *Submission 43*, p. 3.

⁷⁵ Lifeblood, *Annual report 2022–23*, p. 29.

⁷⁶ Stuart Chesneau, *Transcript of evidence*, p. 55.

⁷⁷ Department of Health and Aged Care, *Inquiry into increasing the number of registered organ and tissue donors*, response to written questions on notice received 15 August 2023, p. 6.

⁷⁸ Stuart Chesneau, *Transcript of evidence*, pp.45, 50.

⁷⁹ *Ibid.*, p. 55.

⁸⁰ Lisa Smith, *Transcript of evidence*, p. 2.

Victorian Government to provide greater leadership in this space.⁸¹ With the support of the Australian Government and ABMDR, Lifeblood and the Victorian Government could work collaboratively to increase donor recruitment targets, brand awareness and stem cell donor promotion.⁸²

FINDING 57: The Victorian Government has a contract with Lifeblood to recruit stem cell donors. Lifeblood's current consent processes and network of blood donors limits its ability to recruit ideal stem cell donors. There are opportunities for the Australian and Victorian Governments, the Australian Bone Marrow Donor Registry and Lifeblood to increase collaboration to maximise opportunities for large scale stem cell donor recruitment, including the recruitment of younger Victorians and those from ethnically diverse backgrounds.

RECOMMENDATION 32: The Victorian Government review the current arrangements for stem cell donor recruitment in Victoria and make changes to allow for the larger scale recruitment of stem cell donors.

RECOMMENDATION 33: The Victorian Government support Lifeblood and the Australian Bone Marrow Donor Registry to ensure stem cell donor recruitment activities in Victoria target the recruitment of younger Victorians and those from ethnically diverse backgrounds through initiatives like education campaigns in schools or higher education institutions.

Australian Bone Marrow Donor Registry

Section 6.3.3 describes some of the challenges in ABMDR's funding model. Inquiry participants stressed the urgency for sustainable funds to be released and for stem cell donor recruitment to be an ongoing national priority.⁸³

Intermittent and variable 12-month funding for Strength to Give and donor recruitment is a persistent issue⁸⁴ that adds to the challenge of establishing meaningful relationships in diverse communities to recruit donors.⁸⁵ For example, UR the Cure, a charity and partner of ABMDR, suggested all jurisdictions should agree to release the full balance of the exported umbilical cords funds (around \$13 million) upfront:

Releasing money in small amounts is counterproductive and eats into this vital pool of funds, it is an inefficient use of funds ... We understand that the government are now looking at releasing a small amount of funds to go towards donor recruitment

⁸¹ Stuart Chesneau, *Transcript of evidence*, p. 55; Leukaemia Foundation, *Submission 20*, p. 4.

⁸² Stuart Chesneau, *Transcript of evidence*, p. 55; Louise McKinlay, Acting Deputy Secretary, Commissioning and System Improvement, Department of Health, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, p. 15.

⁸³ UR the Cure, *Submission 44*, p. 5; Leukaemia Foundation, *Submission 20*, pp. 5–6; Lisa Smith, *Transcript of evidence*, pp. 2–3.

⁸⁴ Leukaemia Foundation, *Submission 20*, pp. 5–6; Lisa Smith, *Transcript of evidence*, pp. 2–3.

⁸⁵ UR the Cure, *Submission 44*, p. 5.

until June 2024. This is again too short term. It will act like another pilot program as they will no doubt pause the program in June next year to undertake more reviews. We don't need more pilot programs to prove what we already know. The previous pilot has already proved its success, the rest of the world are using cheek swabs as the gold standard for recruitment.⁸⁶

UR the Cure indicated one reason for the delay in establishing a permanent cheek swab campaign is the government's decision to establish Australian labs to process the samples, rather than using overseas labs.⁸⁷

ABMDR appealed to the Victorian Health Minister to prioritise the needs of Victorian patients by more urgently seeking national consensus about funding for donor recruitment.⁸⁸ The Leukaemia Foundation suggested the Victorian Government advocate through the national Health Ministers' Meeting to 'help improve Australia's stem cell donor architecture and funding arrangements', including by stressing the need to modernise donor recruitment processes and donation practices.⁸⁹

A long-term strategic objective of the *National HPC Framework* is to enable the development and implementation of national, state and territory strategies 'to support governance and operations that enhance coordination across the sector.'⁹⁰ While the framework does not provide further detail on this objective and its implementation, the Committee believes it indicates that state governments have an important role in contributing to the stem cell sector's governance and coordination.

FINDING 58: Australian Government funding and support for stem cell donor recruitment has been intermittent and delayed, negatively impacting the ability to recruit donors and build relationships in diverse communities.

RECOMMENDATION 34: The Victorian Department of Health advocate through the national Health Ministers' Meeting for:

- immediate funding to expand Strength to Give and stem cell donor recruitment
- the immediate release of the \$1 million in stem cell donor recruitment funds agreed to in 2023
- a commitment to establish a permanent and ongoing funding mechanism for stem cell donor recruitment.

⁸⁶ UR the Cure, *Submission 44*, p. 5.

⁸⁷ *Ibid.*, p. 6.

⁸⁸ Lisa Smith, *Transcript of evidence*, pp. 2–3.

⁸⁹ Leukaemia Foundation, *Submission 20*, p. 4.

⁹⁰ Department of Health and Aged Care, *National HPC Framework*, p. 12.

Part 2: Living organ donation

This part considers living organ donation. It discusses what living organ donation is and then considers the process, current landscape and opportunities for improvement in relation to living kidney donations.

6.5 What is living organ donation?

Living organ donation involves donating a kidney or part of a liver. Living donors undergo testing to determine their suitability to donate and must be in good psychological and physical health. Most commonly, living organ donation involves donating a kidney to a close friend or relative with end-stage kidney disease (see Figure 6.4).

Living donor liver transplants usually occur when a parent donates part of their liver to their child. They are far rarer than living donor kidney transplants as they are significantly riskier.⁹¹ No living liver donations were conducted in 2022 in Australia.⁹² From 2016–2022, there were three living liver donors in Victoria and seven in Australia.⁹³ The Committee notes the waitlist for liver transplants has risen by 48% from 2013 to 2022.⁹⁴

This part of the chapter focuses on living kidney donation as the Committee received little evidence on living liver donors.

6.5.1 How do you become an anonymous living kidney donor?

People become anonymous living kidney donors—known as altruistic donation—by donating directly to someone on the transplant waitlist or through the Australian and New Zealand Paired Kidney Exchange (ANZKX) program.⁹⁵

Established in 2019, the ANZKX matches incompatible kidney donor and recipient pairs (relatives or friends that are not a match) with incompatible pairs from across

⁹¹ Organ and Tissue Authority, *Understanding living donation*, n.d., <<https://www.donatelife.gov.au/all-about-donation/understanding-living-donation>> accessed 13 September 2023.

⁹² Organ and Tissue Authority, *Australian donation and transplantation activity report 2022*, 2023, p. 7.

⁹³ Organ and Tissue Authority: *Australian donation and transplantation activity report 2022*, p. 7; *Australian donation and transplantation activity report 2021*, p. 19; *Australian donation and transplantation activity report 2020*, p. 11; *Australian donation and transplantation activity report 2019*, p. 8; *Australian donation and transplantation activity report 2018*, p. 8; *Australian donation and transplantation activity report 2017*, p. 5; *Australian donation and transplantation activity report 2016*, p. 5; Australia and New Zealand Liver and Intestinal Transplant Registry, *Data report for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, May 2023, p. 5.

⁹⁴ See Chapter 1, Figure 1.6.

⁹⁵ Organ and Tissue Authority, *Understanding living donation*; Organ and Tissue Authority, *Information for patients—ANZKX program*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/ANZKX/information-patients-anzkx-program>> accessed 12 October 2023.

Australia and New Zealand. The program is funded by the Organ and Tissue Authority (OTA) and New Zealand Ministry of Health.⁹⁶ The Royal Melbourne Hospital facilitates the program⁹⁷ and individual hospital transplant units enter patient information into it.⁹⁸ To become an altruistic donor, people can talk to a general practitioner about the process and obtain a referral to a nephrologist, or speak directly to a kidney specialist.⁹⁹

6.6 Living kidney donation landscape

The number of living kidney donors in Australia increased from 78 in 1991 to a peak of 354 in 2008. This represented 17% of all kidney transplants in 1991 and 44% of all kidney transplants in 2008.¹⁰⁰

However, the number of living kidney donors has declined since 2008.¹⁰¹ Figure 6.4 shows the trend from 2013–2022. In 2022, Victoria had 75 living kidney donors and Australia had 224. This meant in 2022, only 24% of kidney transplants involved a living donor in Australia and 26% in Victoria.¹⁰²

96 Organ and Tissue Authority, *Australian and New Zealand Paired Kidney Exchange (ANZKX) program*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/ANZKX>> accessed 13 September 2023.

97 Ibid.

98 Organ and Tissue Authority, *Pathway 1. ANZKX registration: Version 2.0*, fact sheet, November 2021; Organ and Tissue Authority, *Information for transplant units—ANZKX program*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/ANZKX/information-transplant-units-anzkx-program>> accessed 23 November 2023.

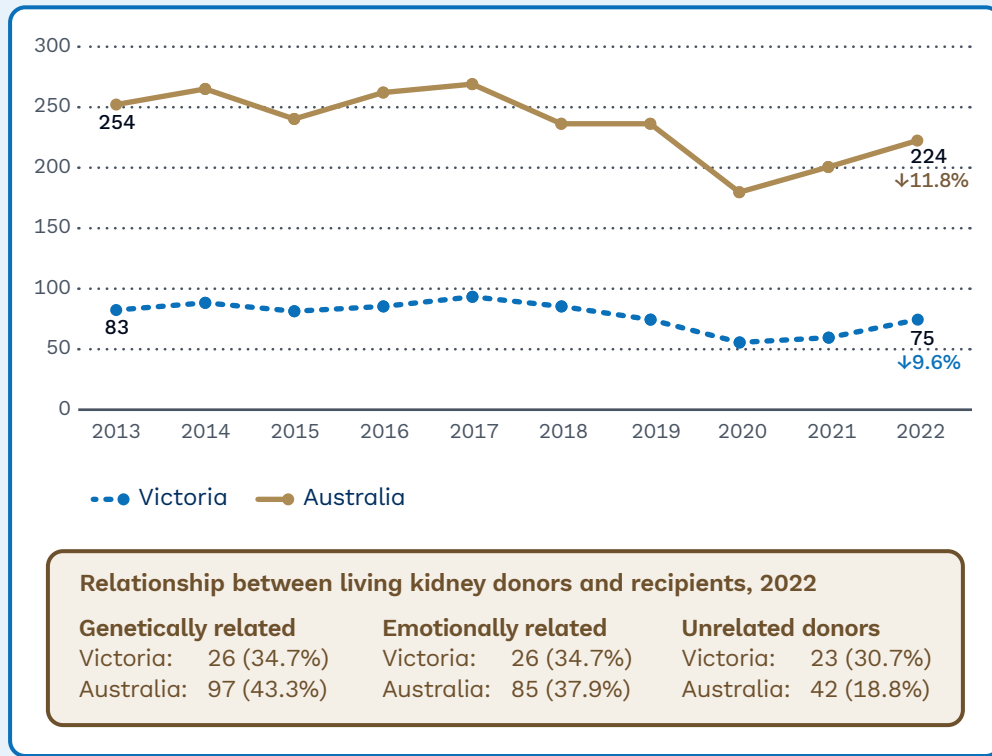
99 NSW Health, *Policy directive—living kidney donation and transplantation*, 2022, p. ii; Kidney Health Australia, *Kidney donation*, n.d., <<https://kidney.org.au/your-kidneys/treatment/kidney-transplants/kidney-donation>> accessed 12 October 2023. Nephrologists are medical doctors that specialise in the care of kidneys.

100 Australian Healthcare Associates, *Factors contributing to the decline in living organ donations: Final report December 2013*, 2013, pp. 9–11.

101 Ibid.

102 ANZDATA, *Living kidney donation data report for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, September 2023, pp. 2–3.

Figure 6.4: Number of living kidney donors in Australia and Victoria, 2013–2022



Source: Australia and New Zealand Living Kidney Donation Registry, *Monthly report on living kidney donation in Australia, December 2022, 2023*, pp. 4–5; Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), *Living kidney donation data report for Victorian Legislative Assembly’s Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors*, 2023, p. 1. Unrelated donors commonly donate through the ANZKX but can donate directly to a person on the transplant waitlist, see Organ and Tissue Authority, *Information for patients—ANZKX program*, n.d., <<https://www.donatelife.gov.au/for-healthcare-workers/ANZKX/information-patients-anzkx-program>> accessed 12 October 2023.

6.6.1 The need for more living kidney donors

The reasons for declining numbers of living kidney donors are not well understood but there is a recognised need for more donors. A 2013 Australian study on the factors contributing to the decline in living organ donor rates found ‘no conclusive explanation for the decline’, but hypothesised that the:

increased rate of deceased donation had led to a decrease in the waiting list for a deceased donor kidney transplantation ... which ‘took the pressure off’ the need to go ahead with living donation, in the minds of some nephrologists, potential donors and recipients.¹⁰³

¹⁰³ Australian Healthcare Associates, *Factors contributing to the decline in living organ donations*, p. 5. See also Transplant Australia, *Submission 23*, received 18 May 2023, p. 12.

However, since 2013 there has been a 31% increase in the waitlist for kidney transplants.¹⁰⁴ The 2013 study indicated there was consensus in support of lifting living kidney donations and:

broad agreement that if the living donation experience is positive, streamlined and rewarding, and that the donor is given due respect for the gift they are giving, then people may be more inclined to donate, but that optimising outcomes for the donors and recipients should be the primary goal.¹⁰⁵

The Committee did not receive detailed evidence to explain the longstanding decline in living kidney donations, nor is it covered in other past reviews and reports. OTA advised that early in the COVID-19 pandemic, hospital's living kidney donation programs were suspended for some time.¹⁰⁶ Transplant Australia suggested the initial decrease in living donation was 'in direct response to the increase in deceased donation rates'.¹⁰⁷ Transplant Australia advocated for a working group to understand the barriers to increasing living donation, recommending a 'nationally coordinated living donation program' (instead of responsibility falling to individual transplant units) with 'key performance measures to increase living donation to at least the level achieved in 2009' (326 transplants).¹⁰⁸

OTA's 2022–2027 strategic plan includes a goal to 'return donation and transplantation activity to pre-pandemic levels', including by exploring 'further opportunities for living kidney donation with the aim of increasing rates'.¹⁰⁹ The plan sets a target of 14 living organ donors per million population by 2027, which equates to around 380 living donations in Australia per year.¹¹⁰ In 2022, this rate was 8.6 in Australia (surpassing a target of 7.8).¹¹¹ While this metric includes living liver donations, as these occur rarely it predominately relates to living kidney donations.

More living kidney donors can:

- save more lives¹¹²
- provide better early and long-term outcomes for patients because:
 - kidneys from living donors are subject to less stress and damage than kidneys from deceased donors¹¹³

¹⁰⁴ See Chapter 1, Figure 1.6.

¹⁰⁵ Australian Healthcare Associates, *Factors contributing to the decline in living organ donations*, p. 5.

¹⁰⁶ Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 26.

¹⁰⁷ Transplant Australia, *Submission 23*, p. 12.

¹⁰⁸ *Ibid.*, pp. 12, 13. See also Chris Thomas, Chief Executive Officer, Transplant Australia, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 28.

¹⁰⁹ Organ and Tissue Authority, *Strategy 2022–2027*, 2022, p. 4.

¹¹⁰ *Ibid.*, p. 9.

¹¹¹ Organ and Tissue Authority, *Annual report 2022–23*, 2023, p. 20. In 2010, Australia achieved 13.2 in this metric, see Australian Healthcare Associates, *Factors contributing to the decline in living organ donations*, p. 12.

