41ST PARLIAMENT

Report 41

STANDING COMMITTEE ON PUBLIC ADMINISTRATION

The donation conversation: Organ and tissue donation in Western Australia

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Presented by
Hon Pierre Yang MLC (Chair)

February 2024

Standing Committee on Public Administration

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Government response

This report is subject to Standing Order 191(1):

> Where a report recommends action by, or seeks a response from, the Government, the responsible Minister or Leader of the House shall provide its response to the Council within not more than 2 months or at the earliest opportunity after that time if the Council is adjourned or in recess.

The two-month period commences on the date of tabling.

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EXECUTIVE SUMMARY

1 Australia's deceased organ donation rates are significantly lower than other countries with comparable health care systems and are below predicted potential.

2 Western Australia's organ donation and transplantation system does not meet present demand and is unlikely to meet future needs.

3 Only about 2% of patients who die in Australian hospitals are eligible to donate their organs. For organs to be viable for donation, a person must die in an Intensive Care Unit or Emergency Department. Given the limited circumstances allowing for organ donation, it is crucial to maximise all potential organ donation opportunities.

4 Organ and tissue donation involves surgically removing an organ or tissue from one person (the organ donor) and placing it into another person (the recipient). Transplantation is necessary because the recipient's organ has failed or has been damaged by disease or injury. In many cases, the recipient is very ill or dying.

5 Organs that can be transplanted include the heart, lungs, liver, kidneys, intestines, and pancreas. Tissues that can be transplanted include heart tissue, bone, tendons, ligaments, skin and parts of the eye such as the cornea and sclera.

6 Donation decisions should be based on accurate information, free from misconceptions. There will always be some people who do not support organ donation and this should continue to be respected. This inquiry aims to maximise the opportunity for people to become organ and tissue donors.

7 This inquiry looked into the issues impacting organ and tissue donation rates in Western Australia, opportunities to improve rates and the efficacy of the current model.

The current model

8 Whilst each Australian state and territory has legislation governing organ and tissue donation in its jurisdiction, the Commonwealth leads a nationally coordinated approach to organ and tissue donation through the Organ and Tissue Authority (OTA).

9 The OTA funds DonateLife WA, which coordinates all organ and tissue donor activities in Western Australia. DonateLife WA employs specialist donor medical, nursing and administrative staff.

10 The Commonwealth provides funding for DonateLife WA staff and some transplant activity in hospitals. State governments remain responsible for donation in their hospitals and downstream services, such as retrieval surgery and transplant services.

11 Australia's legislative framework is an 'opt-in' consent model. Individuals are encouraged to register on the Australian Organ Donor Register (AODR); however, registration is not legally binding. In practice, family consent is always sought regardless of registration with the AODR.

12 Only 36% of Australians and 38% of eligible Western Australians are registered on the Australian Organ Donor Registry.

13 Some submissions to this inquiry called for Western Australia to move from its current 'opt-in' model to an 'opt-out' or 'deemed consent' model. This means a person is presumed to consent to organ donation unless they have expressed otherwise. 'Opt-out' systems, such as those in Spain and the United Kingdom (UK), still require family consent before donation can proceed. The experience in the UK and Spain shows that for any legislative change to have a

positive effect, it must be carried out in conjunction with other comprehensively integrated supporting measures.

14 The AODR registration rate does not necessarily reflect the current level of support for organ donation within the community. Australian attitudes and perspectives of an opt-out system should be ascertained.

15 Any legislative change must avoid eroding public trust and would require thorough communication with the public, including cultural and religiously sensitive outreach. Any change should only take place with public support.

16 While it is possible for a state jurisdiction to adopt an opt-out model, an evidence-based nationally consistent approach is preferrable.

Issues impacting organ and tissue donation in Western Australia

17 The significant issues impacting organ and tissue donation in Western Australia can be categorised as follows:

- low consent rates;
- low registration rates;
- insufficient funding for technology; and
- lack of public education and awareness.

Summary of recommendations

18 Low consent rates are Western Australia's primary barrier to organ and tissue transplantation. Families must consent to donating a loved one's organs and tissues, even if that person has registered a decision on the AODR. The most significant barrier to consent is people not knowing the donation wishes of their loved ones and defaulting to 'no' in the face of uncertainty.

19 Consent rates can be raised by:

- Increasing rates of registration on the AODR: when a potential donor has registered a wish to be an organ and tissue donor on the AODR, families will agree to donation in approximately 90% of cases, compared to 40% when a loved one's wishes are unknown.
- Ensuring that all intensivists and clinical teams involve DonateLife WA staff in 100% of donor family conversations. Western Australia continues to underperform in this area, which is detrimental to its transplantation rates. The requirement to involve DonateLife staff has existed for approximately 5 years and other Australian jurisdictions have successfully embedded these best practices into their clinical practice. Western Australia's organ donation rates would improve if this clinical best practice model was consistently followed.
- Providing sufficient education and information about organ and tissue donation to Western Australians: there are some commonly held misunderstandings around organ donation. For example, many Western Australians believe their wish to be an organ donor is noted as part of their Drivers Licence. Therefore, efforts should focus on educating the public about registration and organ and tissue donation processes.
- Providing adequate funding to ensure DonateLife WA staff have the resources and personnel to implement the best practice model.

20 Efforts to increase registration rates on AODR should focus on the following:

- Increasing the number of pathways to register a decision on the AODR: the option to register or renew a decision when applying for and renewing a driver's licence has proven successful in other jurisdictions and should be reintroduced. Other opportunities for pathways to registration could include lodging tax returns, applying for a WA photo card, interacting with general practitioners and registering to vote.
- Providing targeted information and education to culturally and linguistically diverse Australians about organ and tissue donation in collaboration with community and faith leaders, particularly concerning religious beliefs.
- Providing authorised education and information to secondary students about the organ and tissue donation process.
- Ensuring organ and tissue donation and transplantation forms part of all medical student curricula and organ and tissue donation is treated as a natural extension of end-of-life care.

21 Missing a potential donor can lead to preventable death, disability or poor quality of life of transplant candidates and increased healthcare costs. The limited circumstances allowing for organ donation should be maximised through the following measures:

- Funding and supporting machine perfusion technology in Western Australian hospitals. This technology improves organ utilisation by reducing the risk of damage to organs and increasing transport timeframes.
- Introducing clinical and ethical guidelines for the use of Abdominal Normothermic Perfusion, which has increased transplant rates in Spain.
- Introducing guidelines and amending legislation to enable organ and tissue donation after Voluntary Assisted Dying for patients who are eligible and wish to do so.
- Ensuring Western Australian clinicians utilise the new organ waitlisting and matching software, OrganMatch, and provide adequate ongoing training in the use of OrganMatch.
- Expanding the donor suitability criteria and employing an 'old-for-old' allocation system.
- Establishing a licenced Therapeutic Goods Administration-accredited pathology service for nucleic acid testing rather than relying on interstate facilities.
- Ensuring timely referrals for potential tissue donors from the coronial pathway.
- Providing the Coroner with discretionary authority to conduct an internal post-mortem examination for tissue donation with the consent of the next-of-kin.

22 The Standing Committee on Public Administration Committee (Committee) also found data relating to organ and tissue transplantation rates was, at times, insufficient or difficult to locate. All data relating to organ and tissue transplantation and donation rates, including statistical information about the AODR and wait lists, should be published in one easily accessible format.

23 The Committee sincerely thanks all those who contributed to this inquiry and, most importantly, all donor families for their selfless generosity.

Findings and recommendations

Findings and recommendations are grouped as they appear in the text at the page number indicated:

FINDING 1 Page 9

Even if a potential donor's organs are deemed unsuitable for donation, the person may remain a viable candidate for tissue donation.

FINDING 2 Page 33

The South Australian experience indicates the option to join the organ donation registry when applying for a driver's licence increases registration rates, particularly among younger adults.

FINDING 3 Page 35

Increasing the number of pathways to register a decision on the Australian Organ Donor Register can assist with turning favourable attitudes into action. Interactions between the public and government offer an opportunity to provide education about organ and tissue donation and encourage registration.

RECOMMENDATION 1 Page 35

The Department of Transport and the Department of Health collaborate with the Organ and Tissue Authority to identify and implement methods for Western Australians to join the Australian Organ Donation Register when applying for and renewing a driver's licence and WA Photo Card. When identifying methods, the following should be considered:

- accommodating applications and renewals made via e-payment, online and in-person;
- feeding the information directly into the national Australian Organ Donor Register;
- a simple tick box option (the option to tick 'yes' or leave the box unticked, indicating the person does not wish to decide at that time); and
- planning for any future implementation of electronic licenses or identification documents.

RECOMMENDATION 2 Page 35

DonateLife WA create an informational pamphlet on organ and tissue donation to be distributed by the Department of Transport in conjunction with driver's licence renewal communications.

RECOMMENDATION 3 Page 35

The Department of Health advocate for the inclusion of an option to 'share' a registration decision through social media (such as Facebook messenger or Instagram direct message) or by electronic communication immediately after online registration on the Australian Organ Donor Register.

RECOMMENDATION 4 Page 35

The Western Australian government advocate for the Commonwealth government to incorporate the ability to register as an organ and tissue donor when applying for or renewing a Medicare card.

FINDING 4 Page 37

Lack of education about organ and tissue donation can lead to enduring misunderstandings within the community, which discourages registration. Educational efforts should focus on areas of misconceptions and myths and provide information on the following facts:

- Organ retrieval is performed the same way as any other surgery, in a hospital theatre room by trained professionals.
- The deceased will have no visible injury after donation, and an open casket funeral is possible.
- Organ donation is only raised as an option after doctors reach a medical consensus that the patient has no chance of recovery (circulatory death or brain death).
- All major religions permit organ donation.
- Families will be asked to make the final decision about donation, even if a person has registered to be a donor on the Australian Organ Donor Register.

FINDING 5 Page 39

In 2022, Western Australia had the lowest rate of families consenting to donate their deceased relatives' organs and tissue of all Australian states.

FINDING 6 Page 49

When intensivists involve DonateLife WA specialist staff during conversations about donation, family consent rates increase significantly.

FINDING 7 Page 49

Western Australia has consistently lower rates of involvement by donation specialist nurses in donor conversations than the national average.