¹¹² Australian Healthcare Associates, *Factors contributing to the decline in living organ donations*, p. 14.

¹¹³ Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 7–8.

- quicker access to a transplant (ideally before dialysis is required) results in better outcomes¹¹⁴
- kidney transplantation improves recipients' long-term quality of life and health prospects, and allows people with kidney failure to 'regain their freedom' to work, travel and return to their lives¹¹⁵
- reduce the time someone waits for a transplant¹¹⁶
- reduce waitlists by increasing the number of kidneys available for transplant¹¹⁷
- improve access to transplants for patients from diverse backgrounds¹¹⁸
- lead to cost-savings by reducing dependence on dialysis (see Chapter 1).¹¹⁹

When considering the benefits of living kidney donation, it is important to consider the potential risks. About a third of Austin Health's transplants involve living donors, higher than the national average. Austin Health noted that a living kidney donation has higher stakes and should not be undertaken lightly, because the surgery has no personal benefit for the donor. It requires healthy donors who can go on to live fulfilling lives after the operation. Austin Health noted that it is 'unlikely' that living donation will replace the need for deceased donors because many patients with kidney failure 'do not have suitably healthy living donors that can give them a kidney or do not have individuals offer to donate them a kidney.'¹²⁰

FINDING 59: The number of Victorian and Australian living kidney donors has decreased over the past ten years. But increasing living kidney donor rates can save lives, provide better early and long-term outcomes for patients who receive a transplant, reduce the time spent waiting for a kidney transplant and kidney transplant waitlists, and lead to cost savings by reducing dependence on kidney dialysis.

6.7 Opportunities to improve living kidney donation rates

The Australian Government's *Supporting Living Organ Donors Program* provides financial support to living donors, including reimbursement to employers to provide paid leave to their employees (342 hours, approximately 14 days at minimum wage) and reimbursement for out-of-pocket expenses (up to \$1,000).¹²¹ This includes

¹¹⁴ Ibid.

¹¹⁵ Austin Health, *Submission 34*, p. 4, with sources.

¹¹⁶ Transplant Australia, *Submission 23*, p. 12; Associate Professor John Whitlam, *Transcript of evidence*, pp. 7–8.

¹¹⁷ Associate Professor John Whitlam, *Transcript of evidence*, pp. 7–8.

¹¹⁸ Transplant Australia, *Submission 23*, p. 12.

¹¹⁹ Australian Healthcare Associates, *Factors contributing to the decline in living organ donations*, p. 14.

¹²⁰ Associate Professor John Whitlam, *Transcript of evidence*, pp. 7–8.

¹²¹ Department of Health and Aged Care, *Supporting Living Organ Donors Program*, 2 June 2023, <<https://www.health.gov.au/our-work/supporting-living-organ-donors-program>> accessed 14 September 2023; Monash Bioethics Centre, *Submission 37*, received 1 June 2023, p. 2; Department of Health and Aged Care, *Supporting living organ donors program—Guidelines: Version 5 March 2021*, 2021, p. 9.

accommodation (based on reasonable amounts), economy airfares, public transport and taxi fares, car hire, parking, petrol and road tolls. Other expenses such as meals, childcare and medical expenses cannot be claimed.¹²²

The Victorian and Tasmanian Transplantation Committee recommended to expand the living kidney donor program and ‘improve funding to cover assessment tests, other health costs and lost wages’.¹²³ Austin Health observed ‘a sense’ in Australia that more could be done to support living donors for the associated time and cost.¹²⁴ Transplant Australia advocated for an education program so potential living donors have enough information to make the right choice.¹²⁵

Jeff Ryall shared with the Committee his experience becoming a living kidney donor and highlighted how there is a general lack of awareness in the community about living donation and what it involves.

Jeff, living kidney donor

Jeff is a living kidney donor for his 40 year old son. He identified there is little awareness about the opportunity to be a living donor, explaining:

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. I wouldn't know that had I not gone through the entire medical work up. There's apparently 1800 people on the wait list, whose lives are greatly impacted, and could be transformed by transplant. So they could increase donorship by greater promotion that they can do it while alive.

Jeff said he would definitely be a living donor for family, probably for friends and acquaintances, and maybe for an unknown person: ‘This requires a level of altruism that really tests one.’

A secondary benefit to Jeff’s donation is that it required him to maintain and improve his health leading up to the operation, particularly because his son depended on him. Jeff said his engagement with Austin Health has been ‘outstanding’ and a ‘personally enriching experience’:

50 years ago, people died. Now they have a second opportunity at life. I feel grateful to be able to do that for my son.

Source: Jeff Ryall, *Submission 46*, received 5 October 2023.

¹²² Department of Health and Aged Care, *Supporting living organ donors program—Guidelines*, p. 9.

¹²³ Victorian and Tasmanian Transplantation Committee, *Submission 39*, received 2 June 2023, p. 1.

¹²⁴ Associate Professor John Whitlam, *Transcript of evidence*, p. 13.

¹²⁵ Transplant Australia, *Submission 23*, p. 12. See also Chris Thomas, *Transcript of evidence*, p. 28.

Monash Bioethics Centre (MBC), who undertake research into biomedicine, technology and healthcare ethics,¹²⁶ made a submission about facilitating living and deceased donation through four conceptual categories of financial gain. MBC's submission contended that reimbursement, compensation and reward are compatible with the paradigm of donation as 'gift-giving' as they do not induce someone to act a certain way but mitigate the disincentives or honour the action:

- **Reimbursement** involves counteracting the financial costs associated with a course of action (but not leaving someone financially better off). Donor reimbursement, such as travel costs, lost wages and expenses incurred while recovering, is appropriate as it seeks to facilitate altruistic donation by mitigating some disincentives to donate.
- **Compensation** involves counteracting the disadvantages of doing something (for example, time, effort or suffering) with the aim to return the compensated party to their former baseline of wellbeing. Donor compensation, such as a financial entitlement for risks to health and wellbeing, is appropriate if carefully implemented to avoid being so generous as to motivate donors who would not donate in the absence of the entitlement.
- **Reward** involves recognising service, effort or achievement (financial or otherwise). Donor rewards are appropriate if carefully implemented to ensure they do not constitute an incentive.¹²⁷

The final category, financial inducement, involves financial benefits or incentives that outweigh any drawbacks—it involves trying to get somebody to do something they would not otherwise be inclined to do, if not for the inducement.¹²⁸ Both financial and indirectly financial (like tax credits or health insurance discounts) inducements are incompatible with donation as gift-giving for both deceased and living donors.¹²⁹

MBC noted there are further opportunities to promote living donation and address waitlists. Living donation should be financially neutral for donors and Australia's current *Supporting Living Organ Donors Program* more generous.¹³⁰

¹²⁶ Monash University, *Monash Bioethics Centre: About*, n.d., <<https://www.monash.edu/arts/bioethics/about>> accessed 8 January 2024.

¹²⁷ Monash Bioethics Centre, *Submission 37*, pp. 1–2; Dr Julian Koplin, Lecturer, Monash Bioethics Centre, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, pp. 13–14.

¹²⁸ Dr Julian Koplin, *Transcript of evidence*, p. 13.

¹²⁹ Monash Bioethics Centre, *Submission 37*, pp. 1–2; Dr Julian Koplin, *Transcript of evidence*, pp. 13–14.

¹³⁰ Monash Bioethics Centre, *Submission 37*, pp. 2–3; Dr Julian Koplin, *Transcript of evidence*, p. 14.

The Committee received evidence about further and different types of support that are provided for living donors in New Zealand and Israel.¹³¹ Australia had a kidney transplant from living donors per million population rate (KTLDPMP) of 8.66 in 2022,¹³² but comparatively:

- New Zealand had a KTLDPMP of 13.87 in 2022.¹³³ New Zealand provides financial compensation for loss of earnings (up to 12 weeks), travel and accommodation.¹³⁴
- Israel had a high KTLDPMP at 33.75 in 2022.¹³⁵ Israel's support framework includes reimbursement for psychological treatment, a certificate of appreciation and lifetime free entry to all national parks and nature reserves.¹³⁶

It is noted that the Netherlands also had a high KTLDPMP at 30 in 2022.¹³⁷ The Netherlands provides reimbursement for medical costs not covered by private health insurance, childcare, travel and accommodation to and from hospital—for the donor and a person accompanying them—as well as a fixed sum for minor hospital costs.¹³⁸ A contribution towards a mandatory council fee for municipal support to help people live at home is also provided.¹³⁹

By way of example, for egg donors in Australia, while 'direct or indirect inducements are prohibited', it is considered reasonable for a donor to be reimbursed by a clinic or recipient for a range of verifiable out-of-pocket expenses. This includes medical and counselling costs before and after donation, travel and accommodation costs, loss of earnings, insurance, childcare and legal advice.¹⁴⁰

The Committee notes that the 2012 *Inquiry into organ and tissue donation in Victoria* also found costs like travel, meals, accommodation, loss of income and childcare deter people from becoming living donors. It recommended the Victorian Government consider a reimbursement scheme for living donors to cover reasonable expenses.¹⁴¹

¹³¹ For example, see Monash Bioethics Centre, *Submission 37*, pp. 3–4; Dr Julian Koplin, Inquiry into increasing the number of registered organ and tissue donors hearing, response to questions on notice received 24 July 2023, p. 1.

¹³² International Registry in Organ Donation and Transplantation, *Database*, 4 January 2024, <<https://www.irodat.org/?p=database#data>> accessed 29 January 2024.

¹³³ Ibid.

¹³⁴ New Zealand Ministry of Health, *Compensation for live organ donors: Information pack*, Ministry of Health, Wellington, 3 December 2017; New Zealand Ministry of Health, *Compensation for loss of earnings*, 13 August 2021, <<https://www.health.govt.nz/your-health/conditions-and-treatments/treatments-and-surgery/organ-donations-and-transplants/live-organ-donation/compensation-loss-earnings>> accessed 21 November 2023.

¹³⁵ International Registry in Organ Donation and Transplantation, *Database*.

¹³⁶ Monash Bioethics Centre, *Submission 37*, p. 2.

¹³⁷ International Registry in Organ Donation and Transplantation, *Database*.

¹³⁸ Government of the Netherlands, *Can I be reimbursed for the cost of living organ donation?*, n.d., <<https://www.government.nl/topics/organ-tissue-donation/question-and-answer/reimbursed-cost-organ-donation>> accessed 21 November 2023.

¹³⁹ Government of the Netherlands, *Social Support Act (Wmo 2015)*, n.d., <<https://www.government.nl/topics/care-and-support-at-home/social-support-act-wmo>> accessed 21 November 2023.

¹⁴⁰ Ibid., p. 3; National Health and Medical Research Council, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (updated 2023)*, Canberra, 2017, p. 32; Australian Parliament, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp. 55–56; IVF Australia, *Egg donation: a guide to the donation process*, 2022, p. 16; Melbourne IVF, *Become an egg donor*, n.d., <<https://www.mivf.com.au/our-donor-bank/become-an-egg-donor>> accessed 30 January 2024.

¹⁴¹ Parliament of Victoria, Legislative Council Legal and Social Issues References Committee, *Inquiry into organ donation in Victoria*, March 2012, p. 79.

FINDING 60: Increasing support for living donors may help reduce some of the barriers and potential financial burden to becoming a living donor.

RECOMMENDATION 35: The Victorian Department of Health consider methods to provide greater support for living donors and advocate to the Australian Government for the *Supporting Living Organ Donors Program* to be expanded.

Part 3: Other types of living donation

Lifeblood is responsible for some other types of living donations, including:

- Donated human breast milk from mothers who have had full-term babies. Lifeblood collects, processes and tests the milk before sending it to neonatal intensive care units for treatment of extremely premature babies. This occurs in most states and Lifeblood is considering opportunities for expansion.
- Faecal microbiota transplants to treat a certain gut condition. It is centred in Western Australia but is supplied nationally, including to Alfred Health.¹⁴²

These are relatively new forms of living donation. However, as mentioned in Section 6.4.4, Lifeblood is limited in what it can do to increase any type of donation other than blood because of its consent practices. Lifeblood can conduct general donation awareness campaigns but identified opportunities to expand this.¹⁴³

Donated egg and sperm are other forms of living donation (see Chapter 1). As the Committee did not receive evidence in relation to these they are not discussed.

¹⁴² Stuart Chesneau, *Transcript of evidence*, p. 44.

¹⁴³ *Ibid.*, pp. 45, 50.

Chapter 7

Health settings and further opportunities to increase donation rates

Throughout the Inquiry, the Committee heard from many expert witnesses deeply committed to increasing organ and tissue donation and transplantation rates.

While the Committee's evidence gathering focused on ways to increase the number of registered organ and tissue donors, witnesses provided evidence that highlighted other opportunities to improve donation rates.

Much work has been done nationally and in hospitals to reduce logistical barriers to donation, requiring 'whole-of-health-care investment—right from the community aspect of it to the hospital and then aftercare'¹—but further opportunities exist to increase donation rates.

This chapter considers some of the ways, other than registration on the Australian Organ Donor Register (AODR), to further enhance donation opportunities in Victoria that were raised by inquiry participants. It discusses tissue donation governance and logistics, and donation in rural and regional settings. It also examines considerations at end of life, such as donor identification and extended criteria organ donors, medical technologies, coroners' consent decisions, voluntary assisted dying and advance care planning.

7.1 Tissue governance and logistics

The Donor Tissue Bank of Victoria (DTBV) is the main multi-tissue bank in the State. The Melbourne Lions Eye Donation Service (LEDS) facilitates eye tissue donation and the Barwon Heads Bone Bank (located in University Hospital Geelong) stores femoral heads from living donors undergoing hip replacements.²

Chapter 1 explains deceased tissue donation. Living tissue donation includes amnion and cardiovascular tissue, but in Victoria most living tissue donations are musculoskeletal in the form of bone tissue taken when undergoing joint replacement surgery.³

1 Dr Rohit D'Costa, State Medical Director, DonateLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*.

2 Barwon Health Bone Bank, *Therapeutic Goods Order: standards for minimising infectious disease transmission via therapeutic goods that are human blood and blood components, human tissues and human cellular therapies: consultation submission*, 2010, pp. 1–2. DTBV and LEDS are discussed in Chapter 2.

3 Australia and New Zealand Eye and Tissue Donation Registry (ANZETD), *Eye and tissue donation in Australia, monthly report July 2023: preliminary data*, 2023, pp. 22, 32.

Several challenges exist to maximising deceased tissue donation opportunities in Victoria.

7.1.1 Victoria's supply and demand for tissue

The statistics on living and deceased tissue donation in Victoria show a complex story.

Victoria's number of living tissue donors decreased by 79% from 620 in 2015 to 130 in 2022. This compares to a national decrease of 37% from 3,928 in 2015 to 2,472 in 2022.⁴ Victoria's number of living tissue donors in 2022 was also significantly lower than other states, with New South Wales (NSW) at 1,262 and Queensland at 224.⁵

A key reason for Victoria's decrease in living tissue donors is that the preferred product of DTBV's customers, the freeze-dried Cancellous Bone Matrix (CBM), cannot be manufactured at scale from living donations. Due to this and the COVID-19 pandemic,⁶ DTBV reduced its living donor program which collects bone tissue from patients undergoing hip replacements and cardiac valves from heart recipients.⁷

Across all jurisdictions and in Victoria over time, one living tissue donor generally results in one tissue donation.⁸ However, one deceased tissue donor in Victoria results in up to 100 times more tissue product than a living bone tissue donation.⁹

Victoria's number of deceased tissue donors and donations has decreased since 2015 (see Figure 7.1) and in 2022 Victoria had fewer deceased donors and donations than NSW and Queensland.¹⁰ However, in 2022 Victoria also experienced:

- a greater proportion of its total tissue donors being deceased donors at 32%¹¹ compared to 7.7% in NSW¹² and 27% in Queensland¹³

4 Committee calculation: $(620 - 130) / 620 \times 100 = 79$; $(3928 - 2472) / 3928 \times 100 = 37$, see ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, 2023, p. 8; ANZETD, *Eye and tissue donation in Australia, 2015 year end report*, 2016, p. 6.

5 ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, p. 8.

6 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, received 2 November 2023, pp. 4–5.

7 Victorian Institute of Forensic Medicine, *Annual report 2021–22*, 2022, p. 63.

8 For example, in 2022, 2,472 donors resulted in 2,484 donations, see ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, pp. 8, 22. In 2018, 3,810 donors resulted in 3,881 donations, see ANZETD, *Eye and tissue donation in Australia, quarterly report January–December 2018: preliminary data*, 2019, pp. 6, 8. In 2015, 3,528 donors resulted in 3,973 donations, see ANZETD, *Eye and tissue donation in Australia, 2015 year end report*, pp. 6, 9.

9 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, pp. 4–5.

10 ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, pp. 11, 22. The Committee notes that it has compared Victoria against NSW and Queensland because these states are the most comparable based on both population size and volume of deceased tissue donors and donations.

11 Committee calculation: $60 + 130 = 190$. $(60 / 190) \times 100 = 31.57\%$, see ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, p. 8.

12 Committee calculation: $105 + 1262 = 1366$. $(105 / 1366) \times 100 = 7.68\%$, see ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, p. 8.

13 Committee calculation: $83 + 224 = 307$. $(83 / 307) \times 100 = 27.03\%$, see ANZETD, *Eye and tissue donation in Australia, monthly report December 2022: preliminary data*, p. 8.

- the second highest average rate of deceased tissue donors per million state population at 13.8 compared to 12.1 in NSW and 23.7 in Queensland¹⁴
- more donations from individual deceased donors than other states, with a donor to donation ratio of 1.667 compared to 1.029 in NSW and 1.307 in Queensland (Victoria's ratio also increased from 1.757 in 2015 to 2.045 in 2021, before decreasing in 2022)¹⁵
- more growth as DTBV supplied 1,103 total tissue grafts for transplantation in 2014–15, 1,941 in 2020–21 and 4,569 in 2022–23 (representing a 314% increase from 2014–15 to 2022–23).¹⁶

There are several reasons for the disparity in the number of deceased tissue donors and donations between the states. Tissue banks in Australia operate under different governance structures and production processes.¹⁷ For example, the main tissue banks in Queensland, NSW and Western Australia (WA) receive 'rapid electronic notification of a person's death in their hospitals' leading to more timely discussions to obtain consent and retrieve tissue.¹⁸ The main tissue banks in NSW and Queensland are also located in their health departments, whereas in Victoria DTBV is 'somewhat of an anomaly' being located in the Department of Justice and Community Safety (DJCS).¹⁹

The market for tissue products—known as allografts—also differs between products. For example, the 'skin and cardiac allograft markets are not competitive as the cost of production is extremely high and tissues are limited', and both allograft types are in short supply. Tissue banks are working 'co-operatively to meet patient needs for skin and cardiac allografts and are currently aiming to set up a national register of skin allograft inventory'.²⁰ In comparison, the bone and tendon allograft market is competitive and dominated by the only for-profit manufacturer in Australia (Australian Biotechnologies). But currently domestic bone donations do not meet local need and some is imported from overseas. In this context, not-for-profit tissue banks cannot be passive to maintain prominence in the market.²¹

¹⁴ Committee calculation: NSW: (12.3 + 15.0 + 13.8 + 15.0 + 10.6 + 9.0 + 8.3 + 12.7) / 8 = 12.0875; Vic: (16.9 + 18.3 + 14.6 + 12.2 + 13.0 + 12.5 + 13.6 + 8.9) / 8 = 13.75; Qld: (28.3 + 34.2 + 25.6 + 19.8 + 21.1 + 19.7 + 25.3 + 15.4) / 8 = 23.675, see Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, p. 5.

¹⁵ See Figure 7.1.

¹⁶ While this partly reflects requests from surgeons for tissue, the Committee recognises DTBV's increased output. Committee calculation: Allografts in 2014–15 (37 + 78 + 507 + 481 = 1103). Allografts in 2020–21 (17 + 140 + 569 + 1215 = 1941). Allografts in 2022–23 (23 + 159 + 747 + 3640 = 4569). Percentage increase in allografts 2014–15 to 2022–23 ((4569 - 1103 = 3466) / 1103 x 100 = 314.23%), see Victorian Institute of Forensic Medicine, *Annual report 2022–23*, p. 68; Victorian Institute of Forensic Medicine, *Annual report 2017–18*, 2018, pp. 68–69.

¹⁷ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40a*, p. 4.

¹⁸ ANZICS Death and Organ Donation Committee, *Submission 41a*, received 18 August 2023, p. 1.

¹⁹ QFinder, *Queensland Tissue Bank*, n.d., <<https://qfinder2.health.qld.gov.au/HealthServiceProvider/Index/6457528a-af36-e611-80d2-00505601056f>> accessed 19 December 2023; Associate Professor William Silvester, Chair, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 33; Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 38.

²⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, received 16 June 2023, pp. 5–6.

²¹ *Ibid.*, p. 6.

While differences between state tissue banks account for some variance in donors and donations, the statistics highlight improvements can be made to increase the number of deceased tissue donors in Victoria. Both DTBV and the Australia and New Zealand Intensive Care Society Death and Organ Donation Committee (ANZICS DODC) recognise this.²²

DTBV's further growth would allow it to operate at scale, reduce costs and provide more tissue products. DTBV advised the 'number of [deceased] tissue donors has stagnated over the past 15 years despite population growth.'²³ DTBV estimates it requires 100–130 deceased donors per year (and future growth should align with population growth) to operate efficiently at scale and meet demand.²⁴ This means Victoria would need to almost double the number of deceased tissue donors from 2022.

DTBV is at risk of 'running out of the stockpiles of bone that are supporting its current allograft supply volumes, renewal and future.'²⁵ If DTBV runs out, it will have to restrict its supply of tissue products to hospitals and will be 'solely dependent upon donors as they become available—creating a secondary risk of unreliable supply.' DTBV suggested its 'survival depends upon a guaranteed and increased supply of donors and corresponding guaranteed supply to the market.'²⁶

Promoting Victorian tissue production supports Victorian-based jobs and manufacturing and the international market will not always meet supply for some tissue products, like skin and cardiovascular, because it is unprofitable.²⁷ Alfred Health—where nearly all DTBV's skin donations go—prefers DTBV's tissue processing method, seeking skin tissue from NSW in the past only when DTBV could not meet demand.²⁸ DTBV explained its:

preference is to leverage the goodwill of the local community rather than import retrieved human bone from other jurisdictions and contribute to a foreign economy. Further, within the DTBV's surgical community there is definite preference for local product. These surgeons trust the DTBV and appreciate onshore access to a supplier. Those surgeons who are innovators appreciate that they can talk to the DTBV directly and get specific sized bone grafts designed for the nature of their surgical speciality.²⁹

²² Ibid., p. 1; ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1.

²³ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 9.

²⁴ Ibid.

²⁵ Ibid., p. 7.

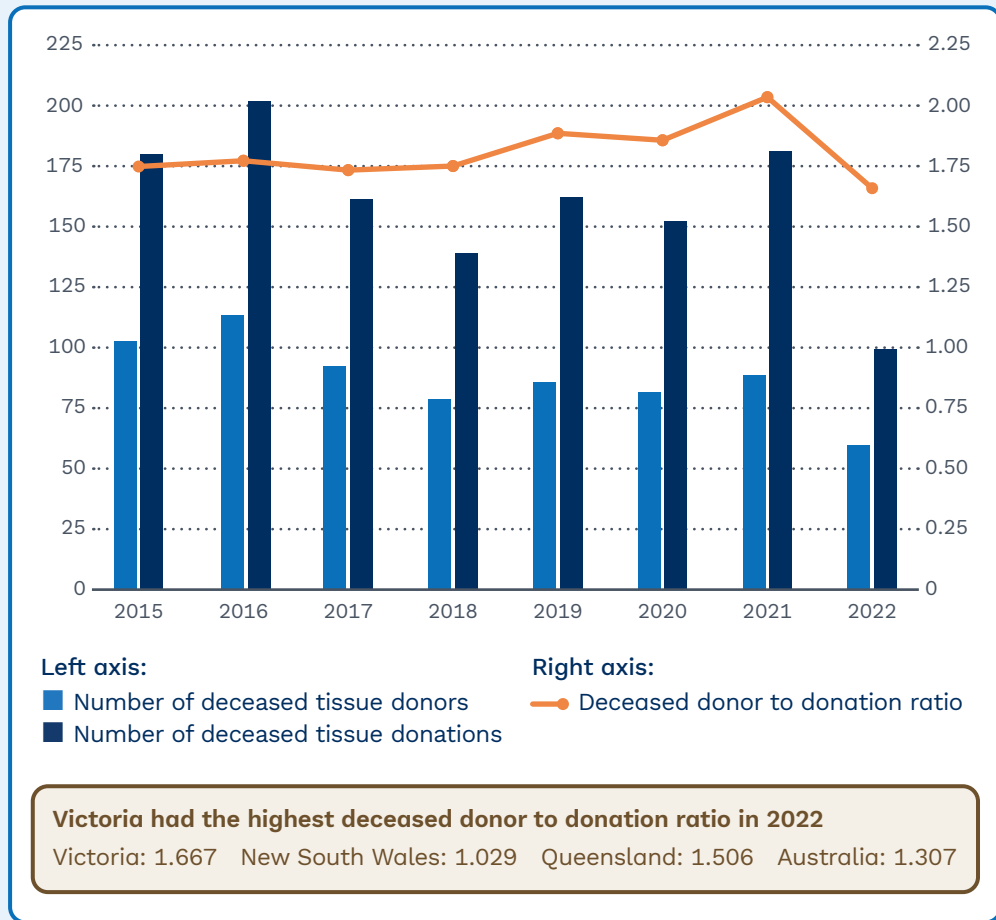
²⁶ Ibid.

²⁷ Ibid., pp. 7–8.

²⁸ Brendan Sullivan, *Transcript of evidence*, p. 48.

²⁹ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 8.

Figure 7.1: Number of deceased tissue donors and donations and donor to donation ratio in Victoria, 2015–2022



Source: ANZETD: *Eye and tissue donation in Australia, monthly report December 2022: preliminary data, 2023*, pp. 8, 22; *Eye and tissue donation in Australia, monthly report December 2021: preliminary data, 2022*, pp. 8, 22; *Eye and tissue donation in Australia, monthly report December 2020: preliminary data, 2021*, pp. 8, 22; *Eye and tissue donation in Australia, monthly report December 2019: preliminary data, 2020*, pp. 8, 22; *Eye and tissue donation in Australia, quarterly report January–December 2018: preliminary data, 2019*, pp. 6, 9; *Eye and tissue donation in Australia, 2017 year end report, 2018*, pp. 6, 9; *Eye and tissue donation in Australia, 2016 year end report, 2017*, pp. 6, 9; *Eye and tissue donation in Australia, 2015 year end report, 2016*, pp. 6, 9. Deceased donor to donation ratio is based on a Committee calculation.

FINDING 61: The number of deceased tissue donors in Victoria has decreased since 2015 and the Donor Tissue Bank of Victoria (DTBV) is at risk of running out of its stockpile of bone tissue. It is essential to increase the number of deceased tissue donors in Victoria for DTBV to operate efficiently at scale and meet demand in the Victorian market.

7.1.2 Awareness and communication in the tissue donation sector

DTBV identified there are ‘good and viable opportunities to improve tissue donation rates’ through a ‘holistic response ... to transform tissue donation into a streamlined and simple process’.³⁰ This is important as deceased tissue donation must occur within a ‘time critical 24-hour window.’ DTBV outlined the current process ‘has numerous barriers and delays which can lead to the loss of a tissue donation’:³¹

the clock starts ticking, and the difference between us and organ donors is that there can be a certain amount of planning with organ donation. In terms of withdrawal of support, it is often planned in advance so surgical teams can arrive, but the information deficit or the lack of communication with us often means that we are the last in the chain to find out, and the clock has been ticking all of that time.³²

Delays in communicating about deceased tissue donation between different stakeholders and accessing medical information can prevent a donation from occurring.³³ A key contributor to this is low awareness of the potential for deceased tissue donation (both separate to and alongside organ donation) and the role of DTBV amongst the community, medical professionals and in hospitals.³⁴ Dr Kean Kuan, Chief Medical Officer and Deputy Director at the Victorian Institute of Forensic Medicine (VIFM) stated:

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.³⁵

DonateLife Victoria (DLV) and DTBV should work collaboratively to increase awareness of tissue donation and improve the identification of potential tissue donors. Brendan Sullivan, Head of Service at DTBV would like to continue DTBV’s collaboration with DLV and for extra resources to strengthen the relationship and promote tissue donation:

[DLV] are the ones on the floor in the hospitals and we are not, so we cannot really make a claim that we would like to be in hospitals alongside them and waste resources. We would much rather have a collaboration that works closer, and we have improved our relationship over time with [DLV].³⁶

³⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 1.

³¹ *Ibid.*, p. 3.

³² Professor Noel Woodford, Director, Victorian Institute of Forensic Medicine, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 47.

³³ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 9. Tissue donation education in the health sector is discussed in Chapter 4. Tissue donation awareness in the community is discussed in Chapter 5.

³⁴ *Ibid.*, pp. 3, 12; Brendan Sullivan, *Transcript of evidence*, p. 40.

³⁵ Quote from Dr Kean Kuan, Deputy Director and Chief Medical Officer, Victorian Institute of Forensic Medicine, correspondence, 4 September 2023, p. 1. See also Professor Noel Woodford, *Transcript of evidence*, p. 41.

³⁶ Brendan Sullivan, *Transcript of evidence*, p. 52.

FINDING 62: Deceased tissue donation opportunities are being lost in Victoria because communication between different stakeholders and access to medical information is often delayed. There is a lack of awareness and understanding in the medical community about the Donor Tissue Bank of Victoria and the tissue donation process.

One method to reduce communication delays is to facilitate ‘real-time reporting of deaths by hospitals’ to DLV, LEDS and DTBV to identify and assess potential donors more easily and quickly.³⁷ This practice is used in some other jurisdictions, like NSW and Queensland.³⁸ DTBV explained that notification of a death or impending death in hospital does not occur automatically in Victoria but depends on good working relationships with hospital-based DLV staff.³⁹

DTBV suggested that establishing ‘a centralised information hub’ for hospitals, general practitioners (GPs) and police to report deaths could be a way to better identify potential tissue donors and facilitate real-time reporting.⁴⁰ Basic information about the deceased person and an automatic filter could be included so that DTBV or DLV could only view the records of potential donors.⁴¹ DTBV identified this would be a ‘substantial project’ but worthwhile as ‘it has the potential to pay for itself through the increased availability of organs and tissues for transplantation.’⁴²

St Vincent’s Hospital Melbourne’s Organ and Tissue Donation Team (St Vincent’s OTD) explained it currently does not automatically notify DTBV of deaths:

We have not revisited that process at St Vincent’s in the recent past, but the last time we revisited it the organisation had concerns about an unrelated party, [DTBV], contacting a bereaved family immediately after the death of their loved one. I know that the tissue bank have experience with that, but they have experienced it through the coronial process, so families already know that their loved one is in the coronial process. When they receive a phone call from the [DTBV] it is not that much of a shock because they know their family member is in the coronial process. The decision was made at St Vincent’s that if a phone call was going to occur, it should occur from a hospital person, not a [DTBV] employee.⁴³

DTBV advised the Committee that it has experienced a number of delays that impact potential tissue donations, including:

- DTBV cannot access any hospital system and reported that hospital staff might delay responding to requests for records, ‘thereby hampering the process of

³⁷ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 1, 3, 17.