FINDING 8 Page 49

Some intensivists choose not to prioritise engagement with DonateLife WA specialists in donor family conversations, and this is having a detrimental effect on consent rates in Western Australia.

FINDING 9 Page 53

Western Australia is the only Australian jurisdiction which does not give the option for a person to specify their organ donation preferences in a prescribed advance health care planning document.

FINDING 10 Page 53

The *Guardianship and Administration Act 1990* pre-dates organ and tissue donation and transplantation advancements and is now outdated.

RECOMMENDATION 5 Page 53

The Western Australian Government amend the *Guardianship and Administration Act 1990* to provide the ability for an individual to record a decision on organ and tissue donation in an Advance Health Directive.

FINDING 11 Page 54

In England, Wales and Northern Ireland, a person can appoint a representative, known as a substitute decision maker, to make decisions about organ and tissue donation after their death.

RECOMMENDATION 6 Page 54

The Western Australian Government investigate amending the *Human Tissue and Transplant Act 1982* to incorporate provision for a person to appoint a substitute decision maker, including but not limited to amendments providing that an:

- adult may appoint one or more persons to represent them after death for the purpose of consent to organ and/or tissue donation;
- appointment may be made verbally (in the presence of 2 witnesses) or in writing (signed by the person making the appointment in the presence of at least one witness who attests the signature); and
- appointment can be revoked in the same manner as it was made.

FINDING 12 Page 60

Consent rates among Indigenous Australians are substantially lower than the national average.

FINDING 13 Page 60

Culturally appropriate engagement is required to improve organ and tissue donation rates amongst Indigenous Australians.

RECOMMENDATION 7 Page 61

The Western Australian government, in collaboration with Indigenous Australian Elders, academics and medical practitioners, facilitate comprehensive research into the cultural sensitivities and geographical challenges around organ and tissue donation within Western Australian Indigenous communities.

RECOMMENDATION 8 Page 61

The Western Australian government advocate for the Commonwealth government and the Organ and Tissue Authority to provide additional grants for 'grassroots' tailored education about organ and tissue donation in Indigenous communities. This consultation should be undertaken in collaboration with Indigenous Australian Elders, Aboriginal community-controlled health services and other relevant bodies to ensure a culturally appropriate approach.

FINDING 14 Page 67

Engaging with community and faith leaders is likely to have a positive impact on registration and consent rates amongst culturally and linguistically diverse communities.

RECOMMENDATION 9 Page 67

The Western Australian Government advocate for the Organ and Tissue Authority to update and review the DonateLife website to ensure that:

- all statements of religious and cultural support contain up-to-date information and are clearly marked with the date they were last reviewed;
- the content meets accessibility standards; and
- there are prominent options to translate key information into various languages.

RECOMMENDATION 10 Page 67

The Department of Health and DonateLife WA ensure all staff involved with organ and tissue donation are provided with appropriate training in understanding religious and cultural aspects of organ donation.

RECOMMENDATION 11 Page 67

The Western Australian government and the Organ and Tissue Authority provide grants for 'grassroots' tailored consultation with culturally and linguistically diverse communities. This consultation should address specific concerns of the relevant community and should occur in:

- collaboration with community and faith leaders; and
- environments familiar to the relevant community.

FINDING 15 Page 75

The experience in the United Kingdom and Spain shows that for any legislative change to the organ and tissue donation consent model to have a positive effect, it must be carried out in conjunction with other comprehensively integrated supporting measures.

RECOMMENDATION 12 Page 79

In 5 years, the Western Australian government conduct a review of organ and tissue donation.

FINDING 16 Page 79

While it is possible for a state jurisdiction to adopt an opt-out model, an evidence-based nationally consistent approach is preferrable.

FINDING 17 Page 82

Organ transplantation is a significantly more cost-effective option than hospital-based dialysis for patients with kidney failure.

FINDING 18 Page 87

Machine perfusion technology can improve organ transplant outcomes and increase the utilisation rates of donor organs. Machine perfusion technology provides for extended transportation timeframes.

RECOMMENDATION 13 Page 88

The Western Australian Government, after taking into consideration the cost and benefit of perfusion technology:

- obtain perfusion machines and related consumables for each major retrieval hospital; and
- ensure adequately trained staff to manage and coordinate perfusion.

FINDING 19 Page 90

Normothermic Regional Perfusion has been established as a procedure which allows longer total preservation times and could expand the donor pool by achieving higher organ utilisation rates.

RECOMMENDATION 14 Page 90

The Department of Health advocate for the development of ethical and clinical guidelines for Normothermic Regional Perfusion to be incorporated into clinical practice.

RECOMMENDATION 15 Page 90

In consultation with medical professionals, the Western Australian Government obtain legal advice about any legislative barriers to the use of Abdominal Normothermic Regional Perfusion and implement any necessary legislative amendments to remove identified barriers.

RECOMMENDATION 16 Page 91

The Department of Health encourage the use of OrganMatch and facilitate face-to-face training on the OrganMatch system for all relevant healthcare professionals in Western Australia.

FINDING 20 Page 92

Expanding organ suitability criteria and adopting an 'old-for-old' approach to organ transplant can increase the donor pool and transplantation rates.

FINDING 21 Page 93

Using an interstate provider for nucleic acid testing (NAT) causes logistic issues and missed opportunities.

RECOMMENDATION 17 Page 93

The Department of Health engage a Therapeutic Goods Administration-accredited pathology service for nucleic acid testing in Western Australia.

FINDING 22 Page 94

Delays in the lodgement of a P98 form by police dramatically reduce the likelihood of successful bone and tissue donation.

RECOMMENDATION 18 Page 94

Western Australia Police introduce and enforce minimum target times for the lodgement of a P98 form following certification of life extinct.

RECOMMENDATION 19 Page 95

The Department of Health and DonateLife WA collect data on the number of requests made for Coroner's authorisation for organ donation, the outcome of each request and the reason given for any refusals.

FINDING 23 Page 96

Under the current legislation, the Coroner is unable to conduct internal post-mortem examinations for the purpose of tissue and bone donation, and this limits the potential donor pool.

RECOMMENDATION 20 Page 96

The Western Australian Government investigate amending the *Coroner's Act 1996* to provide the Coroner with a discretionary power, with the consent of the next-of-kin, to conduct an internal post-mortem examination for the purpose of tissue and bone donation.

FINDING 24 Page 98

There is a need to identify and support the potential for organ donation as part of the Voluntary Assisted Dying process. All eligible patients accessing Voluntary Assisted Dying should be offered the opportunity to receive information and make an autonomous decision about organ donation.

RECOMMENDATION 21 Page 99

The Department of Health advocate for ethical and clinical guidelines to be developed by the National Health and Medical Research Council and The Transplantation Society of Australia and New Zealand for organ and tissue donation after Voluntary Assisted Dying.

As soon as possible after these guidelines are developed, the Western Australian Government amend the *Voluntary Assisted Dying Act 2019* and the *Human Tissue and Transplant Act 1982* to incorporate provisions to legislate:

- the right of patients accessing Voluntary Assisted Dying to become organ and tissue donors; and
- record-keeping and reporting requirements for patients donating organs and tissue after accessing Voluntary Assisted Dying.

FINDING 25 Page 103

If Western Australia adopted a significant policy change departing from the national program, the existing finding arrangement between the Western Australian Government and the Organ and Tissue Authority would need reviewing.

FINDING 26 Page 105

Involvement of DonateLife WA staff in the organ donation process has proven to increase family consent rates and increase deceased transplantation rates. DonateLife WA should be adequately resourced to implement the National Organ and Tissue Donation strategy.

RECOMMENDATION 22 Page 105

The Department of Health and DonateLife WA in collaboration with DonateLife staff and management, review the staff funding requirements of DonateLife WA and re-negotiate additional funding from the Organ and Tissue Authority.

FINDING 27 Page 107

The Organ and Tissue Authority's regular performance reports are not publicly available.

FINDING 28 Page 108

Australia could collect and publish more comprehensive data on organ and tissue donation and transplantation.

RECOMMENDATION 23 Page 108

The Western Australian Government advocate for the Organ and Tissue Authority to:

- collect further data relating to:
    - the demographics of individuals on the organ and tissue donor waitlist;
    - the Australian Organ Donor Register, including the demographics of registered persons and the number of opt-out registrations; and
- publish this information in a central location.

FINDING 29 Page 109

The United Kingdom and Spain record and publish detailed hospital-specific data relating to organ and tissue donation and transplantation performance benchmarks.

FINDING 30 Page 110

Recording and publishing hospital-specific data relating to organ and tissue donation and transplantation performance benchmarks is appropriate.

RECOMMENDATION 24 Page 110

The Western Australian Government advocate for jurisdiction and hospital-specific data to be published on the Organ and Tissue Authority website in an easily accessible and user-friendly format, relating to the following performance benchmarks:

- referral of potential deceased organ donors;
- the presence of DonateLife staff during organ donation discussions with families;
- neurological death testing; and
- family consent rates and the registration status of the potential donor.

FINDING 31 Page 113

Training future healthcare professionals will enable them to intelligibly disseminate organ and tissue donation information to families and the wider community and provide confidence to advise future patients.

FINDING 32 Page 114

It would be beneficial to explore opportunities to incorporate organ and tissue donation education into the curriculum for school students.

FINDING 33 Page 115

The Spanish National Transplant Organisation (Organización Nacional de Trasplantes) maintains collaborative relationships with journalists, which has proved to be effective in:

- increasing media coverage around organ and tissue donation and reducing promotional costs;
- maintaining community confidence and increasing family consent rates; and
- normalising organ donation conversations and incorporating these conversations into end-of-life care.

RECOMMENDATION 25 Page 116

The Department of Health and DonateLife WA review their existing media communication policies to ensure there is an emphasis on:

- open and effective communication with journalists;
- maintaining community confidence; and
- normalising organ and tissue donation conversations.

FINDING 34 Page 118

DonateLife Week, Eye and Tissue Awareness Week and Thank You Day offer opportunities to increase public awareness about organ and tissue donation.

RECOMMENDATION 26 Page 118

The Western Australian government and DonateLife WA advocate for the Organ and Tissue Authority to increase the effectiveness of the DonateLife Week campaign.

CHAPTER 1
Background of the inquiry

Establishment of the inquiry

1.1 On 13 February 2023, the Standing Committee on Public Administration (Committee) resolved to establish an inquiry into organ and tissue donation in Western Australia.

1.2 The Committee was to inquire into and report on:

- the effectiveness of the current model for organ and tissue donation in Western Australia;
- issues impacting organ and tissue donation rates in Western Australia;
- opportunities to improve organ and tissue donation rates in Western Australia; and
- any other matters considered relevant by the Committee.

1.3 The Committee consists of the following Members:

- Hon Pierre Yang MLC (Chair);
- Hon Colin de Grussa MLC (Deputy Chair);
- Hon Darren West MLC;
- Hon Sandra Carr MLC; and
- Hon Wilson Tucker MLC.

Conduct of the inquiry

1.4 Links to public submissions, transcripts of evidence and other information published by the Committee for this inquiry are available on the Committee's website.

Written submissions

1.5 The Committee called for submissions to the inquiry by:

- issuing a media release;
- publishing an advertisement in The Weekend West on 4 March 2023;
- targeted letters and emails to stakeholders; and
- posting on social media.

1.6 The Committee received 26 submissions.

Hearings

1.7 The Committee held 6 public hearings with various individuals and organisations, including the Department of Health, DonateLife WA, the Organ and Tissue Authority and Transplant Australia.

1.8 The Committee also held 4 private hearings.

1.9 A list of witnesses who appeared at the public hearings is available in Appendix 1.

Travel and site visits

1.10 The Committee conducted site visits to the following organisations:

- Cell and Tissues Therapies WA, Royal Perth Hospital;
- PlusLife (Perth Bone and Tissue Bank Inc.); and
- The Lions Eye Bank.

1.11 On 1 July 2023, the Committee travelled to Spain and the United Kingdom and met with stakeholders including but not limited to the:

- National Transplant Organisation (Organización Nacional de Trasplantes);
- Transplant Coordinator of Cantabria and Hospital Coordinator of Marqués de Valdecilla University Hospital, Dr Eduardo Miñambres;
- Donation and Transplantation Institute;
- NHS Blood and Transplant;
- Human Tissue Authority; and
- British Transplant Society.

1.12 A complete list of stakeholders visited by the Committee overseas is available in Appendix 1.

CHAPTER 2
What is organ and tissue donation?

Chapter summary

2.1 This chapter explains organ and tissue donation and which organs and tissue can be donated.

2.2 An organ donor can be a living person (known as a living donor) or a recently deceased person (known as a deceased donor). This report primarily focuses on deceased donation.

2.3 How the donor dies influences the donation process and which organs and tissue can be donated. Death can occur through 2 pathways, which are explained in this chapter:

- irreparable damage to a person's brain, known as brain death or neurological death; or
- when blood circulation permanently stops, known as a circulatory death.

2.4 This chapter also contains examples of typical types of recipients of organs and tissue transplants and the survival rates associated with the transplant.

Organ and tissue donation explained

2.5 Organ donation is surgically removing an organ from one person (the organ donor) and placing it into another person (the recipient).

2.6 The recipient needs the organ because their own has failed or been damaged by disease or injury. In most cases, the recipient of an organ is very ill or dying. Organs can be damaged or injured for a variety of reasons, such as:

- congenital conditions[1] which affects an organ;
- illness; and
- chronic disease (for example, cystic fibrosis).

2.7 Organs that can be transplanted include the heart, lungs, liver, kidneys, intestines and pancreas.

2.8 Tissue that can be transplanted include heart tissue, bone, tendons, ligaments, skin, and parts of the eye such as the cornea and sclera.

2.9 More people can become tissue donors than organ donors because tissue donation can occur up to 24 hours after death and outside a hospital.[2]

2.10 The recovery of organs is a surgical procedure performed by trained medical professionals in a hospital operating theatre. After organ and tissue donation, generally, the family may still have a traditional funeral service.

2.11 Even though Australian transplant surgeons are some of the most skilled in the world, organ recipients face the risk of serious complications. Receiving an organ transplant involves major surgery, the use of drugs to suppress the immune system (immunosuppressants), and the possibility of infection, transplant rejection and death. Despite these risks, receiving a transplant is often the recipient's best hope of survival.

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1 Conditions that exist at birth.

2 Organ and Tissue Authority, *Eye and tissue donation awareness*, DonateLife, n.d., accessed 13 Nov 23.

The importance of organ and tissue donation

2.12 Donated organs can save someone's life and allow a person to live unaided by medical equipment or medications. One deceased organ donor can save the lives of up to 7 people.[3] For example, one donor could provide a pancreas, 2 kidneys, 2 liver segments, 2 lungs, a small intestine and a heart.

2.13 Donated tissue can be used to dramatically improve someone's quality of life, such as:

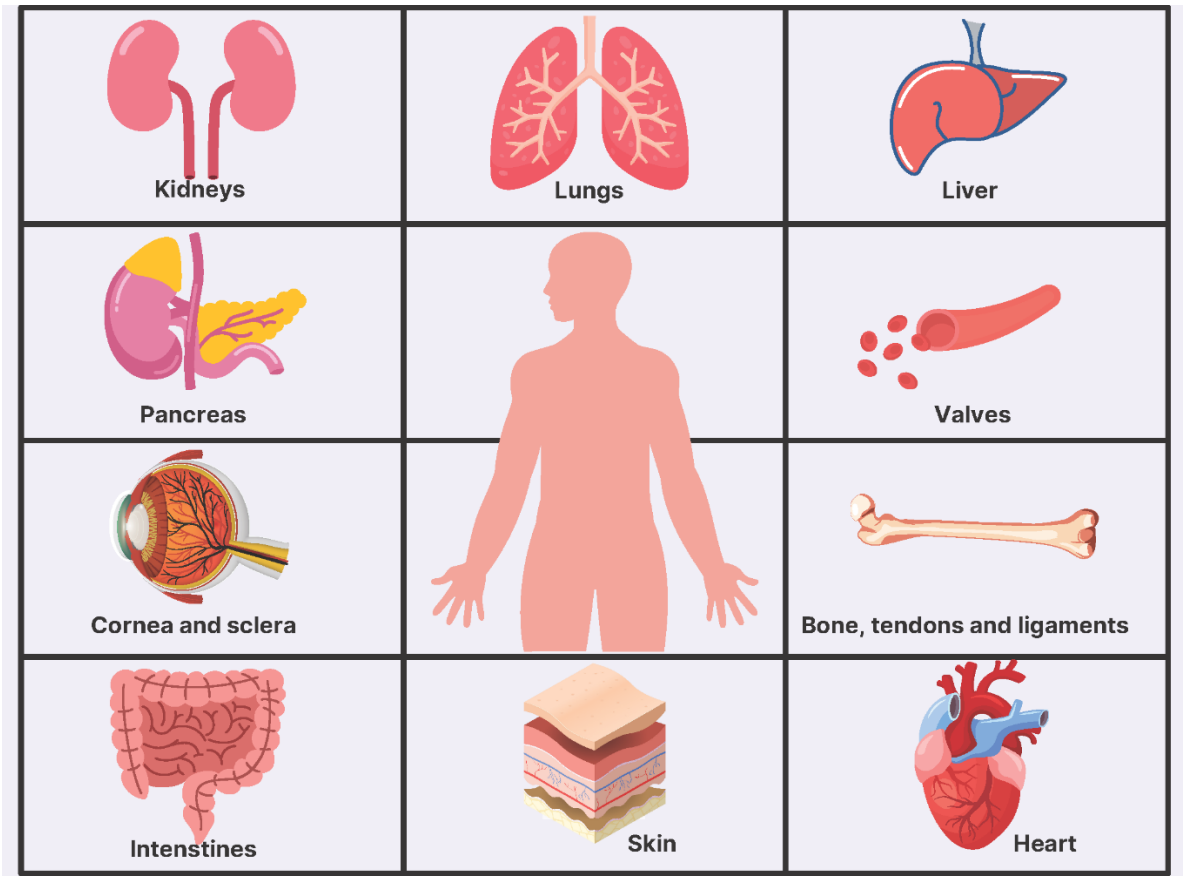
- restoring sight (cornea and sclera);
- treatment of burns (skin); and
- restoring function in limbs (bones, tendons, and ligaments).

2.14 Many transplant recipients can resume an active role in their family, workplace and community. Transplantation can also improve the quality of life of the recipient's loved ones and carers.

2.15 Organ and tissue donation frees up vital medical resources for others in need and can often save public health costs in the long run.

Organs and tissue that can be donated

Figure 1. *Organs and tissue which can be donated in Australia*



[Source: Committee.]

[3] Organ and Tissue Authority, *Statistics in Australia*, DonateLife, 2023, accessed 26 Apr 23.

2.16 A tissue or organ donor can be a:

- living person (living donor); or
- recently deceased person (deceased donor).

Living donation

2.17 A living donor may donate the following organs and tissue:

- Bone marrow: related and unrelated bone marrow donation is well-established in Australia, and there is a national register of potential bone marrow donors.
- Bone and tissue: patients undergoing hip replacement surgery can choose to donate the ball part of their hip joint (femoral head), which is removed and otherwise discarded as a routine part of the procedure.[4]
- Kidney: the remaining kidney adjusts to perform the functions that both kidneys performed previously. Nearly 40% of kidney donations in Australia are from living donors.
- Portion of the liver and lung lobes: both procedures are rare in Australia but will likely become more common in the future.[5]

2.18 Living donation:

- is an essential alternative for patients on the waitlist;
- can provide a more compatible genetic match, lessening the risk of transplant complications;
- increases the overall supply of tissue and organs (required to make up the shortfall between the supply and demand of deceased donation); and
- can provide healthier organs, usually with better long-term outcomes for recipients.[6]

2.19 Living donation can be either directed or non-directed:

- Directed donation is a donation to a specific person, usually a biological relative or a friend and is the most common type of living donation.
- Non-directed donation is a donation to the most suitable recipient on the waiting list, typically through the Australian Bone Marrow Donor Registry or the 'kidney pool'.[7]

2.20 Living donation involves contemporaneous first-person consent. While increasing living donation plays a vital role in saving and improving lives, living donation is largely outside the scope of this report.

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4 PlusLife runs the Western Australian program to retrieve and process bone and tissue donations; see para 3.42.