³⁸ Associate Professor William Silvester, *Transcript of evidence*, pp. 39–40; ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1. The main tissue banks in NSW and Queensland are located in their respective health departments.

³⁹ Brendan Sullivan, *Transcript of evidence*, p. 40.

⁴⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 3, 15, 17.

⁴¹ *Ibid.*, p. 11.

⁴² *Ibid.*, p. 15.

⁴³ Dr Bernadette Hickey, Senior Intensivist and Medical Donation Specialist, St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 50.

assessing the potential donor's suitability and obtaining consent.⁴⁴ DTBV believes its inability to access hospital records is an 'unintended consequence of the separation of the health and justice systems', as DTBV sits within the Victorian DJCS rather than the Department of Health (DH).

- While DTBV has the authority to collect and use health information in relation to tissue donation, DTBV's experience is that hospitals and GPs are reluctant to release information.⁴⁵
- The release of a deceased body from a hospital mortuary to the dedicated tissue retrieval site at Southbank can be delayed.⁴⁶

Another way to improve tissue donation rates in Victoria is to facilitate DTBV's direct access to key health information and hospital records to quickly screen donors and assess their suitability.⁴⁷ DLV assists with obtaining records for organ and tissue donations, but this is harder for tissue-only donations.⁴⁸ Allowing DTBV direct access could alleviate the burden on DLV as the 'conduit for patient information'.⁴⁹ DTBV recommended establishing protocols between itself and all Victorian hospitals to facilitate access to patient information.⁵⁰ ANZICS DODC also recommended 'the Victorian Government establish a method of electronic communication between [DH] and the DTBV'.⁵¹

DTBV advised that 'delays in obtaining medical records to facilitate the final review and confirmation of the suitability of the donated tissue,' means it can take up to 18 months to process and release a tissue product. DTBV would ideally like to release tissue products within 6 to 12 months.⁵²

The Committee notes that a contributing factor to communication and information-sharing delays is that DTBV, as an entity of the VIFM, sits within DJCS. This can make it challenging for DTBV to access hospital records that sit within DH.⁵³

FINDING 63: Collaboration between DonateLife Victoria, the Donor Tissue Bank of Victoria and Victorian hospitals is essential for the identification and referral of potential deceased tissue donors and to increase understanding of tissue donation in the medical community.

44 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 11, 15.

45 *Ibid.*, pp. 14–15.

46 *Ibid.*, p. 12; Chantel Bartolo, Nurse Manager and Tissue Donation Nurse Specialist, Donor Tissue Bank of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 40.

47 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 3, 14.

48 Chantel Bartolo, *Transcript of evidence*, p. 40.

49 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 14.

50 *Ibid.*, pp. 14, 15. See also Samantha Francis-Pester, *Submission 28*, received 19 May 2023, p. 2.

51 ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1; Associate Professor William Silvester, *Transcript of evidence*, p. 33.

52 Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 12.

53 Professor Noel Woodford, *Transcript of evidence*, p. 47; Brendan Sullivan, *Transcript of evidence*, p. 48.

RECOMMENDATION 36: The Victorian Department of Justice and Community Safety and Victorian Department of Health better support DonateLife Victoria and the Donor Tissue Bank of Victoria to increase understanding about tissue donation in the medical community and publicly report on progress.

RECOMMENDATION 37: The Victorian Government explore options and consult with other states with similar initiatives to:

- notify DonateLife Victoria, Melbourne Lions Eye Donation Service and the Donor Tissue Bank of Victoria (DTBV) about deaths that potentially involve organ and tissue and tissue-only donations in real time
- facilitate better sharing of hospital medical records and patient information with DTBV, which may involve seeking better working relationships between agencies in the Victorian Department of Health and Victorian Department of Justice and Community Safety (DJCS)
- consider the appropriateness of DTBV being situated within DJCS.

7.1.3 Eye and tissue donation in national frameworks

The *Transition Action Plan* (TAP) for the draft *National strategy for organ donation, retrieval and transplantation* (draft National Organ Strategy) released in August 2022 considers the eye and tissue sector in some detail. One action is to agree to the scope of the Organ and Tissue Authority's (OTA) role in the eye and tissue sector. This could enhance stakeholder collaboration and efficiency across the sector.⁵⁴ The Australian Department of Health and Aged Care (DHAC) advised the role of OTA is being considered through ongoing Jurisdictional Organ and Tissue Steering Committee (JOTSC) discussions and will require agreement by all states and territories.⁵⁵ Other actions in the TAP relevant to the eye and tissue sector include to:

- 'settle future governance arrangements' to support the implementation of the *National Eye and Tissue Sector Framework*⁵⁶
- develop robust data on deceased eye and tissue donation to support the sustainability of the sector⁵⁷

⁵⁴ Department of Health and Aged Care, *Transition Action Plan: National organ and tissue donation, retrieval and transplantation system*, 2022, p. 5. The draft National Organ Strategy and TAP are discussed in Chapter 2.

⁵⁵ Department of Health and Aged Care, *Inquiry into increasing the number of registered organ and tissue donors*, response to written questions on notice received 15 August 2023, p. 3. The JOTSC is comprised of Commonwealth, OTA and state and territory government representatives.

⁵⁶ Department of Health and Aged Care, *Transition Action Plan*, p. 4. The *National Eye and Tissue Sector Framework* is discussed in Chapter 2.

⁵⁷ *Ibid.*, p. 14.

- '[s]upport further effective engagement between Australian eye and tissue sector stakeholders to collaborate on clinical practice guidelines, professional education and community awareness initiatives.'⁵⁸

The TAP identifies that OTA's Eye and Tissue Advisory Committee—comprising all Australian eye and tissue banks, professional associations and representatives from DHAC and the Therapeutic Goods Administration (TGA)—will:

- support TGA to review its orders to increase eye and tissue donations
- increase community awareness of eye and tissue donation
- provide advice on training and education for the DonateLife Network to support deceased eye and tissue donation clinical best practice in hospitals.⁵⁹

No progress update on the implementation of the TAP was publicly available at the time of this report. It is unclear if a progress update will be released.

DTBV's submission to the Inquiry recommended that the Victorian Government 'undertake a formal review of the tissue donation process with all key stakeholders.'⁶⁰ ANZICS DODC suggested DTBV consult with the main tissue banks in NSW, Queensland and WA and 'comply with a national consensus on inclusion and exclusion criteria and other clinical protocols.'⁶¹

FINDING 64: Improving tissue governance and collaboration in the eye and tissue sector is recognised in the *Transition Action Plan (TAP)* for the draft *National strategy for organ donation, retrieval and transplantation* but it is unclear what action has been taken since the TAP was released in August 2022.

Research and development

DTBV advised it has not been able to invest in research and development because until recently, it 'made significant annual losses.'⁶² In a submission to the Inquiry, DTBV advised that it expected to become self-sufficient in 2023 and hoped to begin investing in new research projects, but its current research 'lags in the market.'⁶³ The Committee confirmed with DTBV that in 2022–23 it was able to 'self-fund its immediate operating costs ... limited to the staff wages, consumables, equipment, and cost of utilities'. While operational costs do not include investment in research and development, DTBV advised this is a 'highly desirable goal'.⁶⁴

⁵⁸ Ibid., p. 16.

⁵⁹ Ibid.

⁶⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 1.

⁶¹ ANZICS Death and Organ Donation Committee, *Submission 41*, received 19 June 2023, pp. 12–13.

⁶² Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 6.

⁶³ Ibid., pp. 6, 8.

⁶⁴ Brendan Sullivan, Head of Service, Donor Tissue Bank of Victoria, correspondence, 15 January 2024.

DTBV outlined it will ‘need new products within [a] 5-year window if it is to stay abreast of competitors and remain viable.’ For example, one of DTBV’s most successful and in demand products, its freeze-dried CBM, was developed from an honours research project commencing in 1995 that took over 20 years to develop ‘because of a lack of resources.’⁶⁵

A 2016 national review of the tissue sector identified the importance of research and development, noting that ‘fostering innovation’ is critical to the Australian tissue sector’s ‘survival and long-term sustainability.’ The review found:

- funding structures did not ‘promote investment in research and development’, constraining the ability of public tissue banks to adapt to changing clinical needs
- the sector’s sustainability ‘rests upon its ability to innovate and meet rapidly changing clinical demand and investigation of funding mechanisms (or incentives) to make this happen is critical.’⁶⁶

The *National Eye and Tissue Framework* published in 2022 states ‘[a]ll Australian governments recognise that research and development is required to address gaps in clinical demand, be responsive to emerging new technologies, and ensure the ongoing sustainability of the Australian eye and tissue sector.’⁶⁷ The framework encourages the sector to ‘pursue opportunities and seek funding to engage in research activities, by accessing research funding available in Australia’. The framework acknowledges ‘there are challenges in seeking funding through competitive processes’ and ‘there should be consideration for reinvestment in upscaling and innovation’⁶⁸ but does not detail how to achieve this.

FINDING 65: The Donor Tissue Bank of Victoria (DTBV) has been unable to invest in research and development due to it making significant annual losses. DTBV’s recent financial self-sufficiency presents an opportunity to invest in research and development to enhance and create tissue products and remain competitive in the market.

7.1.4 Meeting future demand for eye tissue

Since it was established in 1991, LEDS has performed over 7,000 corneal donations and provided eye tissue for over 15,000 transplants.⁶⁹ LEDS currently meets and exceeds demand in Victoria, often providing interstate eye banks with corneas for transplant. But there is the potential for demand to increase, noting it has grown 45% since LEDS was established.

⁶⁵ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 8.

⁶⁶ PwC, *Final report: analysis of the Australian tissue sector, report for Organ and Tissue Authority, 2016*, pp. v, vii.

⁶⁷ Department of Health and Aged Care, *National Eye and Tissue Sector Framework, 2022*, p. 11.

⁶⁸ Ibid.

⁶⁹ Centre for Eye Research Australia, *About the eye bank*, n.d., <<https://www.cera.org.au/lions-eye-donation-service/about-us>> accessed 14 September 2023.

While demand dropped during the COVID-19 pandemic, population growth indicates it could rise in the future.⁷⁰ LEDS advised it would therefore ‘need to seek additional donors, however, [it is] at capacity now, due to [its] current outdated facility.’⁷¹ LEDS stated it has declined eye donations on occasion due to logistical issues, for example:

A donor in Mildura—we just cannot facilitate that unless we get a seat on the plane with the multi-organ team. So we just cannot facilitate that, purely through logistics, but we also cannot facilitate the donation from a logistical point of view and the number of staff that we have. It would be great to have more staff, but we cannot fit them in.⁷²

LEDS advised that to meet future demand it needs a new or refurbished facility to test and process tissue in a sterile environment and allow staff to work in a confidential way (not an open plan office).⁷³ A new facility would also allow for the future development of bioengineered technologies to increase donations.⁷⁴ LEDS is currently located at the Royal Victorian Eye and Ear Hospital.⁷⁵

FINDING 66: The Melbourne Lions Eye Donation Service’s facility for coordinating eye tissue donation, retrieval and testing is at capacity which may prevent it from meeting future increased demand for eye tissue.

RECOMMENDATION 38: The Victorian Department of Health monitor the capacity of the Melbourne Lions Eye Donation Service (LEDS) facility at the Royal Victorian Eye and Ear Hospital and consider the potential for expansion, relocation or a purpose-built facility to ensure LEDS has the capacity to meet future demand.

7.2 Rural and regional donation

Most Victorian donation activity occurs in the metropolitan area. DLV stated ‘about 75 to 80% of [Victoria’s] activity happens within the Melbourne metro area, and then 25 to 30% is in regional and out of metropolitan Melbourne.’⁷⁶ Donors ‘come from all across Victoria’ with ‘all major trauma in Victoria com[ing] to the Alfred or the Royal

70 Melbourne Lions Eye Donation Service, *Submission 18*, received 12 May 2023, p. 1; Bronwyn Cohen, Quality Manager and Acting Director, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 34. LEDS describes meeting demand rather than need, because demand is based on the number of requests from surgeons. Need is based on other requirements, like the capacity of operating theatres and number of surgeons, see Dr Heather Machin, Senior Project Manager, Melbourne Lions Eye Donation Service, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, pp. 37, 41.

71 Bronwyn Cohen, *Transcript of evidence*, p. 31.

72 *Ibid.*, p. 39.

73 *Ibid.*, p. 41.

74 Dr Heather Machin, *Transcript of evidence*, pp. 41–42.

75 Centre for Eye Research Australia, *The Lions Eye Donation Service*, n.d., <<https://www.cera.org.au/lions-eye-donation-service>> accessed 14 September 2023.

76 Tony Holland, General Manager, DonatLife Victoria, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 4.

Melbourne'.⁷⁷ Meaning, while the donation occurs 'within metropolitan hospitals', a number of Victoria's donors 'are people from the regions.'⁷⁸

DLV advised 'nurse donation specialists ... work predominantly in the regional and outer-metro hospitals.' Seven staff are in the 'outer metro and the regional' areas, including 'Albury, Ballarat, Bendigo, Geelong, Northern Hospital and [Mornington P]eninsula.'⁷⁹

Where a donation occurs in a regional area, donor coordinators travel to the site as needed.⁸⁰ DLV stated it has adequate staff to service the State and the base site of donor coordinators does not impact the management of a donation case.⁸¹

LEDS considered it essential that donor coordinators 'are in place in as many facilities as possible'.⁸² An absence of dedicated donation coordinators onsite in regional hospitals can make it harder to embed a donation culture and increase donation knowledge.⁸³ Alfred Health described that 'sometimes it is just the pure logistics of some of our regional centres ... but given the distance of some of the hospitals within the state, it might not be possible for a donation specialist to be present to support that intensive care unit [ICU] or emergency department [ED] to raise organ donation.'⁸⁴ In these circumstances the conversation about donation is undertaken by another clinician who may not have specific training.⁸⁵

Employing donor coordinators in regional health services can help normalise donation, build relationships with local communities and healthcare teams and facilitate the donation consent process.⁸⁶ Alfred Health recognised the potential for regional donation coordinators to be employed part-time or in a dual role.⁸⁷ While acknowledging the benefits of having an onsite donation coordinator to build culture and improve donation knowledge and services in hospitals, DLV confirmed that current arrangements 'never' impact 'the workup of a particular donor.'⁸⁸

⁷⁷ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 7.

⁷⁸ Ibid.

⁷⁹ Tony Holland, DonateLife Victoria, *Transcript of evidence*, p. 4.

⁸⁰ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 5; Anna McNamara, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, pp. 28–29.

⁸¹ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 5; Tony Holland, DonateLife Victoria *Transcript of evidence*, p. 5.

⁸² Bronwyn Cohen, *Transcript of evidence*, p. 32.

⁸³ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 5.

⁸⁴ Georgina Callaghan, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 20.

⁸⁵ Ibid.

⁸⁶ Laura Fleckner, Donation Specialist Nursing Coordinator, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 28; Georgina Callaghan, *Transcript of evidence*, p. 28; Anna McNamara, *Transcript of evidence*, pp. 28–29.

⁸⁷ Georgina Callaghan, *Transcript of evidence*, p. 29; Laura Fleckner, *Transcript of evidence*, p. 29; Dr Joshua Ihle, Senior Intensivist and Clinical Lead of Organ Donation, Alfred Health, public hearing, Melbourne, 19 June 2023, *Transcript of evidence*, p. 29.

⁸⁸ Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 5.

FINDING 67: Supporting rural and regional hospitals to employ donation specialists part-time or in a dual role could help to embed an organ and tissue donation culture and improve donation knowledge for broader hospital staff.

RECOMMENDATION 39: The Victorian Department of Health in consultation with DonateLife Victoria explore the potential for rural and regional hospitals to employ donation specialists part-time or in a dual role to better embed an organ and tissue donation culture and improve donation knowledge for broader hospital staff.