5 National Health and Medical Research Council (NHMRC), *Organ and Tissue Donation by Living Donors*, Commonwealth Government, 2007, accessed 22 Sep 23, p 1.

6 NHMRC, *Organ and Tissue Donation by Living Donors*, p 1.

7 NHMRC, *Organ and Tissue Donation by Living Donors*, p 1.

Deceased donation

2.21 How a person dies influences the donation method and which organs and tissue can be donated.

2.22 The determination of death can occur through two pathways:

- Brain death: when a person's brain permanently stops functioning.
- Circulatory death: when blood circulation in a person permanently stops.

Brain death

2.23 Brain death occurs when the brain has been damaged and completely and permanently stops functioning.

2.24 The DonateLife website explains the process of brain death:

> [Brain death] can occur as the result of severe head injury, a stroke from bleeding (haemorrhage) or blockage of blood flow in the brain, brain infection or tumour, or following a period of prolonged lack of oxygen to the brain.
>
> When the brain is injured it swells… As the brain swelling increases, the pressure inside the skull increases to the point that blood is unable to flow to the brain. Without blood and oxygen, brain cells die.
>
> The brain and brainstem control many of the body's vital functions, including breathing. When a person has suffered a brain injury, they are connected to a machine called a ventilator, which artificially blows oxygen into the lungs. The oxygen is then pumped around the body by the heart. The heartbeat does not rely on the brain, but is controlled by a natural pacemaker in the heart that functions when it is receiving oxygen…However, even with continued artificial ventilation, the heart will eventually deteriorate and stop functioning.[8]

How brain death is determined

2.25 Several physical changes take place when the brain dies, such as reduced blood pressure, lower body temperature, loss of the normal constriction of the pupils to light, inability to cough and inability to breathe without a ventilator.[9]

2.26 Two senior doctors independently conduct the same set of clinical brain death testing to confirm whether the brain has stopped functioning.[10]

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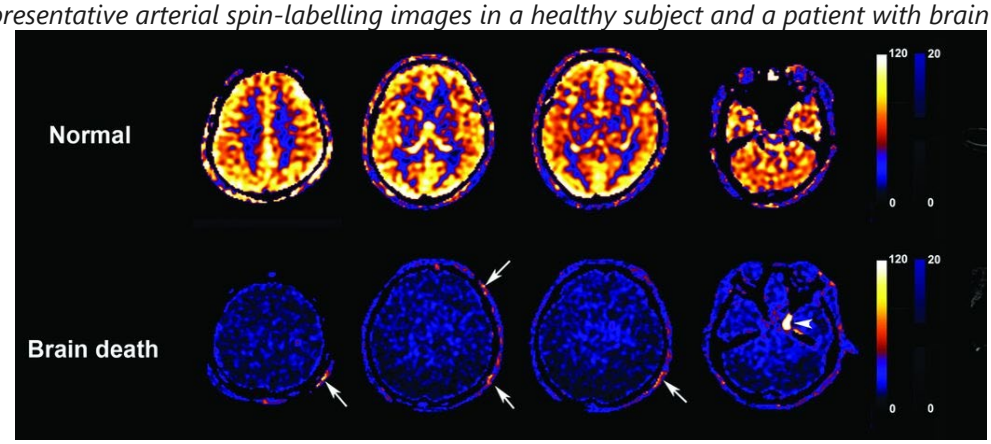
8 Organ and Tissue Authority (OTA), *Understanding death and donation*, DonateLife, 2021, accessed 19 Sep 23.

9 OTA, *Understanding death and donation*.

10 OTA, *Understanding death and donation*.

Figure 2. *Representative arterial spin-labelling images in a healthy subject and a patient with brain death*[11]



[Source: Kang et al.[12]]

Circulatory death

2.27 Circulatory death occurs when a person stops breathing and their heart stops beating so that no blood is circulating. Circulatory death can occur after a sudden illness or accident or be the final stage of a long illness.

2.28 Organ donation is possible after circulatory death, although only in particular situations, as organs quickly deteriorate once blood flow to them stops. The usual circumstance is when a person is in an intensive care unit following a severe illness from which they cannot recover and the doctors and family agree it is in the person's best interests to remove artificial ventilation and any other life-sustaining treatment.

Body donation

2.29 Body donation is outside the scope of this report.

2.30 A person cannot register to donate their body through the Australian Organ Donor Registry. Those wishing to be a body donor sign up at their local (university-based) body donation program whilst they are living.[13]

2.31 Body donation enables medical education, surgical and other post-graduate clinical training and defence, pharmaceutical, road safety and medical device research.[14]

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11 This figure shows images of a healthy 46-year-old woman (upper row) and a 75-year-old woman with brain death (bottom row). The images of the patient with brain death show extremely impaired brain perfusion in the whole brain, bright vessel signal intensity around the level of entry of the carotid artery to the skull (arrowhead) and patent external carotid circulation, compared to the healthy subject.

12 Kang et al., 'Clinical utility of arterial spin-labelling as a confirmatory test for suspected brain death', *American Journal of Neuroradiol*, 2015, 36(5):909-914, accessed 22 Aug 23.

13 The University of Western Australia is licensed to accept body donations from members of the Western Australian community, see: University of Western Australia, *Body Donation Program*, n.d., accessed 8 Nov 23.

14 R Jenkin et al., 'Altruism in death: Attitudes to body and organ donation in Australian students', *Anatomical Sciences Education*, 2023, 16(1):27-46, accessed 22 Aug 23.

Table 1. *Organ and tissue transplantation typical recipients and survival rates*

Type	Typical recipient
Kidney	People with advanced, irreversible kidney failure. A kidney transplant is a lifesaving alternative to dialysis. Survival rate after 1 year: 96% 5 years: 86%.[15]
Pancreas	People with diabetes who also have kidney failure or cannot keep their blood sugar levels within an acceptable range. Survival rate after 1 year: 83%, 5 years: 72%.[16]
Liver	People who have severe chronic liver failure due to long-term liver disease, early stages of liver cancer, severe polycystic liver disease or inherited diseases.[17] Survival rate after 1 year: 94%, 5 years: 70-75%.[18]
Lung	People whose lungs no longer function. For example, due to severe chronic obstructive pulmonary disease, cystic fibrosis or heart abnormalities present at birth.[19] Survival rate after 1 year: 97%, 5 years: 90%.[20]
Heart	People with severe heart failure, coronary artery disease, irregular heart rhythms or other severe heart disorders. Survival rate after 1 year: 94%, of which 95% are better able to do daily activities and 70% return to full-time employment, 5 years: 88%.[21]
Small intestine	People with bowel failure who develop complications from total parenteral nutrition (TPN)[22] or if TPN is not possible.[23]
Cornea and other eye tissue, such as sclera	Transplanted to restore sight and repair traumatic damage to the eye. Lions Eye Bank processes corneal grafts from donors in WA for local use.[24]
Skin	People who need temporary biological dressing for burns and chronic unhealed wounds and ulcers. When skin is donated, only a thin layer is taken (similar to skin peel from sunburn), usually from the back or legs.[25]
Musculoskeletal tissue	Used for orthopaedic, neurosurgical, and plastic surgery to replace damaged bone and aid growth or as an alternative to amputation. PlusLife is the WA bone and tissue service that processes donated bone and other musculoskeletal tissue for use in WA.[26]

15 Australian and New Zealand Intensive Care Society (ANZICS), *The Statement on Death and Organ Donation*, 2021, accessed 10 Oct 23, p 34.

16 ANZICS, *The Statement on Death and Organ Donation*, 2021, accessed 10 Oct 23, p 34.

17 Liver Foundation, *Liver transplant*, 2022, accessed 26 Sep 23.

18 Australian and New Zealand Intensive Care Society, *The Statement on Death and Organ Donation*, 2021, accessed 10 Oct 23, p 34.

19 Lung Foundation Australia, *Lung Transplantation*, 2018, accessed 26 Sep 23.

20 Australian and New Zealand Intensive Care Society, *The Statement on Death and Organ Donation*, 2021, accessed 10 Oct 23, p 34.

21 Y Joshi et al., 'Heart Transplantation from DCD Donors in Australia: Lessons learned from the first 74 cases', *Transplantation*, 2023, 107(2):361-371.

22 TPN is where a person requires all their nutrition to be given through a drip into a vein because their bowel is unable to absorb nutrients from any food they eat.

23 National Health Service (United Kingdom), *Small bowel transplant*, 2019, accessed 26 Sep 23.

24 Submission 25 from Department of Health, 14 Apr 23, p 2.

25 Organ and Tissue Authority, *Who will be helped by my donation?*, DonateLife, n.d., accessed 22 Oct 23.

26 Submission 25 from Department of Health, 14 Apr 23, p 2.

Type	Typical recipient
Stem cell	Stem cell transplantation is used mainly as part of the treatment for blood disorders such as leukaemia, sickle cell disease, aplastic anaemia and some types of lymphoma. Stem cell transplant aims to repopulate the bone marrow with healthy blood stem cells following high-dose treatment and rebuild the body's blood and immune systems.[27]

Who is eligible to donate organs and tissue?

2.32 Having an illness, medical condition or being older does not necessarily preclude a person from becoming an organ and tissue donor. There are very few conditions that preclude donation completely.

2.33 Medical specialists will decide whether organs are suitable for transplant at the time. Testing ensures the potential donor has no transmissible illnesses or viruses and a donor's medical, travel and social history is considered.

2.34 Even if a potential donor's organs are ruled unsuitable for organ donation, the donor may remain a viable candidate for tissue donation.

FINDING 1

Even if a potential donor's organs are deemed unsuitable for donation, the person may remain a viable candidate for tissue donation.

Allocation of organs

2.35 The allocation of organs is a complex process and varies depending on the type of organ. Strict ethical and clinical guidelines govern eligibility for transplant and allocations of organs in Australia.[28]

2.36 The Transplantation Society of Australia and New Zealand produces comprehensive clinical guidelines for organ allocation. The guidelines require consideration of the following factors:

- relative urgency of need;
- medical factors that affect the likelihood of success, such as comorbidities, tissue matching and logistical matters;
- relative severity of illness and disability;
- relative length of time on the waiting list; and
- likelihood that the recipient will be able to comply with the necessary ongoing treatment after transplantation.[29]

2.37 There must be no unlawful or unreasonable discrimination against potential recipients based on factors such as race, religious belief, gender, marital status, sexual orientation, social or other status, disability or age, location of residence or past lifestyle.[30]

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27 Australian Government, *Cancer Australia,* Stem cell transplant, 2024, accessed 12 Feb 24.

28 Clinical and ethical guidelines are discussed in further detail in para 3.23 to 3.27.

29 The Transplantation Society of Australia and New Zealand (TSANZ), Clinical Guidelines for Organ Transplantation from Deceased Donors, May 2023, accessed 18 Oct 23, p vii.

30 TSANZ, Clinical Guidelines for Organ Transplantation from Deceased Donors.

2.38 In relation to the allocation of organs other than kidneys:

> When organs other than kidneys become available, they are offered first to transplant units in the state where the donation occurs. The allocation of these organs involves a team at the transplant unit making a clinical judgement as to which person is best suited to receive that particular organ, at that particular time. Most donated organs are allocated within their home state or territory. If no suitable recipient is identified in the state where the organ was donated, the organ is offered to transplant units in other states and territories and New Zealand.[31]

2.39 In relation to the allocation of kidneys specifically:

> Around 20 percent of kidneys are allocated outside the state of origin under the National Interstate Exchange Program to extremely well matched recipients. The remainder are allocated within the state of origin according to state-specific algorithms, which consider factors including waiting time, tissue matching, paediatric status and sensitisation.[32]

31 TSANZ, Clinical Guidelines for Organ Transplantation from Deceased Donors.

32 TSANZ, Clinical Guidelines for Organ Transplantation from Deceased Donors.

CHAPTER 3
Legislative framework, processes and protocols

Chapter summary

3.1 This chapter summarises the legislative framework, processes and protocols for organ and tissue donation in Western Australia.

3.2 Each Australian state and territory has legislation governing organ and tissue donation in its jurisdiction.[33] The *Human Tissue and Transplant Act 1982* regulates the donation, retrieval and use of organs and tissue for transplantation from living and deceased donors in Western Australia. National ethical and clinical guidelines also govern organ and tissue donation.

3.3 Whilst each Australian jurisdiction has its own legislation, the Commonwealth leads a national organ and tissue donation program administered by the Australian Organ and Tissue Donation and Transplantation Authority (OTA).[34] Australia has an 'opt-in' system of registration, which requires individuals to register their donation decision on the Australian Organ Donor Register.

3.4 The OTA coordinates and funds a national network of clinicians and hospital staff dedicated to organ and tissue donation in hospitals across Australia, leading community awareness and education programs and collecting data.

3.5 The state and territory governments are responsible for organ donation in their hospitals and downstream services, such as tissue typing, retrieval surgery and transplant services.

3.6 This chapter summarises the:

- key provisions of the *Human Tissue and Transplant Act 1982*;
- main provisions of the ethical and clinical guidelines; and
- national program, including the best practice approach for offering organ and tissue donation to families.

3.7 The OTA has developed national guidelines for the best practice approach for referral of potential organ and tissue donors and discussing donation with families.[35] Data shows a positive association with higher donor identification and consent rates and implementation of the best practice guidelines.

Human Tissue and Transplant Act 1982

3.8 The *Human Tissue and Transplant Act 1982* (Act) deals with the following matters:

- donations of organs and tissue by living persons;
- donations of organs and tissue by deceased persons;
- blood transfusions;
- post-mortem examinations; and
- prohibition of trading in organs and tissue and offences concerning unauthorised removal.

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33 See Appendix 2.

34 Established in 2009 pursuant to the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth).

35 Organ and Tissue Authority, Best Practice Guidelines for Offering Organ and Tissue Donation in Australia, 2021, accessed 6 Oct 23, p 4.

3.9 The Act distinguishes between 'regenerative' and 'non-regenerative' organs and tissue.

- 'Regenerative organs and tissue' are those that, after injury or removal, are replaced in the body of a living person by natural processes or growth and repair, such as the liver, skin and bone marrow.
- 'Non-regenerative organs and tissue' are those that are not regenerative, such as hearts, kidneys and corneas.

Donations of organs and tissue whilst alive

Donations by living adults

3.10 A living person who is 18 years or older and of sound mind can give signed written consent to the removal[36] of:

- non-regenerative organs and tissue for:
  - transplantation to the body of another living person.[37]
- regenerative organs and tissue for:
  - transplantation to the body of another living person;
  - therapeutic, medical, or scientific purposes; and
  - training, education, or quality assurance relating to therapeutic, medical or scientific purposes.[38]

3.11 A person who has given consent may revoke their consent (either orally or in writing) at any time before the removal of organs and tissue.[39]

Donations by living children

3.12 It is unlawful to remove non-regenerative organs or tissue from the body of a living child for transplantation.[40]

3.13 Regenerative organs or tissue can be removed if the parent of a child consents in writing to the removal of a specified regenerative organ or tissue to transplant it to a family member or relative of the child.[41]

3.14 For consent to be valid, the following criteria must be met:

- the parent and the child must receive medical advice regarding the nature and effect of the removal and the nature of the transplantation;
- the child must have the mental capacity to understand the nature and effect of the removal and the nature of the transplantation; and
- the child agrees to the removal of the regenerative organ or tissue for transplantation.[42]

3.15 The child, or the parent of the child, can withdraw consent, either orally or in writing, at any time before the removal of the organ or tissue.[43]

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36 The removal must occur 24 hours or more after consent.

37 *Human Tissue and Transplant Act 1982* (HTTA Act) s 9(1).

38 HTTA Act ss 8 and 9(1).

39 HTTA Act s 8(2).

40 HTTA Act s 12(2).

41 HTTA Act s 13(1).

42 HTTA Act s 13(2).

43 HTTA Act s 14.

3.16 Consent (unless revoked) is sufficient authority for a medical practitioner to remove the organ or tissue for transplantation.[44] The medical practitioner removing the organ or tissue must not be the same medical practitioner who provided medical advice to the donor.[45]

Donations of organs and tissue after death

3.17 A designated officer[46] may authorise the removal of organs and tissue from the body of a person who has died in a hospital or whose body has been brought into the hospital for the:

- purpose of the transplantation of organs and tissue to the body of a living person;
- use of the tissue for other therapeutic purposes or medical or scientific purposes; or
- purpose of training, education or quality assurance relating to therapeutic, medical, or scientific purposes.[47]

3.18 A designated officer for a hospital may only authorise the removal:

- where, after making enquiries, the designated officer is satisfied that the deceased person during their lifetime expressed a wish for, or consent to donation and had not withdrawn the wish or revoked the consent; or
- where, after making enquiries, the designated officer has no reason to believe that the deceased person expressed an objection to donation and the designated officer is satisfied that the senior available next of kin consents to the removal.[48]

3.19 The organs and tissue which may be removed and the use of those organs and tissue is restricted by the express terms of the wishes of the deceased person or consent of the senior available next of kin.[49]

Table 2. *What a designated officer must be satisfied of before authorising any retrieval of organs or tissue from the deceased*

Category of deceased persons' wishes during their lifetime	**What the designated officer must be satisfied of before retrieval can occur**
The deceased indicated their wish or consent to donate organs and tissue during their lifetime.	That the deceased had not since withdrawn or revoked this wish or consent.[50]
The deceased did not indicate their wishes during their lifetime.	That, after making enquiries, they have no reason to believe that the deceased person had expressed an objection to donation and that the senior available next of kin consents.[51]
The deceased registered a 'no' decision on the Australian Organ Donor Register.	Donation will not occur.

44 HTTA Act ss 15-17.

45 HTTA Act ss 15-17.

46 A designated officer is a medical practitioner who the chief medical administrator officially appoints to be responsible and accountable for the process of organ and tissue donation in that hospital: HTTA Act s 4(1).

47 HTTA Act s 22(1).

48 HTTA Act s 22(2).

49 HTTA Act s 22(3).

50 HTTA Act s 22(2)(a).

51 HTTA Act s 22(2)(b).

Coroner's consent required in some cases

3.20 If the designated officer for a hospital has reason to believe that the death of a person is or may be a reportable death, they must not authorise the removal of tissue from the body until the coroner has given consent.[52]

People on life support

3.21 When a person's respiration and circulation are maintained by artificial means, organs and tissue must not be removed unless 2 medical practitioners[53] have declared an irreversible cessation of all functions of the person's brain.[54]

Trading in organs and tissue

3.22 It is unlawful for a person to enter into a contract or arrangement for payment, for the sale or supply of organs or tissue or to the post-mortem examination or anatomical examination of a body after death.[55]

3.23 It is unlawful to advertise the buying of human organs or tissue in Australia.[56]

Ethical and clinical guidelines

Ethical guidelines issued by the National Health and Medical Research Council

3.24 The National Health and Medical Research Council (NHMRC) produces ethical guidelines for organ and tissue donation (Ethical Guidelines).[57] The Ethical Guidelines are summarised in Table 3.

3.25 The NHMRC is working with the OTA to review all the guidelines with a view of consolidating them into a single guideline, which will detail the ethical considerations that apply to a range of different circumstances. The NHMRC advised:

> We anticipate having a draft ready for public consultation late in 2023 or early 2024.[58]

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52 HTTA Act s 23.

53 Both medical practitioners must have been practising for at least 5 years and have a specialist qualification.

54 *Human Tissue and Transplant Act 1982* s 24A(2).

55 HTTA Act s 29.

56 HTTA Act s 30.

57 National Health and Medical Research Council, *Ethical guidelines on organ and tissue donation and transplantation*, Australian Government, 2007, accessed 19 May 23.