ANZICS DODC described that the shortage of transplant surgeons is a particular challenge for regional areas because longer travel times make logistical coordination harder.⁸⁹ Professor Gregory Snell, the Medical Head of the Lung Transplant Service at Monash University and Alfred Hospital explained in relation to donation after circulatory death (DCD)⁹⁰ in regional areas, that sometimes ‘we do not go to consented organ donors because of the perception of staffing and transport.’⁹¹ Professor Snell advised the current arrangement involves donation nurse coordinators calling aviation companies to negotiate for surgeons to travel to regional or interstate areas (for example, Tasmania) for retrieval. Professor Snell suggested transport arrangements and logistics could be more efficient.⁹²

A 2018 review of the Australian organ donation, retrieval and transplantation system found an ‘increasing volume of organ donations ... has placed pressure on retrieval teams across the country.’⁹³ It identified an ‘impending shortage of resources for retrieval resulting in inefficiencies, risks to quality and safety and the potential to decline retrieval due to logistical reasons’. This was exacerbated by an absence of a ‘national approach to the sourcing or procurement of aviation services for the organ retrieval process.’⁹⁴ The review recommended OTA ‘develop a national organ retrieval resource plan’ and ‘national sourcing of aviation services by the state and territories to support organ retrieval service in a more coordinated manner.’⁹⁵ The draft National Organ Strategy also states: ‘All governments agree to consider elements including national coordination for retrieval and transplantation, and review of efficiencies across the system and workforce planning to build capability and capacity.’⁹⁶

⁸⁹ Associate Professor William Silvester, *Transcript of evidence*, p. 36. See also Robert Manning, closed hearing, Melbourne, 25 August 2023, *Transcript of evidence*, p. 11.

⁹⁰ DCD is discussed in Section 7.3.2.

⁹¹ Professor Gregory Snell, Medical Head, Lung Transplant Service, Monash University and Alfred Hospital, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 13.

⁹² *Ibid.*, pp. 13, 15, 19.

⁹³ EY, *Review of the Australian organ donation, retrieval and transplantation system: final report*, report for Australian Department of Health and Aged Care, 2018, p. [127].

⁹⁴ *Ibid.*, p. [130].

⁹⁵ *Ibid.*, p. [131].

⁹⁶ Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, May 2022, p. 9.

Austin Health Transplant Infectious Diseases Clinical Service (Austin Health TIDCS) advised that coordinating additional sampling and microbiological testing to ascertain donor suitability can cause delays in donor evaluation and transplants, particularly for regional donors or those with cultural and religious burial requirements. To expedite the assessment of donors, Austin Health TIDCS suggested that donor screening be undertaken at the laboratory nearest to the potential donor.⁹⁷

Enhancing the sector's organ retrieval capacity is discussed in Section 7.3.3.

7.2.1 Rural and regional tissue donation

For deceased tissue donation in Victoria, sometimes families incur costs to transport a deceased family member from a regional area to the dedicated mortuary in Southbank. This can prevent a tissue donation from occurring within the required time and reduce the likelihood that a family provides consent for a donation proceed.⁹⁸ DTBV outlined 'it is in the process of establishing regional transport services with funeral directors, so that families in regional areas are not charged with the cost of transportation'.⁹⁹

Other states have 'mobile tissue retrieval teams' that travel to different hospitals.¹⁰⁰ DTBV is currently not resourced to conduct retrievals at hospitals.¹⁰¹ Establishing mobile tissue retrieval teams in Victoria would require hospitals' cooperation and use of facilities, and ensuring hospital mortuaries are sufficiently clean to prevent contamination. DTBV recommended it be provided additional funding to conduct a study on the feasibility of different decentralised tissue retrieval models, including in regional locations.¹⁰² ANZICS DODC also recommended the Victorian Government increase funding for DTBV to retrieve and process tissue at different sites.¹⁰³

7.2.2 Rural and regional eye donation

Eye tissue retrieval is different to other tissues and can be recovered at hospitals. The retrieval of eye tissue from rural and regional hospitals is lower than from metropolitan hospitals.¹⁰⁴ Inquiry participants identified a greater need for appropriately qualified staff in regional hospitals to retrieve eye tissue for donation and to support its transport back to Melbourne.¹⁰⁵ LEDS stated it has 'had to say no to quite a lot of regional donors purely on logistics' and it would like more regional

⁹⁷ Austin Health, Transplant Infectious Diseases Clinical Service, *Submission 22*, received 18 May 2023, p. 1.

⁹⁸ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, pp. 12, 15. See also ANZICS Death and Organ Donation Committee, *Submission 41*, p. 13; Associate Professor William Silvester, *Transcript of evidence*, p. 33.

⁹⁹ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 15.

¹⁰⁰ *Ibid.*

¹⁰¹ Brendan Sullivan, *Transcript of evidence*, p. 43.

¹⁰² *Ibid.*, p. 44; Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 15.

¹⁰³ ANZICS Death and Organ Donation Committee, *Submission 41a*, p. 1; Associate Professor William Silvester, *Transcript of evidence*, pp. 33–34.

¹⁰⁴ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 14.

¹⁰⁵ *Ibid.*; Dr Heather Machin, *Transcript of evidence*, p. 34.

eye donors.¹⁰⁶ LEDS has recently partnered with Bloodbikes¹⁰⁷ to deliver tissue, alleviating some logistical challenges for regional donations.¹⁰⁸ It is also in discussion with a Bendigo facility to recover eye tissue locally before it is delivered by a Bloodbiker to Melbourne to facilitate a transplant.¹⁰⁹

Figure 7.2: Bloodbiker helping deliver an eye tissue donaton



Source: image supplied by the Centre for Eye Research Australia, 14 February 2024, photo credit: Anna Carlile.

FINDING 68: There is a lack of capacity in Victoria to facilitate tissue and eye retrieval in rural and regional Victoria, with logistical challenges often preventing retrieval and transport to Melbourne. Sometimes for tissue donations, a family incurs costs to transport their deceased loved one from a rural or regional area to the dedicated tissue retrieval mortuary in Southbank.

RECOMMENDATION 40: The Victorian Government support the Donor Tissue Bank of Victoria to determine the feasibility of employing mobile tissue retrieval teams to travel to different sites, including in rural and regional locations, to retrieve and transport tissue donations.

¹⁰⁶ Bronwyn Cohen, *Transcript of evidence*, p. 40.

¹⁰⁷ A group of volunteer motorcyclists that transport blood and medical supplies across Australia, free of charge, see Bloodbikes Australia, *Bloodbikes Australia*, n.d., <<https://www.bloodbikesaustralia.com.au/about.html>> accessed 19 December 2023.

¹⁰⁸ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 14.

¹⁰⁹ Bronwyn Cohen, *Transcript of evidence*, pp. 39–40.

7.3 Considerations at end of life

Inquiry participants highlighted the importance of identifying, assessing and referring donation opportunities to enable better outcomes,¹¹⁰ particularly at end of life.¹¹¹

7.3.1 Donor identification as part of end of life care

End of life care is healthcare people receive as they approach death. It ‘can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers.’¹¹² Ensuring high-quality end of life care requires ‘open communication, informed decision making and collaboration among healthcare providers, families and carers.’¹¹³

In 2018, the Victorian Government announced an initiative to embed donation into end of life care processes in public hospitals. Under an automatic assessment approach, all patients facing end of life in the ICU and ED are automatically referred to DLV experts to assess their suitability for donation before clinicians discuss this with the family. The Victorian Government stated ‘[a]utomatic referral is expected to see the number of Victorian organ donors rise by 10 per cent.’¹¹⁴

OTA identified in this Inquiry that all states can improve the routine referral of patients at end of life in the ICU or ED to the relevant DonateLife agency to achieve better donation outcomes.¹¹⁵ This is a performance measure for OTA, with the target of 81% in 2022 being exceeded by 2%¹¹⁶—suggesting there is scope for the target to be increased to ensure it is sufficiently challenging to drive improvement in the routine referral of all patients.

Various inquiry participants discussed the importance of embedding donation into hospital procedures to ensure that patients receiving end of life care are given the opportunity to become donors.¹¹⁷ ANZICS DODC considered that donation should be a routine consideration in end of life care for all patients, suggesting:

- national funding is required to embed systems so patients at end of life are identified for donation through the provision of high-quality care

¹¹⁰ Robert Manning, *Submission 15*, received 6 May 2023, p. 17; Brian Myerson, *Submission 33*, received 22 May 2023, p. 3.

¹¹¹ Organ and Tissue Authority, *Submission 31*, received 19 May 2023, pp. 2, 6; ANZICS Death and Organ Donation Committee, *Submission 41*, p. 7; Dr Beatriz Domínguez-Gil, General Director, Organización Nacional de Trasplantes, Spain, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 70. See also World Medical Association, *WMA statement on organ and tissue donation*, 21 August 2020 <<https://www.wma.net/policies-post/wma-statement-on-organ-and-tissue-donation>> accessed 23 January 2024.

¹¹² Australian Commission on Safety and Quality in Health Care, *End-of-life care*, n.d., <<https://www.safetyandquality.gov.au/our-work/end-life-care>> accessed 22 August 2023.

¹¹³ Department of Health, *End of life care*, 5 October 2015, <<https://www.health.vic.gov.au/patient-care/end-of-life-care>> accessed 22 August 2023.

¹¹⁴ Hon Daniel Andrews, *Identifying more organ donors to save more lives*, media release, Victorian Government, Melbourne, 20 October 2018.

¹¹⁵ Organ and Tissue Authority, *Submission 31*, p. 6. See also Chris Thomas, Chief Executive Officer, Transplant Australia, public hearing, Melbourne, 25 July 2023, *Transcript of evidence*, p. 21.

¹¹⁶ Organ and Tissue Authority, *Annual report 2022–23*, 2023, p. 20.

¹¹⁷ For example, see Melbourne Lions Eye Donation Service, *Submission 18*, p. 3; Laura Fleckner, *Transcript of evidence*, pp. 18–19; Georgina Callaghan, *Transcript of evidence*, p. 28.

- increasing funding to educate all hospital staff on donor identification and donation processes
- nearly all deceased organ donations occur in patients who die in the ICU, but the process to identify potential donors also begins in the ED and wards (auditing the referral of potential donors from wards would ensure potential donors are not missed)
- all potential donors should be admitted to the ICU to facilitate more donations.¹¹⁸

Austin Health TIDCS submitted that providing access to existing information on government databases (for example, the Australian Immunisation Registry) would facilitate more timely donor assessment and alleviate the need for donor families to provide this information.¹¹⁹

DTBV recommended educating ‘all parties in the donation pipeline to prioritise tissue donation cases in the coronial system’ to increase the identification of donors.¹²⁰ This is especially relevant as potential tissue donors do not need to die in the ICU or ED and can die in the community. While this is an uncommon pathway to deceased donation due to ‘medical unsuitability and the requirement that tissue is retrieved within 24 hours of the person last being seen alive’,¹²¹ DTBV advised:

A lot of GPs do not necessarily know about tissue donation. If they have gone to someone’s home to verify someone as deceased, as needs to be done, and to complete a cause of death medical certificate, then there is an opportunity there that [the] person might also be a suitable candidate for tissue donation.¹²²

DTBV raised the potential of researching community deaths to consider if there is an opportunity for GPs to notify DTBV so it can assess the potential for tissue donation to increase donations. Although this may not achieve many tissue donations because the deceased suffered a condition or disease precluding donation, further research could help identify any potential opportunities.¹²³

FINDING 69: Victorian hospitals have an opportunity to improve deceased organ and tissue donation rates by implementing routine procedures to ensure all patients at end of life have the chance to become donors.

¹¹⁸ ANZICS Death and Organ Donation Committee, *Submission 41*, pp. 6–7, 15; Associate Professor William Silvester, *Transcript of evidence*, p. 40. OTA’s current audit of hospital deaths only applies to deaths in the ICU; ANZICS DODC suggested this should be extended to all deaths in hospitals. The Committee notes Austin Health stated life support should be withdrawn in the operating theatre rather than ICU, as this ‘respects the privacy of the family, reduces indignity associated with the current practice of rushing donors to theatre from the [ICU], and optimally preserves organ function by minimising the amount of time organs are without adequate blood supply, mitigating against organ damage.’ This is standard practice in NSW, see Austin Health, *Submission 34*, received 25 May 2023, p. 7; Associate Professor John Whitlam, Nephrologist and Medical Director of the Kidney Transplant Service, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 3.

¹¹⁹ Austin Health, Transplant Infectious Diseases Clinical Service, *Submission 22*, p. 1. Austin Health TIDCS is formally contracted to provide expert opinion to DLV to assist in determining potential organ donor suitability.

¹²⁰ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 16.

¹²¹ *Ibid.*

¹²² Chantel Bartolo, *Transcript of evidence*, p. 43.

¹²³ Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, *Submission 40*, p. 16; Brendan Sullivan, *Transcript of evidence*, p. 43.

7.3.2 Extended criteria organ donors

As discussed in Chapter 1, only a small number of people become deceased donors each year. The way death occurs influences the donation process. Donation can occur after:

- circulatory death—when circulation of blood in a person permanently stops—with subsequent donation known as donation after circulatory death (DCD)
- brain death—when a person’s brain permanently stops functioning—with subsequent donation known as donation after brain death (DBD).¹²⁴

Inquiry participants identified there are opportunities to increase the number of donors from the existing donor pool by accepting a wider range of organs, known as extended criteria donors.¹²⁵ This includes older people, DCD donors, less healthy donors or those with a low risk of disease transmission.¹²⁶ Austin Health noted these organs are currently underutilised, partly ‘due to real or assumed concerns regarding organ injury, quality and post-transplant function, despite evidence for good outcomes and quality for appropriately selected recipients.’¹²⁷ Spain and the United Kingdom (UK) have ‘more expanded practices’ than Australia—proceeding with donation from ‘older donors, those with a slight though increased risk of disease transmission’ and more DCD.¹²⁸ For example, OTA explained 57% of Spain’s donors are over 60 compared to 30% in Australia (Case Study 7.1).¹²⁹

Inquiry participants reported that extended criteria donation opportunities are restricted in Australia by transplant unit capacity, a lack of technology and more selectivity about organ suitability.¹³⁰ Austin Health noted ‘[t]echnological advancements, careful recipient selection, and improved cooperation between retrieval teams and intensive care units can support expanded utilisation of and improved outcomes from these [extended criteria] donors.’¹³¹

FINDING 70: There are several opportunities to increase organ donations from the existing potential donor pool by accepting a wider range of organs, for example, from older or less healthy donors. Extended criteria donation opportunities are restricted by current transplant unit capacity, technology and selectivity about organ suitability.

¹²⁴ *Human Tissue Act 1982* (Vic) part IX s 41; Organ and Tissue Authority, *Understanding death and donation*, n.d., <https://www.donatelife.gov.au/sites/default/files/2021-08/OTA_NDFSS_Understanding%20Death%20%26%20Donation%20July%202021.pdf> accessed 19 December 2023, p. 3.

¹²⁵ DonateLife Victoria, *Submission 27*, received 19 May 2023, p. 9; Austin Health, *Submission 34*, p. 6, with sources; Organ and Tissue Authority, *Submission 31*, pp. 6–7; Victorian and Tasmanian Transplantation Committee, *Submission 39*, received 2 June 2023, p. 1; Dr Rohit D’Costa, Victorian Representative, ANZICS Death and Organ Donation Committee, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 37.

¹²⁶ Organ and Tissue Authority, *Submission 31*, pp. 6–7; Austin Health, *Submission 34*, p. 6, with sources; Associate Professor John Whitlam, *Transcript of evidence*, p. 2.

¹²⁷ Austin Health, *Submission 34*, p. 6, with sources.

¹²⁸ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 10.

¹²⁹ Associate Professor Helen Opdam, National Medical Director, Organ and Tissue Authority, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 27; Professor Gregory Snell, *Transcript of evidence*, p. 13.