58 Submission 16 from National Health and Medical Research Council, 28 Mar 23, p 2.

Table 3. *National guidelines for organ and tissue donation issued by the National Health and Medical Research Council*

Guideline	Target audience	Key principles or information
Organ and tissue donation after death, for transplantation: Guidelines for ethical practice for health professionals (2007)	Health professionals, clinical practices, and institutions	• Organ and tissue donation is an altruistic act that benefits those in need and society as a whole. • Organ and tissue procurement should be conducted with respect for human dignity, including the worth, welfare, rights, beliefs, perceptions, customs and cultural heritage of all involved. • The wishes of the deceased, the needs of the potential donor and their family and the protection of recipients from harm should be prioritised. • Fair and transparent processes should be followed when allocating organs and tissue.[59]
Making a decision about organ and tissue donation after death (2007)	Individuals considering deceased donation	• The systems in place to ensure all those involved in organ and tissue donation are cared for and supported. • The process of organ and tissue donation. • An outline of common factors and views a person may wish to consider before making their decision to donate or not to donate.[60]
Organ and tissue donation by living donors: Guidelines for ethical practice for health professionals (2007)	Health professionals and institutions dealing with living donation	The key ethical practice in living donation is supporting free and informed decision-making so that the donor can make an independent decision. This involves understanding individual situations and the complex pressures and motives that may affect decision-making about living donation within families.[61]
Making a decision about living organ and tissue donation (2007)	Individuals considering living donation	• Living donation is only possible if the donor can still live healthily without that organ or tissue. • Living donation must be altruistic and an informed decision must be made freely and voluntarily. • Cultural issues must be considered in planning programs and working with families.[62]
Ethical guidelines for organ transplantation from deceased donors (2016)	Health professionals, clinical practices, and institutions	Provides guidance for: • determining eligibility for organ transplantation; • assessing donor organ suitability; and • organ allocation.[63]

[59] National Health and Medical Research Council (NHMRC), Organ and tissue donation after death, for transplantation, NHMRC, Australian Government, 2007, accessed 19 May 23.

[60] NHMRC, *Making a decision about organ and tissue donation after death*, NHMRC, Australian Government, 2007, accessed 19 May 23.

[61] NHMRC, *Organ and tissue donation by living donors – Guidelines for ethical practice for health professionals*, Australian Government, 2007, accessed 19 May 23.

[62] NHMRC, *Making a decision about living organ and tissue donation*, Australian Government, 2007, accessed 19 May 23.

[63] NHMRC, *Ethical guidelines for organ transplantation from deceased donors*, Australian Government, 2007, accessed 19 May 23.

Clinical guidelines issued by the Transplantation Society of Australia and New Zealand

3.26 The Transplantation Society of Australia and New Zealand (TSANZ) produces the Clinical Guidelines for Organ Transplantation from Deceased Donors (Clinical Guidelines).

3.27 The OTA funds the TSANZ to develop and maintain the Clinical Guidelines, which govern:

- eligibility criteria for organ transplantation; and
- the allocation of donated organs.[64]

3.28 The Ethical Guidelines inform the Clinical Guidelines.

Therapeutic Goods Administration

3.29 Eye and tissue donations are governed by the Therapeutic Goods Administration (TGA).

3.30 The TGA sets certain guidelines and standards, such as mandatory testing, to maintain the safety and quality of collected blood, cells, and tissue.

3.31 Eye and tissue must be recovered within 24 hours of death.

The national approach

The National Reform Program 2008

3.32 In 2008, the Council of Australian Governments (COAG) agreed to a national organ and tissue donation reform program.

3.33 The program aimed to improve organ and tissue donation practices to achieve a lasting increase in transplants. COAG endorsed 9 measures:

- Measure 1: A national authority and network of organ procurement organisations
- Measure 2: Specialist hospital staff and systems dedicated to organ donation
- Measure 3: New funding for hospitals
- Measure 4: National professional awareness and education
- Measure 5: Coordinated ongoing community awareness and education
- Measure 6: Support for donor families
- Measure 7: Safe, equitable and transparent national transplantation process
- Measure 8: National eye and tissue donation and transplantation
- Measure 9: Additional national initiatives, including living donation programs.[65]

The Organ and Tissue Authority

3.34 In 2009, a national coordinating agency, the OTA was established to implement the reform program.

3.35 The OTA's responsibilities include:

- coordinating a national network of clinicians and other hospital staff dedicated to organ and tissue donation in hospitals across Australia;
- overseeing a national network of state and territory organ and tissue donation agencies;
- formulating national policies and protocols;

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64 See para 2.35 to 2.39.

65 Tabled Paper 3336, Legislative Council, 17 May 11, p 11.

- leading community awareness and education programs; and
- national data, monitoring, and reporting.

3.36 Under the national program, the Commonwealth government provides resources to enhance organ and tissue donation, while the state and territory governments are responsible for the delivery of the donation program in hospitals and downstream services, including tissue typing, retrieval surgery and transplant services.[66]

3.37 The OTA administers financial support grants to state and territory governments to deliver organ donation and transplantation services.[67] The funding provided by the OTA to Western Australia is discussed in Chapter 12.

3.38 Although Australia has a nationally consistent model for organ and tissue donation, there is some flexibility for states and territories. The OTA described this flexibility as follows:

> Jurisdictions do have the ability to have some flexibility to adapt to their local environment, but in the actual donation process, they follow the national program with that. There is some flexibility in community engagement in particular, noting different ways that they may come back and say, "We want to engage in this way." So, it is all collaboration to make sure we get it, but there is an underlying national consistent process that we follow that comes out and is agreed. It is not just the OTA saying, "You need to do this". We sit down three times a year and discuss all of the clinical program and the community program with the leadership from DonateLife.[68]

DonateLife WA

3.39 DonateLife WA is the state agency that supports, in partnership with OTA:

- activity to increase registrations by Western Australians on the Australian Organ Donation Registry;
- coordination of all organ and tissue donor activities across the state;
- collaboration with hospitals and hospital-based DonateLife medical and nursing specialists to provide donation services and encourage best practice; and
- delivering a national professional education program to train donation specialists.[69]

3.40 DonateLife WA has a state medical director and agency manager and employs medical, nursing and administrative staff.

Eye and Tissue Banks

3.41 Established in 1986, the Lions Eye Bank is an independent organisation responsible for collecting, processing and distributing corneal and sclera tissue throughout Western Australia for surgical needs.

3.42 PlusLife is an independent not-for-profit organisation responsible for retrieving, processing and distributing human bone and tissue in Western Australia. It provides medical professionals safe and effective human bone and tissue allografts for various surgical needs.[70]

3.43 The Lions Eye Bank and PlusLife work collaboratively with DonateLife WA. DonateLife WA receives referrals from hospitals, the police and the coroner of potential tissue donors, determines suitability

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66 Submission 23 from Organ and Tissue Authority, 12 Apr 23, p 2.

67 *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth) ss 54-55.

68 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 12.

69 Organ and Tissue Authority, *DonateLife Western Australia*, Australian Government, n.d., accessed 12 Feb 24.

70 Submission 22 from PlusLife, 31 Mar 23, p 6.

and manages the consent process. The tissue is then retrieved, processed and distributed by the Lions Eye Bank (eyes) or PlusLife (bone and tissue).

The opt-in system

3.44 The Australian organ and tissue donation system is based on a 'soft' opt-in model, which requires individuals to nominate their organ and tissue donation preferences on the Australian Organ Donation Register.

3.45 Registration is not a legally binding directive. In practice, even if an individual has recorded their wishes to donate their organs after death, no retrieval will occur without obtaining consent from the family of the deceased.[71]

3.46 The opt-in system is discussed in detail in Chapter 10 of this report.

The donor register

3.47 The Australian Organ Donor Register (AODR) is the national register for people (aged 16 years and older) to record their decision about becoming an organ and tissue donor after death, including which organs and tissue the person wants to donate.[72]

3.48 Only 38% of the eligible Western Australian population has registered a decision on the AODR.

3.49 The AODR is discussed in detail in Chapter 5 of this report.

Best practice guidelines for offering organ and tissue donation in Australia

3.50 As part of the national reform program, the OTA developed national guidelines for the best practice approach for referral of potential organ and tissue donors and discussing donation with families (Best Practice Guidelines).[73]

3.51 Data shows a positive association with higher donor identification and consent rates and implementation of the best practice guidelines:

> Evidence from the data of the last 12 years demonstrates that family consent for donation is granted more often, and organ donation proceeds more often when this best practice model is followed.[74]

Roles of the clinical team

Table 4. *Responsibilities of the donation process according to role*

Role	Responsibilities
Senior treating doctor	Manages a patient's end-of-life care and leads the end-of-life communication with their family.
Critical care nurses	Supports the process by reinforcing the medical information conveyed, often having developed a rapport with the family while providing care to their relative.

71 National Health and Medical Research Council, Organ and Tissue Donation After Death, For Transplantation: Guidelines for Ethical Practice for Health Professionals, Australian Government, 2007, pp 33-34.

72 Services Australia, *Australian Organ Donor Register: How to change your choices*, Australian Government, 2023, accessed 19 Sep 23.

73 Organ and Tissue Authority, *Best practice guideline for offering organ and tissue donation in Australia*, Australian Government, 2021, accessed 6 Oct 23, p 4.

74 Submission 25 from Department of Health, 14 Apr 23, p 11.

Role	Responsibilities
Donation Specialist Nurse	Provides detailed and accurate information about donation and possesses the skills to sensitively introduce the topic of donation and openly explore what donation may mean for a family, thereby assisting them in making a fully informed decision.[75]

[Source: Adapted from the Best Practice Guidelines for offering organ and tissue donation.[76]]

The steps involved in offering organ and tissue donation

3.52 The steps in paragraphs 3.53 to 3.61 summarise the best practice model for organ and tissue donation. The guideline acknowledges that a flexible approach is required in some circumstances:

> It is appreciated that the individual aspects of each patient's death and their family's circumstances will influence the timing and approach to discussing donation with the family. A flexible approach that is tailored to the specific circumstances is recommended with consistency in applying the principles and key elements in this Guideline where possible.[77]

Step 1: Medical consensus

3.53 The treating clinical team of a patient in the Intensive Care Unit (ICU) or Emergency Department (ED) reaches a medical consensus that the patient has died or agrees that continuing treatment is not in the patient's interests:

- At the earliest opportunity after the medical consensus is reached, the treating clinical team notifies DonateLife WA. The DonateLife team consider whether the patient might be eligible to be a donor and check the registry.[78]

Step 2: End-of-life conversation between the family and the clinical team

3.54 The family are informed that the patient has died or that death is expected following the withdrawal of treatment.[79]

- It is the senior treating doctor's responsibility to ensure the family understands that death has or is expected to occur before organ and tissue donation is discussed.
- Discussion will occur about the patient's end-of-life wishes, the removal of the ventilator and other treatments, focusing on providing comfort and pain relief. The decision to remove life support is always made with the family before and independently of any donation consideration.