¹³⁰ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 10; Associate Professor Helen Opdam, *Transcript of evidence*, p. 27.

¹³¹ Austin Health, *Submission 34*, p. 6, with sources.

Case Study 7.1 Spain, extended criteria donors and donor identification

The donor identification process in Spain is a key factor to the country's successful donation model. Dr Beatriz Domínguez-Gil, General Director of Spain's Organización Nacional de Trasplantes (ONT) explained that 'if the system is not conceived to routinely identify these exceptional circumstances of death, donation would never happen'. ONT has:

organised the process in a way that we intend not to fail in donor identification and then ensure that the rest of the phases are performed in the best possible manner.

Spain has the highest rate of donors aged over 60 (22 per million population (PMP) compared to 4 PMP in Australia) and Dr Domínguez-Gil explained its 'old-for-old allocation strategy':

Because the expectancies of survival of those organs are going to be shorter than the expectancies of survival of younger organs, those organs are primarily allocated to recipients of advanced age. So that organ is supposed to be covering the expectancy of survival of that recipient. And yes, the source allowed us to increase the number of persons who are waitlisted of advanced age. Not only are our donors getting older but our recipients are also getting older, so we are able to be more flexible with criteria in terms of the age of persons who are waitlisted for transplantation. It is a strategy that not only embraces donation and transplantation opportunities, globally speaking, but drives a flexibilisation in criteria to be admitted onto the waiting list.

Dr Domínguez-Gil described improvements to DCD as 'a revolution in Spain'. It is particularly important as DBD becomes more infrequent due to less people dying from brain death and better treatment options. Dr Domínguez-Gil suggested:

Australia should be able to increase the utilisation of complex donors—for example, ... donors of advanced age. This requires, of course, being more proactive in the identification of these individuals as possible organ donors but also working with the transplant teams to make sure that they can make the most of these very complex transplants. DCD ... has also large room for improvement in Australia ...

Source: Dr Beatriz Domínguez-Gil, General Director, Organización Nacional de Trasplantes, Spain, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 71–74 and PowerPoint presentation.

The donation process that occurs after circulatory death was also raised by some inquiry participants, as a donation may not proceed if a person does not stop breathing quickly after the removal of life support. This is because their organs are no longer viable.¹³²

¹³² Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, p. 5; Associate Professor John Whitlam, *Transcript of evidence*, p. 2. This is less than 30 minutes for liver, pancreas and heart, less than 60 minutes for kidneys and less than 90 minutes for lungs, see Organ and Tissue Authority, *Best practice guideline for donation after circulatory determination of death (DCDD) in Australia*, October 2021, p. 14.

At October 2021, DCD accounted for approximately 30% of deceased organ donations in Australia.¹³³ Circulatory death outside of a 90-minute timeframe accounted for a large proportion of donations not proceeding.¹³⁴ ANZICS DODC submitted that in Australia the DCD process is stood down after 90 minutes if the person has not died ‘due to more restrictive practices that are influenced by surgical retrieval capacity.’¹³⁵ However, in the UK medical practitioners wait ‘3 to 4 hours for the person to die when attempting [DCD] before aborting the process’.¹³⁶

St Vincent’s OTD noted that a prolonged time from death to donation can put stress on families and hospital resources. Families may not provide consent or withdraw consent in this case. The ‘work up time’ before a donation takes place has also ‘increased over recent years’ because it takes longer ‘to complete medical suitability, organ placement and discussion of extended criteria organs,’¹³⁷ meaning between 24 and 48 hours can lapse after a family consents to donation and the time of death:

even if a patient is being kept alive by mechanical and pharmacological support, it may be difficult to predict exactly when a patient will die following withdrawal of such support. While a patient often dies soon after withdrawal of this support, the exact time of death can be challenging to predict. In some circumstances, death occurs many hours or days later due [to] preservation of some intrinsic (poor) cardiac function. Although the patient is alive, their organs are slowly shutting down—and, in the process becoming unsuitable for donation. As a result, a family’s difficult decision to assent might ultimately not lead to a successful donation, often leaving the family with even more disappointment.¹³⁸

Associate Professor Sally Catt provided a submission relating to her personal experience with donation. Her son, Angus, suffered a tragic accident while on holiday in Seoul, South Korea. Following emergency surgery, he remained unconscious and seriously injured. After three weeks, Angus was flown to Melbourne with brain injuries that were ‘severe, permanent, and deteriorating’ and he never regained consciousness. The family made the decision to withdraw Angus’s life support. Angus was a registered donor and his heart, liver and two kidneys were assessed as suitable for donation. Angus breathed independently and died five hours later, meaning that no organs could be donated.¹³⁹

¹³³ Illnesses that can lead to DCD include irreversible brain injury; severe cardiac, respiratory or liver failure; ventilator-dependent quadriplegia; and advanced neuromuscular disease with respiratory failure, see Organ and Tissue Authority, *Best practice guideline for donation after circulatory determination of death (DCDD) in Australia*, p. 4.

¹³⁴ In Australia in 2022, 700 families consented to donation which resulted in 454 actual donors. The gap is largely due to medical reasons, including that people die outside the 90-minute time frame for DCD donors and because the donor is deemed unsuitable, for example, there is a history of cancer, see Dr Rohit D’Costa, DonateLife Victoria, *Transcript of evidence*, pp. 2, 5; Associate Professor John Whitlam, *Transcript of evidence*, p. 8.

¹³⁵ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 10. See also Professor Gregory Snell, *Transcript of evidence*, p. 13.

¹³⁶ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 10.

¹³⁷ St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, received 19 May 2023, p. 1.

¹³⁸ Alfred Health, *Submission 38*, received 1 June 2023, p. 4.

¹³⁹ Associate Professor Sally Catt, *Submission 4*, received 3 April 2023, pp. 1–2.

Associate Professor Catt recommended Victoria legislate to allow for the option to retrieve organs under anaesthesia where the decision has been made to withdraw life support from a donor:

It would involve the patient being taken into surgery and given a general anaesthetic. The organs which are viable for donation would be removed from the patient under anaesthesia and made available to the recipient in the best possible condition. The cause of death for the patient would be the removal of their organs. A change of law to legalise organ donation under anaesthesia would significantly increase organ and tissue donation rates in Victoria because viable organs would not be damaged during the time it takes for someone to die after the withdrawal of life support.¹⁴⁰

Associate Professor Catt suggested families should have the choice to authorise death in this way, noting the potential for this choice to also benefit the patient by respecting their wishes to donate.¹⁴¹

St Vincent's OTD stated this would breach the 'dead donor rule' that donation proceeds after death. St Vincent's OTD considered there are more 'fundamental and less controversial' changes that could be made to increase donation.¹⁴²

The Catholic Archdiocese of Melbourne advised that it 'accepts the current legal definition of death and would be deeply concerned about any practice that does not establish with certainty that there is irreversible loss of circulation or irreversible loss of all brain function, and rejects any move to weaken these requirements for determining death.'¹⁴³ Rev Dr Paschal Corby stated that changing the definition of death may be counter-productive because people may doubt the quality of care they expect to receive.¹⁴⁴

7.3.3 Medical technologies and machine perfusion

Ex-vivo machine perfusion artificially pumps 'blood or preservation fluid through a donated organ while outside of the body, reducing damage to that organ arising from lack of blood supply and/or rejuvenating the organ prior to transplantation.'¹⁴⁵ Inquiry participants highlighted several benefits to these machines, including that they:

- can be used to better assess organ quality¹⁴⁶
- maintain or improve organ function for donation¹⁴⁷

¹⁴⁰ Ibid., p. 1.

¹⁴¹ Associate Professor Sally Catt (submitter 4) regarding submission 19, p. 1.

¹⁴² St Vincent's Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2; Dr Bernadette Hickey, *Transcript of evidence*, p. 46.

¹⁴³ Catholic Archdiocese of Melbourne, *Submission 19*, received 16 May 2023, p. 3 cover letter. See also Rev Dr Paschal Corby, *Submission 29*, received 19 May 2023, p. 2.

¹⁴⁴ Rev Dr Paschal Corby, *Submission 29*, p. 2.

¹⁴⁵ Austin Health, *Submission 34*, p. 6.

¹⁴⁶ Alfred Health, *Submission 38*, p. 10; Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 1; ANZICS Death and Organ Donation Committee, *Submission 41*, p. 9; Associate Professor William Silvester, *Transcript of evidence*, p. 36; Professor Gregory Snell, *Transcript of evidence*, pp. 13–14.

¹⁴⁷ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 9; Associate Professor John Whitlam, *Transcript of evidence*, p. 8.

- extend preservation times to enable organ retrieval from rural, regional, interstate and distant locations¹⁴⁸ and allow recipients to travel when required¹⁴⁹
- enable the retrieval of DCD organs¹⁵⁰ and use of other categories of DCD organs (for example, delayed DCD pathway, DCD donors from outside the ICU)¹⁵¹
- improve outcomes from extended criteria donor organs by improving organ function, limiting complications and improving recipients' quality of life.¹⁵²

Austin Health has used liver machine perfusion successfully for four years and is 'introducing kidney machine perfusion as part of a state-wide comprehensive Machine Perfusion Programme.'¹⁵³ Alfred Health has a lung perfusion machine, purchased to to assess DCD lungs several hours after the withdrawal of life support.¹⁵⁴ But Professor Snell advised Alfred Health's 'machine sits idly at present due to limited space, staff, and consumable funding.'¹⁵⁵

Several inquiry participants expressed support for further adoption of machine perfusion.¹⁵⁶ Investment in this technology can help honour 'the altruistic intentions' of donors 'by maximising the life-saving potential of each donation.'¹⁵⁷ Austin Health and Alfred Health require additional resources to operate the machines, particularly for trained technicians and consumables.¹⁵⁸ Alfred Health explained:

Ex-vivo perfusion machines and consumables are expensive to purchase and maintain, and require dedicated space and staff with specific technical expertise to run the systems, as well as access to suitable transport vehicles. Resourcing hospitals to increase the use of ex-vivo assessment systems will positively impact the number [of] donor organs utilised for transplantation.¹⁵⁹

Machine perfusion technologies can reduce some of the pressures associated with logistical barriers to donation like a shortage of retrieval or transplant surgeons or facilities that are not equipped for donation to occur.¹⁶⁰ Several participants noted more resourcing is needed for transplant and retrieval surgeons, services and facilities

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- 148 Alfred Health, *Submission 38*, p. 10; Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 1; Professor Robert Jones, Liver Transplant Unit Director, Austin Health, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, p. 4; Associate Professor William Silvester, *Transcript of evidence*, p. 36; Professor Gregory Snell, *Transcript of evidence*, p. 14.
- 149 ANZICS Death and Organ Donation Committee, *Submission 41*, p. 9; Associate Professor John Whitlam, *Transcript of evidence*, pp. 2–3.
- 150 ANZICS Death and Organ Donation Committee, *Submission 41*, p. 9; Associate Professor John Whitlam, *Transcript of evidence*, pp. 2, 8; Professor Gregory Snell, *Transcript of evidence*, p. 14.
- 151 Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 1; Professor Gregory Snell, *Transcript of evidence*, p. 14.
- 152 Austin Health, *Submission 34*, p. 1; Associate Professor John Whitlam, *Transcript of evidence*, pp. 2–3; Professor Robert Jones, *Transcript of evidence*, p. 4.
- 153 Austin Health, *Submission 34*, p. 6.
- 154 Professor Gregory Snell, *Submission 17*, received 8 May 2023, p. 1.
- 155 Ibid.
- 156 ANZICS Death and Organ Donation Committee, *Submission 41*, p. 9; Organ and Tissue Authority, *Submission 31*, p. 7; Austin Health, *Submission 34*, p. 1; Department of Health, *Submission 42*, received 25 July 2023, p. 3.
- 157 Austin Health, *Submission 34*, p. 6; Associate Professor John Whitlam, *Transcript of evidence*, p. 3.
- 158 Austin Health, *Submission 34*, p. 6; Professor Gregory Snell, *Submission 17*, p. 1.
- 159 Alfred Health, *Submission 38*, p. 10. See also Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 1.
- 160 Dr Rohit D'Costa, DonateLife Victoria, *Transcript of evidence*, pp. 3, 6; Professor Robert Jones, *Transcript of evidence*, p. 4.

to enable better donation and transplantation outcomes.¹⁶¹ This is a priority area of the draft National Organ Strategy which identifies that there is a ‘need to address capacity and capability issues, with a particular emphasis on workforce planning and coordination of retrieval and transplantation services.’¹⁶²

Some new technologies used internationally to support the donation process and assess donor suitability are not currently used in Australia. For example, technologies that artificially restart circulation are not consistent with the definition of death requiring the ‘irreversible cessation of circulation.’¹⁶³ Normothermic regional perfusion, used in the UK and Europe, involves ‘a pump to circulate blood in the deceased donor’s abdominal organs during organ retrieval after the heart has stopped beating’, thereby reducing ‘injury to the abdominal organs arising from time without adequate blood oxygenation.’¹⁶⁴

Alfred Health submitted that the *Human Tissue Act 1982* (Vic) (HT Act) ‘requires regular review’ to ensure it keeps pace with ‘contemporary medical technology’.¹⁶⁵ Austin Health identified that modifying the HT Act to ‘embrace a brain blood flow-based conception of death, in line with recent international medical consensus, is necessary to permit application’ of normothermic regional perfusion. Austin Health submitted that the Transplant Society of Australia and New Zealand has written to the Australian Attorney-General to request the Australian Law Reform Commission review all state HT Acts.¹⁶⁶ St Vincent’s OTD considered the adoption of these new technologies in Australia could be confronting for the community and medical professionals and should not be adopted at this stage.¹⁶⁷

FINDING 71: Machine perfusion technologies have many benefits, including extending organ preservation times that help to overcome logistical barriers that may prevent a deceased organ donation from occurring. There is opportunity to expand the use of current machine perfusion technology in Victorian hospitals and consider other emerging medical technology to improve deceased organ and tissue donation outcomes.

¹⁶¹ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 4; Austin Health, *Submission 34*, p. 2; Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 2; Dr Rohit D’Costa, DonatLife Victoria, *Transcript of evidence*, p. 3; Associate Professor John Whitlam, *Transcript of evidence*, p. 3; Associate Professor William Silvester, *Transcript of evidence*, p. 35; Professor Gregory Snell, *Transcript of evidence*, p. 13; St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2.

¹⁶² Department of Health and Aged Care, *Draft National strategy for organ donation, retrieval and transplantation*, p. 9. ‘Enhanced organ retrieval and transplantation capability and capacity to optimise transplant outcomes’ is identified as a priority area of the draft National Organ Strategy.

¹⁶³ Dr Joshua Ihle, *Transcript of evidence*, p. 25; Alfred Health, *Submission 38*, pp. 9–10, with sources.

¹⁶⁴ Austin Health, *Submission 34*, p. 6, with sources.

¹⁶⁵ Alfred Health, *Submission 38*, p. 10.

¹⁶⁶ Austin Health, *Submission 34*, pp. 6–7.

¹⁶⁷ Dr Bernadette Hickey, *Transcript of evidence*, p. 46; St Vincent’s Hospital Melbourne, Organ and Tissue Donation Team, *Submission 35*, p. 2.