3.55 If the family raises donation early or during the end-of-life conversation, and a Donation Specialist Nurse is not present, the senior treating doctor acknowledge the family's request and advise them that it would be preferable to defer the discussion.

Step 3: Planning for the family donation conversation

3.56 A planning meeting occurs before the family donation conversation with the senior treating doctor, the Donation Specialist Nurse, relevant critical care nurse/s and other appropriate staff. The discussion

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75 Organ and Tissue Authority (OTA), *Best Practice Guidelines for Offering Organ and Tissue Donation in Australia*, Commonwealth Government, 2021, accessed 4 Sep 23, p 5.

76 OTA, *Best practice guideline for offering organ and tissue donation in Australia*.

77 OTA, *Best Practice Guidelines for Offering Organ and Tissue Donation in Australia*, p 4.

78 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 9.

79 When doing so, the senior treating doctor discusses the patient's neurological status, the outcome of examinations to determine neurological death or the planned withdrawal of cardio-respiratory support and expected death.

will include sharing information about the patient's AODR registration status and each staff member's roles during the family donation discussion.

Step 4: Discussion about organ donation with the family

3.57 A collaborative approach requires the involvement of a Donation Specialist Nurse in every discussion of donation with the potential donor's family. Accurate information tailored to a family's circumstances should be delivered to the family sensitively and respectfully.

3.58 The collaborative team will sensitively support the family and assist them in making a fully informed decision about donation. They will explore a family's decision-making process to ensure that it is based on accurate information and that any decision is free of misconceptions. The family will be assured that, whatever they decide, their decision will be supported. The decision-making process can sometimes require a series of discussions over time.

3.59 If the family consents to organ donation, the patient continues to be cared for in the ICU just as they had previously.

- The Donation Specialist Nursing Coordinator communicates with transplant teams across Australia to align appropriate recipients. Organ donation does not proceed in Australia unless there is a suitable recipient.
- Once arrangements are made, the person is moved to the operating theatre for the donation operation. The ventilator and any other life support will be removed.
- The donor family receives continued bereavement support if requested.

3.60 If the family does not consent to donation, the ventilator is removed, the person's heart will stop beating due to a lack of oxygen and blood circulation will stop.

Step 5: Team review

3.61 A team review occurs after each family donation conversation process to provide an opportunity to reflect upon and improve practice. The most important outcome of the family donation conversation is that the family reaches a decision that is right for them.

CHAPTER 4
Deceased donation rates and the current waitlist

Chapter summary

4.1 Australia's donation and transplantation rates are among the lowest in the developed world.

4.2 Despite the 2008 National Reform Program, Australia continues to underperform.

4.3 There are significantly more people needing an organ transplant than organs available.

4.4 This chapter explores:

- the current transplant waitlist;
- Australia's deceased donation rates in comparison to international jurisdictions; and
- Western Australia's deceased donation rates in comparison to other Australian jurisdictions.

4.5 The factors contributing to Australia's low transplantation rates and recommendations to increase Australia's transplantation rates are discussed in later chapters of this report.

4.6 Australia performs very strongly regarding quality of care and organ and tissue transplantation outcomes.

The organ transplant waitlist

4.7 As of 1 October 2023, approximately 1,859 adult Australians and 7 children are on the active waitlist for an organ transplant.[80]

4.8 There are also a further 13,000 on dialysis due to kidney failure who may need a kidney in the future.[81]

4.9 Waitlist data does not necessarily correlate to the actual demand for transplantation. People on the organ waitlist are those who would be transplanted immediately if an organ became available. For some organs, there are groups of patients who have been assessed but not yet 'activated' on the waiting list, people who have been removed temporarily or made 'inactive':

> For example, patients may develop a medical problem that makes them temporarily or permanently unfit for transplantation.[82]

80 Australia and New Zealand Organ Donation Registry, *Organ Waiting List*, 2023, accessed 10 Oct 23.

81 DonateLife, *Statistics in Australia*, 2023, accessed 26 Apr 23.

82 Australia and New Zealand Dialysis and Transplant Registry, *2023 Annual Report: Deceased organ transplant waiting lists*, 2023, accessed 20 Oct 23, p 3.

Table 5. *Number of adults (17 years and older) enrolled on the organ waiting list who would be transplanted immediately if an organ were available, as at 1 Oct 23*

Organ	Number of adults
Kidney	1,492
Liver	118
Heart	62
Lung	107
Pancreas	65
Pancreas Islets	14
Intestine	1
Total	**1,859**

[Source: Australia and New Zealand Organ Donation Registry.[83]]

Table 6. *Number of children (16 years and under) on the transplant waitlist as at September 2023*

Organ	Number of children
Kidney (no living-related donor match)[84]	3
Heart	3
Liver	1
Total	**7**

[Source: Department of Health.[85]]

4.10 Adults are usually on the waitlist for between 6 months and 4 years, but some wait even longer.[86]

4.11 The national median wait time for a kidney transplant (from first going on dialysis to transplantation) for children is 1.1 years.[87]

4.12 Some people die whilst on the active transplant waitlist.

83 Australia and New Zealand Organ Donation Registry, *Organ Waiting List*, 2023, accessed 10 Oct 23.

84 Of the children receiving a kidney transplant, most receive from a living donor. The ratio between living-related and deceased donors is close to 2:1.

85 Letter from Elysia Washer, Acting Principal Project Officer, Department of Health, 4 Oct 23, p 1.

86 DonateLife, *Statistics in Australia*, 2023, accessed 26 Apr 23.

87 Letter from Elysia Washer, Acting Principal Project Officer, Department of Health, 4 Oct 23, p 1.

Table 7. *Number of people who died whilst on the active transplant waitlist from 2017 to 2022 by organ type*

	2017	2018	2019	2020	2021	2022
Kidney	5	9	10	3	5	8
Liver	6	8	12	11	24	5
Heart	8	12	17	4	5	2
Lung	4	18	20	10	10	18
Pancreas	0	4	3	0	0	1

[Source: Australia and New Zealand Organ Donor Register.[88]]

Deceased donation rates

Donors per million population (dpmp)

4.13 The most widely-used methodology for measuring and comparing organ donation rates internationally is the 'donors per million population' (dpmp) method. This method compares rates of donation against population counts.[89]

International comparison

4.14 In 2022, Australia's deceased donation rate was 16.3 dpmp. In comparison, the world's leading rate was in the United States of America (USA) (41.6 dpmp) followed by Spain (40.8 dpmp).

4.15 However, it is noted that some caution is required when comparing international figures:

- Donation does not necessarily translate to organ utilisation. Australia only retrieves organs and tissue once a suitable recipient is identified.
- The donation rate in the USA must be viewed in the context of the number of deaths in circumstances that make organ donation a viable option, such as fatal opioid overdose, gunshot wounds and road fatalities.

4.16 In relation to the rates seen in the USA, the OTA advised:

> people look at the US, because they have got high rates. I mean, it is important to note that six per cent of donors in the US die as a result of gunshot wounds, and 17 per cent from drug overdose. They have an opioid crisis. We also do, but not of the same degree. We would have a much smaller proportion of people dying from drug overdose who could become donors. And 11 per cent of donors in the US last year died from a motor vehicle accident as compared with five per cent in Australia. We do not want more donors as a result of more people dying from gunshots and drug overdose and motor vehicle accidents, but we do have the potential to expand our pool of donors…[90]

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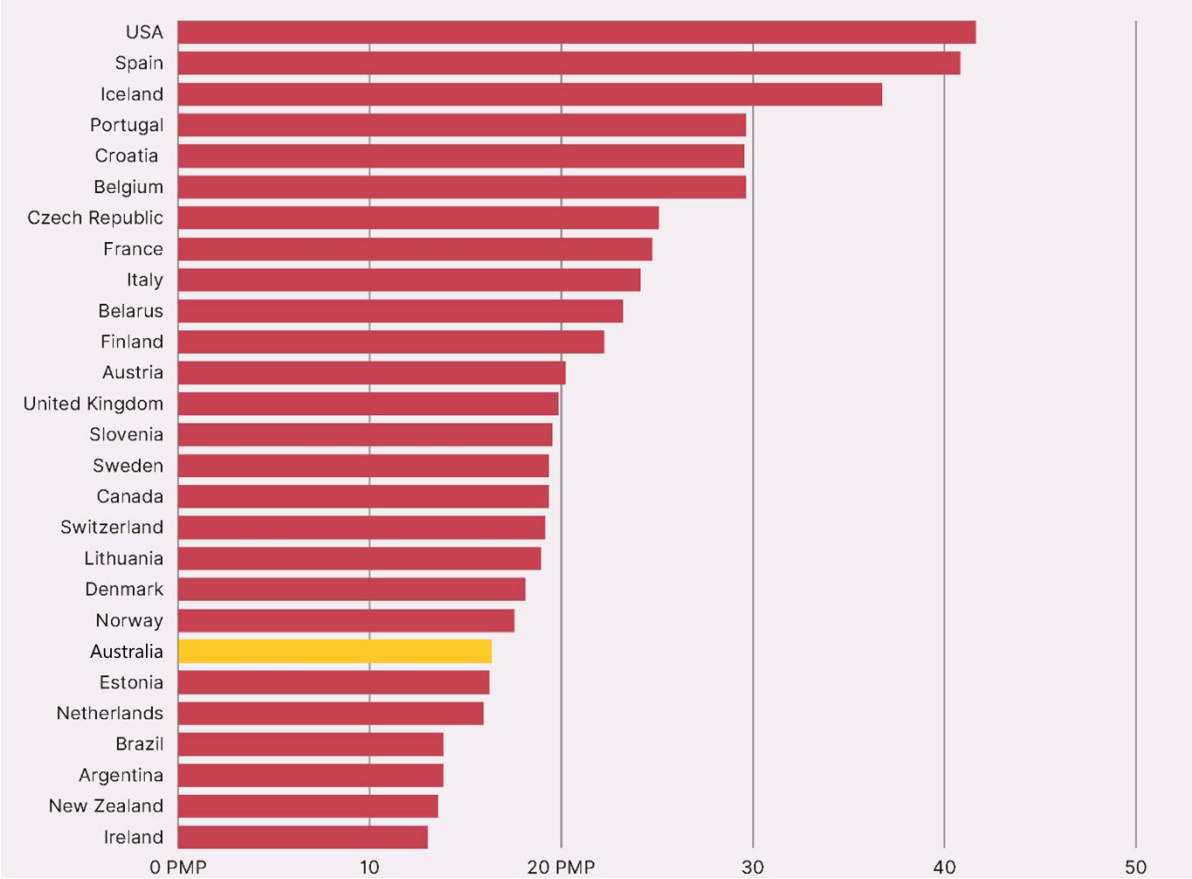
88 Australia and New Zealand Organ Donation Registry, *Annual Report 2023: Deceased Organ Donor Transplant Waiting Lists*, 2023, accessed 23 Oct 23, ch 11.