7.3.4 Coroners' consent to organ and tissue donation

Under section 27 of the HT Act in Victoria, when a person dies in circumstances requiring a coroner to investigate their death, a coroner must give consent before organ and tissue donation can proceed.¹⁶⁸ This ensures that the removal of organs and/or tissue does not compromise a coroner's investigation.¹⁶⁹

The *Coroners Act 2008* (Vic) (Coroners Act) provides a framework to assist a coroner required to make a consent decision while investigating a death. This includes consideration of:

- whether the death is distressing for friends and family requiring referral to professional support; whether a protracted coronial investigation may exacerbate this distress; respect for different cultural practices or beliefs about death; and promoting safety and public health (section 8)
- expert medical advice 'as to whether the requested donation would impact the investigation and/or criminal proceedings' or would affect the ability to determine cause of death and make required findings (section 67).¹⁷⁰

The Coroners Court of Victoria (CCV) advised that a coroner making a consent decision will also have regard to the wishes of family members about donation.¹⁷¹ CCV noted that coroners support 'donation requests wherever possible, provided this does not impede their ability to fulfil the paramount duty to independently investigate and make findings with respect to the death'.¹⁷²

A joint submission from Alfred Health and ANZICS DODC stated that the HT Act provides 'no guidance to the Coroner about how to approach the consent decision' and 'no clear direction in exercising their functions and powers under the [HT Act]'.¹⁷³ They proposed amending section 27 of the HT Act to include a presumption in favour of donation and a right of appeal,¹⁷⁴ noting such amendments would be consistent with the Coroners Act and 'make everyone's role clearer'.¹⁷⁵ But CCV indicated that a presumptive test and right of appeal might 'give rise to practical difficulties', for example, the time at which the coroner would withdraw consent noting that information about a death may be received progressively.¹⁷⁶

Alfred Health and ANZICS DODC suggested that because of 'the absence of express guidance from the Parliament, Coroners are seemingly declining to authorise organ donation if there is even the most remote possibility that the deceased's donatable

¹⁶⁸ *Human Tissue Act 1982* (Vic) s 27(21).

¹⁶⁹ Coroners Court of Victoria, *Submission 49*, received 9 January 2024, p. 1.

¹⁷⁰ *Ibid.*, p. 2.

¹⁷¹ *Ibid.*

¹⁷² *Ibid.*

¹⁷³ Alfred Health and ANZICS Death and Organ Donation Committee, *Submission 47*, received 6 October 2023, p. 1.

¹⁷⁴ *Ibid.*, p. 5.

¹⁷⁵ *Ibid.*, pp. 4–5.

¹⁷⁶ Coroners Court of Victoria, *Submission 49*, pp. 4–5.

organs might be relevant to an investigation.¹⁷⁷ However, CCV submitted that the circumstances where a coroner refuses to provide consent are rare¹⁷⁸ and advised that it is committed to supporting donation requests where appropriate:

[CCV] continues to work closely with key stakeholders to identify opportunities to increase understanding of each others roles and explore opportunities to streamline processes with respect to organ donation. To that end, the Court is currently liaising with Alfred Health to arrange an education session to inform Coroners and court staff about the organ donation process.¹⁷⁹

Alfred Health and ANZICS DODC also noted they continue to work with DLV, VIFM and CCV 'to improve processes for donation cases' in Victoria.¹⁸⁰

It is noted that in Queensland, section 24(7) of the *Transplantation and Anatomy Act 1979* (Qld) provides that where a coroner consents to donation, the medical practitioner performing the organ or tissue removal needs to report on its condition to the coroner within seven days.¹⁸¹ There is no equivalent requirement in Victoria, although the coroner may give their consent subject to any conditions.¹⁸² Current Queensland State Coroner guidelines contain advice on when coroners should consent to donation, including that 'there is no reason for coroners to withhold consent' if they are satisfied the transplantation will not compromise a potential investigation or prosecution.¹⁸³

It is also noted that in the UK, the Lord Chancellor, in consultation with the Chief Coroner, can issue guidance on how coroners are expected to operate.¹⁸⁴ The Chief Coroner's guidance on organ and tissue donation outlines that when deciding whether to consent to a donation, coroners should consider the wider public impact of objecting to donation, including that objecting will affect someone on the organ transplant waitlist who could die before an organ becomes available. The guidance also suggests possible conditions the coroner could attach to their decision not to object, such as requiring a statement from the treating clinician that the organ was functioning normally.¹⁸⁵

¹⁷⁷ Alfred Health and ANZICS Death and Organ Donation Committee, *Submission 47*, p. 3.

¹⁷⁸ Coroners Court of Victoria, *Submission 49*, pp. 2–3.

¹⁷⁹ *Ibid.*, p. 5.

¹⁸⁰ Alfred Health and ANZICS Death and Organ Donation Committee, *Submission 47*, p. 5.

¹⁸¹ *Transplantation and Anatomy Act 1979* (Qld) s 24(7). Other jurisdictions do not have analogous requirements, see *Transplantation and Anatomy Act 1978* (ACT) s 29; *Human Tissue Act 1983* (NSW) s 25; *Transplantation and Anatomy Act 1979* (NT) s 24; *Transplantation and Anatomy Act 1983* (SA) s 23; *Human Tissue and Transplant Act 1982* (WA) s 23; *Human Tissue Act 1985* (Tas) s 28A; *Transplantation and Anatomy Act 1979* (NT) s 20.

¹⁸² *Human Tissue Act 1982* (Vic) s 27(24). This is not a requirement in the *Coroners Act 2008* (Vic).

¹⁸³ Coroners Court of Queensland, 'Chapter 4: dealing with bodies', in *State Coroner's guidelines version 4, amended March 2020*, 2013, see section 4.7, p. 14.

¹⁸⁴ *Coroners and Justice Act 2009* (UK) s 42.

¹⁸⁵ Chief Coroner, *Guidance No. 26 Organ and Tissue Donation*, revised guidance, United Kingdom, 16 June 2023, pp. 2–3.

The Victorian process for coroners' providing consent to organ and tissue donation was not raised as an issue with the Committee until later in its Inquiry,¹⁸⁶ limiting its ability to consider the evidence in great detail. However, the Committee appreciates the time taken by Alfred Health, ANZICS DODC and CCV to provide written submissions about the current process, including some of the challenges and opportunities that exist. In this context, it is pleasing that all parties continue to work together to improve processes and support donation requests wherever possible.

FINDING 72: The Coroners Court of Victoria, DonateLife Victoria, the Victorian Institute of Forensic Medicine and Victorian hospitals providing organ and tissue donation services are working together to identify opportunities to increase understanding of each other's roles and responsibilities, and to explore opportunities to streamline donation processes.

7.3.5 Voluntary assisted dying

Under the *Voluntary Assisted Dying Act 2017* (Vic), Victorians at end of life who meet strict eligibility criteria are allowed to take medications to bring about their death at a time they choose.¹⁸⁷ From June 2019 to June 2023, 1,527 permits for voluntary assisted dying (VAD) had been granted in Victoria.¹⁸⁸

2019 Victorian Government guidance on VAD noted organ, tissue or body donation as a support service that should be made available as part of high-quality end of life care.¹⁸⁹ DLV estimates up to 15 people a year would be willing to donate organs or tissues after VAD in Victoria, meaning up to 45 people could receive organ transplants.¹⁹⁰

At the time of this report, across Australia one person had donated organs after VAD: a former nurse from Ballarat diagnosed with motor neuron disease and given months to live. She saved four lives.¹⁹¹ Several others have donated corneas following VAD in Victoria.¹⁹²

¹⁸⁶ The joint submission from Alfred Health and ANZICS DODC, *Submission 47*, was received on 6 October 2023. The submission from the Coroners Court of Victoria, *Submission 49*, was received on 9 January 2024. The Committee called for submissions by 19 May 2023, see Chapter 1, Figure 1.1.

¹⁸⁷ Better Health Channel, *Voluntary assisted dying*, 8 April 2019, <<https://www.betterhealth.vic.gov.au/health/servicesandsupport/voluntary-assisted-dying>> accessed 22 August 2023.

¹⁸⁸ Safer Care Victoria, *Voluntary Assisted Dying Review Board annual report (July 2022 to June 2023)*, n.d., <<https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-review-board-annual-report-july-2022-to-june-2023>> accessed 15 December 2023.

¹⁸⁹ Department of Health, *Voluntary assisted dying considerations in end-of-life care*, guidance, p. [1].

¹⁹⁰ DonateLife Victoria, *Factsheet: organ donation after Voluntary Assisted Dying (VAD) in Victoria*, 2023, p. 2, <<https://www.donatelife.gov.au/sites/default/files/2023-09/2023-DLV-OrganDonationAfterVAD-Factsheet-FINAL.pdf>> accessed 13 February 2024.

¹⁹¹ Organ and Tissue Authority, *Australian first—Victorian woman donates organs after voluntary assisted dying*, 22 September 2023, <<https://www.donatelife.gov.au/news-events/news/2023/australian-first-%E2%80%93-victorian-woman-donates-organs-after-voluntary-assisted-dying>> accessed 19 December 2023.

¹⁹² DonateLife Victoria, *Factsheet: organ donation after Voluntary Assisted Dying (VAD) in Victoria*, p. 2.

There is growing international practice of donation following VAD in Belgium, Spain, Canada and the Netherlands. Each jurisdiction has its own protocols.¹⁹³ In Spain, 49 people (7 in 2021 and 42 in 2022) became donors after medical assistance in dying (MAiD); benefitting 135 transplant patients.¹⁹⁴ Dr Domínguez-Gil advised that in ONT's experience, patients who request MAiD want to be donors and it becomes the responsibility of ONT to make both possible.¹⁹⁵

Several inquiry participants supported donation and VAD to increase the number of donors¹⁹⁶ and some recommended implementing protocols to ensure donation is routinely offered as part of the VAD process.¹⁹⁷ Professor Snell suggested donation after VAD would require a triage system at a major Victorian public hospital, including an independent neurology consultant, a suitable site and resources.¹⁹⁸ Other challenges to donation after VAD may include that people feel more comfortable being supported through VAD at home rather than in hospital.¹⁹⁹

DH acknowledged further work is required on feasibility and funding in Victoria and submitted that VAD 'legislation has opened an opportunity for people to express an interest and consent to organ [and tissue] donation prior to death.'²⁰⁰ While the Committee did not investigate these matters in great depth, it understands DLV are currently developing guidelines on VAD.²⁰¹ DLV published a fact sheet on donation and VAD in 2023.²⁰²

FINDING 73: Voluntary assisted dying (VAD) practices in Victoria present an opportunity for people approved for VAD to express interest and consent to organ and tissue donation. DonateLife Victoria is currently developing guidelines on donation and VAD.

¹⁹³ Jan Bollen, Courtney Hempton, Neera Bhatia and James Tibballs, 'Feasibility of organ donation following voluntary assisted dying in Australia: lessons from international practice', *The Medical Journal of Australia*, 2023, p. 202.

¹⁹⁴ Dr Beatriz Domínguez-Gil, General Director, Organización Nacional de Trasplantes, PowerPoint presentation at public hearing, 23 June 2023, pp. 27-28. Spain's national protocol for donation after MAiD places the patient at the centre of care and includes the following elements: independence in the decision-making process; information for being informed about donation; granular information about the donation process; authorisation signed after approval of MAiD; possibility to change decision about donation at any time; personalised organisation of the process; minimisation of discomfort; MAiD must take place at the hospital.

¹⁹⁵ Dr Beatriz Domínguez-Gil, *Transcript of evidence*, pp. 73-74.

¹⁹⁶ ANZICS Death and Organ Donation Committee, *Submission 41*, p. 6; Department of Health, *Submission 42*, p. 3; Professor Gregory Snell, *Submission 17*, p. 1; DonateLife Victoria, *Submission 27*, p. 9.

¹⁹⁷ Alfred Health, *Submission 38*, p. 10; Victorian and Tasmanian Transplantation Committee, *Submission 39*, p. 3.

¹⁹⁸ Professor Gregory Snell, *Submission 17*, p. 1.

¹⁹⁹ Professor Gregory Snell, *Transcript of evidence*, p. 16.

²⁰⁰ Department of Health, *Submission 42*, p. 3.

²⁰¹ Louise McKinlay, Acting Deputy Secretary, Commissioning and System Improvement, Department of Health, public hearing, Melbourne, 31 July 2023, *Transcript of evidence*, p. 10.

²⁰² DonateLife Victoria, *Factsheet: organ donation after Voluntary Assisted Dying (VAD) in Victoria*.

7.3.6 Advance care planning

Advance care planning involves a person communicating their preferences for future care which can then be documented in an ‘advance care directive’ for health practitioners to consult if the person loses the capacity to make medical decisions.²⁰³

DH has forms to assist people in creating advance care directives.²⁰⁴ The form for adults has a section to select from the following statements on donation:

- I **am** willing to be considered for organ and tissue donation, and recognise that medical interventions may be necessary for donation to take place.
- I **am not** willing to be considered for organ and tissue donation.²⁰⁵

The guide accompanying the form for adults discusses that advanced care directives should clearly state if the person supports donation and these medical interventions.²⁰⁶

Alfred Health supported incorporating donation preferences into government templates for advanced care directives and powers of attorney.²⁰⁷ Some inquiry participants also recommended that donation preferences be incorporated into wills and by probate lawyers.²⁰⁸ For example, Adel Salman, President of the Islamic Council of Victoria stated:

Muslims are encouraged to have wills, so Islamic wills are becoming more and more popular now ... [donation] could be captured in your will and say, ‘Look, here’s my will and this is how I would like my assets and my wealth to be distributed, but also I would like my organs to be donated when I die.’ In that way I think that then becomes an official record for families.²⁰⁹

GPs could also integrate donation into discussions with patients about wills and powers of attorney.²¹⁰ Associate Professor Christopher Hogan, GP and Member of Victoria Faculty for the Royal Australian College of General Practitioners (RACGP) stated:

²⁰³ Department of Health, *Advance care planning—overview*, 9 August 2023, <<https://www.health.vic.gov.au/patient-care/advance-care-planning-overview>> accessed 22 August 2023. An advance care directive under the *Medical Treatment Planning and Decisions Act 2016* (Vic) is the only legally recognised document in Victoria to record medical treatment preferences.

²⁰⁴ Department of Health, *Advance care planning forms*, 7 December 2022, <<https://www.health.vic.gov.au/patient-care/advance-care-planning-forms>> accessed 22 August 2023.

²⁰⁵ Department of Health, *Advance care directive for adults (form)*, p. 3.

²⁰⁶ Department of Health, *Instructions for completing the advance care directive for adults form*, p. [6]. The advance care directive form for young people under 18 years old provides a reminder that in an end of life care situation certain medical interventions may be required for organ and tissue donation to take place and an option for a young person to include details about the circumstances in which they may consent or refuse treatment, see Department of Health, *Advance care directive for young people under 18 years of age*, p. 4.

²⁰⁷ Alfred Health, *Submission 38*, p. 8.

²⁰⁸ Ibid.; Adel Salman, President, Islamic Council of Victoria, public hearing, Melbourne, 23 June 2023, *Transcript of evidence*, pp. 62–63; Name withheld, *Submission 14*, received 5 May 2023, p. 1.

²⁰⁹ Adel Salman, *Transcript of evidence*, p. 62.

²¹⁰ Associate Professor Christopher Hogan, General Practitioner, Member of Victoria Faculty Council, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, pp. 22, 24; Alfred Health, *Submission 38*, p. 8.

I like to incorporate [donation] as part of the routine. I think it is extremely important that people make preparations for their mortality or incapacity, so I have always been an advocate. Even as soon as people were employed I used to encourage them to have a will and to have an enduring power of attorney.²¹¹

Dr Aadhil Aziz, Co-Deputy Chair, Victoria Faculty for RACGP noted that GPs operate under time and resourcing pressures, so people should be encouraged to book an appointment specifically for this purpose rather than discussing it at the conclusion of a consult on a different topic.²¹²

Embedding donation into advanced care planning, wills and powers of attorney are avenues to improve donation rates. The Committee considers this to be an area requiring further exploration.

FINDING 74: Making donation preferences a routine consideration in processes like advance care planning, wills and powers of attorney presents an opportunity to recognise people's organ and tissue donation decisions and increase donation rates.

RECOMMENDATION 41: The Victorian Government explore ways to improve how organ and tissue donation is considered in government templates for advance care planning, wills and powers of attorney, including directly linking Victorians to register on the Australian Organ Donor Register and sharing links to help them talk to their family about donation.

**Adopted by the Legislative Assembly Legal and Social Issues Committee
Parliament of Victoria, East Melbourne
23 February 2024**

²¹¹ Associate Professor Christopher Hogan, *Transcript of evidence*, pp. 23–24.

²¹² Dr Aadhil Aziz, Co-Deputy Chair, Victoria Faculty, Royal Australian College of General Practitioners, public hearing, Melbourne, 24 July 2023, *Transcript of evidence*, p. 24.

Appendix A

About the Inquiry

A.1 Submissions

Submission number	Individual or organisation	Date received
1	Andrew Oliver	29/03/2023
2	Blare Wickham	29/03/2023
3	Emma Buchanan	31/03/2023
4	Associate Professor Sally Catt	3/04/2023
5	Leonard Dark	3/04/2023
6	Leah Macey	5/04/2023
7	Jocelyn Harte	5/04/2023
8	Alison Mackay	5/04/2023
9	Name withheld	7/04/2023
10	Name withheld	14/04/2023
11	Confidential	15/04/2023
12	Chris Healy	2/05/2023
13	Zaidee's Rainbow Foundation	5/05/2023
14	Name withheld	5/05/2023
15	Robert Manning	6/05/2023
16	Leanne Campbell	7/05/2023
17	Professor Gregory Snell	8/05/2023
18	Melbourne Lions Eye Donation Service	12/05/2023
19	Catholic Archdiocese of Melbourne	16/05/2023
20	Leukaemia Foundation	17/05/2023
21	Donor Families Australia	17/05/2023
22	Transplant Infectious Diseases Clinical Service, Austin Health	18/05/2023
23	Transplant Australia	18/05/2023
24	Name withheld	18/05/2023
25	Graham Harrison	18/05/2023
26	ShareLife Australia Limited	19/05/2023
27	DonateLife Victoria	19/05/2023
28	Samantha Francis-Pester	19/05/2023
29	Rev Dr Paschal Corby	19/05/2023

Submission number	Individual or organisation	Date received
30	Confidential	19/05/2023
31	Organ and Tissue Authority	19/05/2023
32	Dr Brooke Huuskes and Dr Stacey Hokke	19/05/2023
33	Brian Myerson	22/05/2023
34	Austin Health	25/05/2023
35	Organ and Tissue Donation Team, St Vincent's Hospital Melbourne	19/05/2023
36	Donor Mate	31/05/2023
37	Monash Bioethics Centre	1/06/2023
38	Alfred Health	1/06/2023
39	Victorian and Tasmanian Transplantation Committee	2/06/2023
40	Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine	16/06/2023
40a	Supplementary submission	2/11/2023
41	Australian and New Zealand Intensive Care Society Death and Organ Donation Committee	19/06/2023
41a	Supplementary submission	18/08/2023
42	Department of Health	25/07/2023
43	Australian Bone Marrow Donor Registry	17/08/2023
44	UR the Cure	29/08/2023
45	Department of Transport and Planning	8/09/2023
46	Jeff Ryall	5/10/2023
47	Alfred Health and Australian and New Zealand Intensive Care Society Death and Organ Donation Committee	6/10/2023
48	pixel42	25/10/2023
49	Coroners Court of Victoria	9/01/2024

Additional information

Number	Individual or organisation	Date received
1	Australia and New Zealand Liver and Intestinal Transplant Registry: Data report	15/05/2023
2	South Australian Department for Health and Wellbeing: Information about driver licence registrations	19/07/2023
3	Australian Department of Health and Aged Care: Response to written questions on notice	15/08/2023
3a	Australian Department of Health and Aged Care: Response to additional written questions on notice	13/09/2023
4	Chair and Deputy Chair, meeting with Ethnic Communities' Council of Victoria Policy Advisory Committee on Health and Wellbeing, 23 August 2023	4/09/2023
5	Quote from Dr Kean Kuan, Deputy Director and Chief Medical Officer, Victorian Institute of Forensic Medicine	4/09/2023

Number	Individual or organisation	Date received
6	Department of Government Services: Response to written questions on notice	26/10/2023
7	Organ and Tissue Authority: Information about training	14/09/2023 13/10/2023
8	Australia and New Zealand Dialysis and Transplant Registry: Living kidney donation data report	20/09/2023

A.2 Public hearings

Monday 19 June 2023, Melbourne

Name	Position	Organisation
Tony Holland	General Manager	DonateLife Victoria
Dr Rohit D'Costa	State Medical Director	DonateLife Victoria
Dr Joshua Ihle	Senior Intensivist and Clinical Lead of Organ Donation, Medical Consultant for DonateLife Victoria	Alfred Health
Georgina Callaghan	Donation Specialist Nursing Coordinator	Alfred Health
Laura Fleckner	Donation Specialist Nursing Coordinator	Alfred Health
Anna McNamara	Donation Specialist Nursing Coordinator	Alfred Health
Bronwyn Cohen	Quality Manager and Acting Director	Melbourne Lions Eye Donation Service
Dr Heather Machin	Senior Project Manager	Melbourne Lions Eye Donation Service
Stuart Chesneau	Executive Director, Strategy and Growth	Lifeblood
Tony Holland	General Manager, DonateLife Victoria	Lifeblood
Dr Brooke Huuskens	Senior Lecturer, Centre for Cardiovascular Disease & Biology Research, Department of Microbiology, Anatomy, Physiology and Pharmacology	La Trobe University
Dr Stacey Hokke	Research Fellow, Judith Lumley Centre, School of Nursing and Midwifery	La Trobe University

Friday 23 June 2023, Melbourne

Name	Position	Organisation
Associate Professor John Whitlam	Nephrologist and Medical Director of the Kidney Transplant Service	Austin Health
Professor Robert Jones	Liver Transplant Unit Director	Austin Health
Lucinda Barry AM	Chief Executive Officer	Organ and Tissue Authority

Name	Position	Organisation
Associate Professor Helen Opdam	National Medical Director	Organ and Tissue Authority
Mark McDonald	National Manager, Analytics and Technology	Organ and Tissue Authority
Brianna Elms	National Manager, Communications and Engagement	Organ and Tissue Authority
Philip Waters	General Manager	Deaf Victoria
Brendan Sullivan	Head of Service	Donor Tissue Bank of Victoria
Professor Noel Woodford	Professor of Forensic Medicine, Monash University and Director, Victorian Institute of Forensic Medicine	Victorian Institute of Forensic Medicine
Chantel Bartolo	Nurse Manager and Tissue Donation Nurse Specialist	Donor Tissue Bank of Victoria
Thea Stinear	Chief Executive Officer	Cool Australia
Naomi Nicholas	Head of Community Engagement	Cool Australia
Adel Salman	President	Islamic Council of Victoria
Maryaan Essa	Bilingual and Bicultural Health Educator (Arabic/English)	Multicultural Centre for Women's Health
Dai Nguyen	Bilingual and Bicultural Health Educator (Vietnamese/English)	Multicultural Centre for Women's Health
Hanh Thi Pham	Bilingual and Bicultural Health Educator (Vietnamese/English)	Multicultural Centre for Women's Health
Dr Beatriz Domínguez-Gil	General Director	Organización Nacional de Trasplantes, Spain

Monday 24 July 2023, Melbourne

Name	Position	Organisation
Chris Tanti	Chief Executive Officer	Leukaemia Foundation
Andrew Mosley	Head of Government Relations and Policy, Blood Cancer Partnerships	Leukaemia Foundation
Dr Julian Koplín	Lecturer	Monash Bioethics Centre
Associate Professor Christopher Hogan OAM	General Practitioner, Member of Victoria Faculty Council, Historian for Royal Australian College of General Practitioners Victoria	Royal Australian College of General Practitioners
Dr Bindiya Sethi	General Practitioner, Co-Deputy Chair Victoria Faculty	Royal Australian College of General Practitioners
Dr Aadhil Aziz	General Practitioner, Co-Deputy Chair Victoria Faculty	Royal Australian College of General Practitioners
Kon Kakris	State Manager, Victoria	Royal Australian College of General Practitioners
Associate Professor William Silvester	Chair	Australia and New Zealand Intensive Care Society Death and Organ Donation Committee

Name	Position	Organisation
Dr Gian Sberna	Chief Executive Officer	Australia and New Zealand Intensive Care Society Death and Organ Donation Committee
Dr Rohit D'Costa	Victorian Representative	Australia and New Zealand Intensive Care Society Death and Organ Donation Committee
Dr Bernadette Hickey	Senior Intensivist and Medical Donation Specialist, Intensive Care Unit	Organ and Tissue Donation Team, St Vincent's Hospital Melbourne
Dr Yvette O'Brien	Intensivist and Medical Donation Specialist, Deputy Director, Intensive Care Unit	Organ and Tissue Donation Team, St Vincent's Hospital Melbourne

Tuesday 25 July 2023, Melbourne

Name	Position	Organisation
Dr Paul Secombe	Senior Specialist Clinician, Intensive Care Unit	Central Australia Health Service
Chrissie Davis	Aboriginal Liaison Officer	Alice Springs Hospital
Donna Lemon	Aboriginal Liaison Officer	Alice Springs Hospital
Linda Bray	Aboriginal Liaison Officer	Alice Springs Hospital
Sally Sena	Aboriginal Liaison Officer	Alice Springs Hospital
Jennifer Armstrong	Aboriginal Liaison Officer	Alice Springs Hospital
Curtis Haines	Aboriginal Liaison Officer	Alice Springs Hospital
Justine Swan-Castine	Acting Leader, Aboriginal Partnership and Strategy Unit	Alice Springs Hospital
Anthony Davis	Aboriginal Liaison Officer	Alice Springs Hospital
Dr Rosalind Beadle	Research Fellow, College of Medicine and Public Health	Flinders University
Professor Gregory Snell	Medical Head, Lung Transplant Service	Monash University and Alfred Hospital
Chris Thomas	Chief Executive Officer	Transplant Australia
Allan Turner	Managing Director	Zaidee's Rainbow Foundation
Dr Dale Gardiner	Associate Medical Director, Deceased Organ Donation	National Health Service Blood and Transplant, United Kingdom
John Richardson	Assistant Director, Organ Donation	National Health Service Blood and Transplant, United Kingdom
Professor Derek Manas	Medical Director, Organ and Tissue Donation and Transplantation	National Health Service Blood and Transplant, United Kingdom
Lisa Mumford	Head of Organ Donation and Transplantation Studies, Statistics and Clinical Research	National Health Service Blood and Transplant, United Kingdom
Phil Walton	Project Lead, Deemed Consent Legislation, Blood and Transplant	National Health Service Blood and Transplant, United Kingdom
Dr Cathy Miller	Head of Education and Professional Development, Organ and Tissue Donation and Transplantation	National Health Service Blood and Transplant, United Kingdom

Monday 31 July 2023, Melbourne

Name	Position	Organisation
Louise McKinlay	Acting Deputy Secretary, Commissioning and System Improvement Division	Department of Health
Dr Joannis Mytilineos	Chief Medical Officer	National Bone Marrow Donor Registry (ZKRD), Germany

Friday 25 August 2023, Melbourne

Name	Position	Organisation
Name withheld	-	-
Robert Manning	-	-
Leanne Campbell	-	-
Anna Gillard	-	-
David Gillard	-	-
Cynthia Caruana	-	-
Lisa Smith	Chief Executive Officer	Australian Bone Marrow Donor Registry
Professor Jeff Szer AM	Director	Australian Bone Marrow Donor Registry

Monday 11 September 2023, Melbourne

Name	Position	Organisation
Jacqui Sampson	Executive Director, Regulatory Programs and Services	Department of Transport and Planning
Tim Mitchell	Director, Operational Policy Customer and Partnerships	Department of Transport and Planning

All public and name withheld submissions, as well as additional information and hearing transcripts, are available on the Committee's website at: parliament.vic.gov.au/organtissuedonor.

A.3 Site visit

Friday 25 August 2023

Donor Tissue Bank of Victoria & Victorian Institute of Forensic Medicine, Southbank

Appendix B

Ways to register on the Australian Organ Donor Register

B

	DonateLife online form ^a	Printed form ^b	myGov website, if Medicare linked	ExpressPlus Medicare app, if myGov linked	Drivers licence (South Australia only) ^c	Phone number
Details required to verify identity	Medicare number	Medicare number OR address, date of birth	N/A—app can be used if Medicare and myGov linked	N/A—app can be used if Medicare and myGov linked	Licence details, already linked	Medicare OR address, contact information (email, address) used to find Medicare number
Asks for date of birth	✓	✓	Assume information linked	Assume information linked	Assume information linked	Assume information linked
Asks for gender	Assume information linked	✓	Assume information linked	Assume information linked	Assume information linked	Assume information linked
Asks for postcode	✓	✓ (full address)	Assume information linked	Assume information linked	Assume information linked	Assume information linked
Option to choose which organs and tissue to donate	✗	✓	✓	✓	✗	✓
Ability to record objection, change decision or be removed from register	✗	✓	✓	✓	✗	✓
Consent or intent registration	Intent	Consent for people aged 18 yrs and above, intent for 16–17 yrs	Consent for people aged 18 yrs and above, intent for 16–17 yrs	Consent for people aged 18 yrs and above, intent for 16–17 yrs	Intent	Intent—phone operator checks it is okay to continue with intent, notes signature required for consent
Asks whether decision discussed with friends and family	✗	✓	Unknown	Unknown	✗	✗
Asks what prompted registration	✓	✗	Unknown	Unknown	✗	✗
Digital donor card available	✗	✗	✗	✓	✗	✗
Hard copy donor card available	Unknown	✓	✓	✓	✗	✓ but phone operator asks you to go online and request it

Key: ✗ = No, ✓ = Yes.

Table note: The Committee received confirmation from the Australian Department of Health and Aged Care that the information in the table is an accurate reflection of the different ways to register on the Australian Organ Donor Register (AODR). Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 15 August 2023, p. 2.

- a. Available at Organ and Tissue Authority, *Join the register*, n.d., <www.donatelife.gov.au/register-donor-today> accessed 15 January 2024. An individual can check their registration status via the online form but is automatically enrolled upon checking.
- b. Available at Services Australia, *Australian Organ Donor Register form*, 17 November 2022, <<https://www.servicesaustralia.gov.au/nh007df>> accessed 15 January 2024. The form can be printed, collected from a service centre, or posted after calling the AODR phone number. It can be submitted at a service centre, or by fax or post. If a Medicare number is provided, the form is used to keep details up to date. Individuals with no Medicare number or who are not Australian citizens can register to be a donor by completing the paper form or calling the AODR phone number.
- c. Available at South Australian Department for Health and Wellbeing, Information about driver licence registrations for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors, July 2023, <<https://www.parliament.vic.gov.au/4a1f31/globalassets/sections-shared/get-involved/inquiries/committees/la-committees/la-lic/sa--victorian-parliamentary-inquiry-into-increasing-the-number-of-registered-organ-and-tissue-donors---july-2023-a5048155.pdf>> accessed 17 January 2024. Only in South Australia (SA) can people agree to donation on a driver licence by ticking yes to an optional question when completing online and manual licence applications and renewals. This is transferred to the AODR as an intent registration and recorded on the person's SA driver licence.

Source: Services Australia, *Annual report 2021–22, 2022*, p. 74; Services Australia, *How to register*, 30 May 2023, <<https://www.servicesaustralia.gov.au/how-to-register-australian-organ-donor>> accessed 18 September 2023; Organ and Tissue Authority, *Join the register*, n.d., <<https://www.donatelife.gov.au/register-donor-today>> accessed 13 September 2023; South Australian Department for Health and Wellbeing, Information about driver licence registrations for Victorian Legislative Assembly's Legal and Social Issues Committee Inquiry into increasing the number of registered organ and tissue donors, July 2023; Department of Health and Aged Care, Inquiry into increasing the number of registered organ and tissue donors, response to written questions on notice received 15 August 2023.