89 This statistic does not consider the number of potential donors (those located in an intensive care unit and identified as suitable) or the number of organs taken from each donor. Different countries also define 'deceased organ donor' in different ways. Nevertheless, this method remains the current means of international comparison.

90 Dr H Opham, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 16.

Figure 3. *Worldwide actual deceased donations 2021*



[Source: Adapted from data obtained from the International Registry in Organ Donation and Transplantation.[91]]

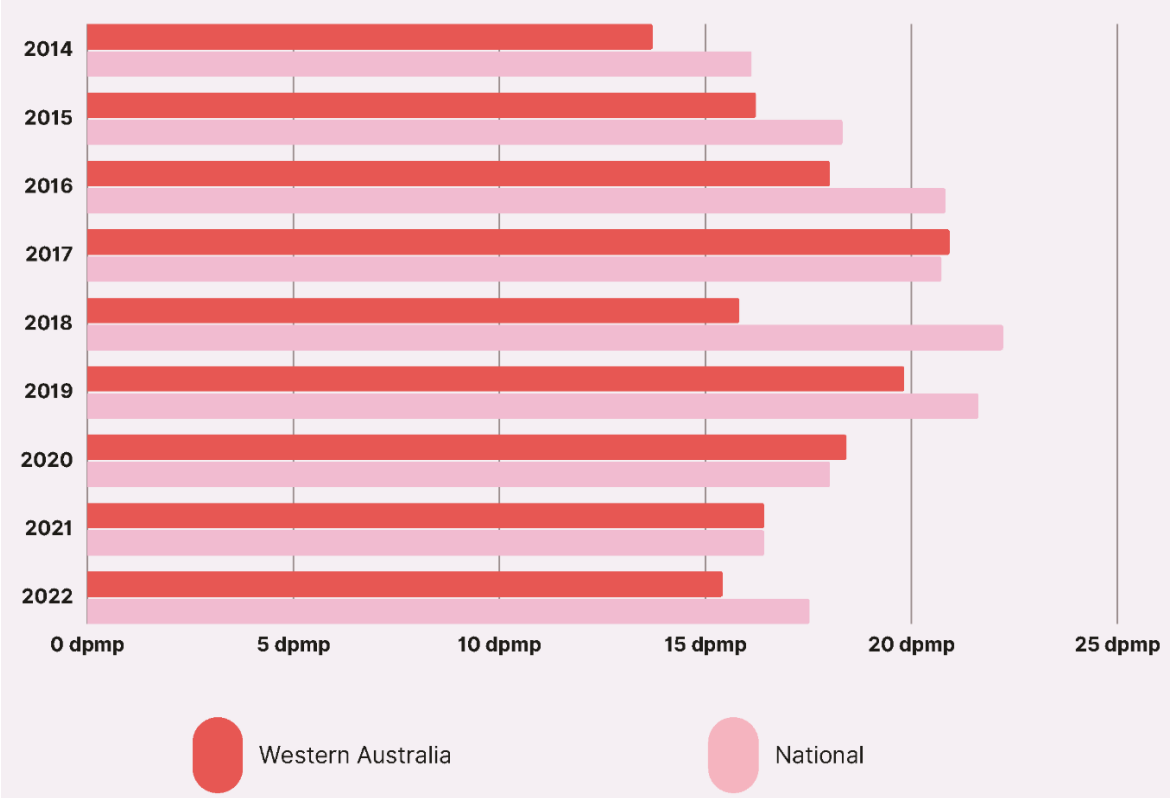
Deceased organ donation rates in Western Australia

4.17 In 2022, Western Australia's rate of dpmp was 15.4, lower than the national average of 16.3.

4.18 Since 2014, Western Australia has only achieved a rate above the national average in 2017 (20.9 compared to 20.7) and 2020 (18.4 compared to 18).

[91] International Registry in Organ Donation and Transplantation, *Worldwide actual deceased organ donors 2021*, 2021, accessed 26 Sep 23.

Figure 4. *Deceased donation rates (dpmp) in Western Australia compared to the national average*



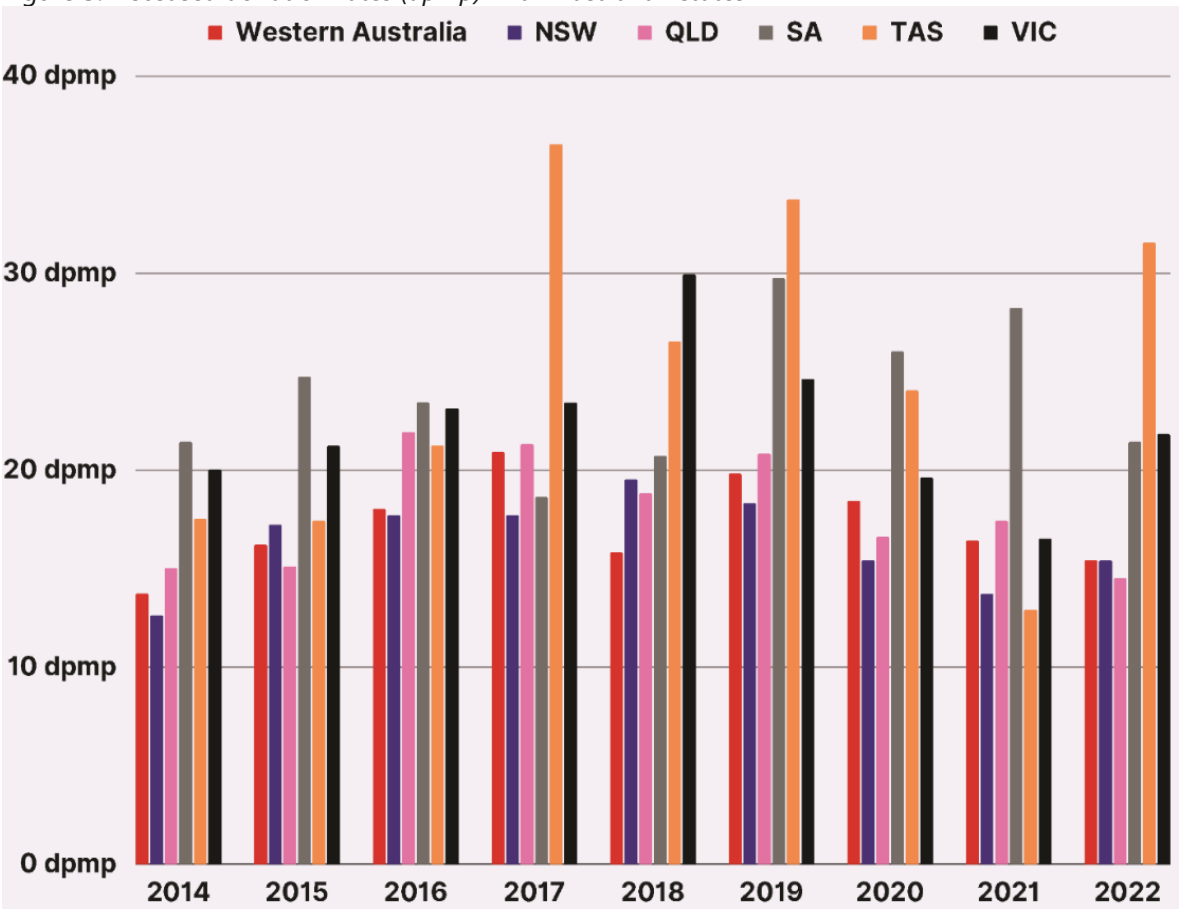
[Source: Adapted from Organ and Tissue Authority annual report data.[92]]

4.19 The relatively small populations of the Northern Territory, the Australian Capital Territory and Tasmania can result in significant fluctuations in outcomes and donation rates from year to year.[93] Therefore, Figure 5 reflects Western Australia's performance only in comparison to other states:

[92] Organ and Tissue Authority (OTA), *2022 Donation and Transplantation Activity Report*, 2022, accessed 23 Oct 23, p 18; OTA, *Donation and Transplantation Activity Report 2018*, 2018, accessed 23 Oct 23, p 5; OTA, *Donation and Transplantation Activity Report 2017*, 2017, accessed 27 Sep 23, p 4; OTA, *Donation and Transplantation Activity Report 2016*, 2016, accessed 23 Oct 23, p 4.

[93] OTA, *Donation and Transplantation Activity Report 2017*, accessed 27 Sep 23, p 4.

Figure 5. *Deceased donation rates (dpmp) in all Australian states*



[Source: Adapted from Organ and Tissue Authority annual report data.[94]]

Impact of COVID-19

4.20 The COVID-19 pandemic caused a decrease in donation and transplantation activity in Australia for the years 2020-2022.

4.21 A similar decrease in transplantation activity occurred worldwide during the height of the COVID-19 pandemic.

4.22 Factors relating to the pandemic that had the effect of decreasing donation and transplantation rates were:

- the risk versus benefit of transplants taking place for immunosuppressed people and the capacity for hospitals to care for transplant patients;
- the restriction of hospital visits and disruption of donation conversations;
- transport restrictions and border closures; and
- reduced or redistributed staff.[95]

Rates of donation after brain death compared to donation after circulatory death

4.23 Most organs are donated through the Donation after Brain Death (DBD) pathway.

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94 OTA, *2022 Donation and Transplantation Activity Report*, 2022, accessed 23 Oct 23, p 18; OTA, *Donation and Transplantation Activity Report 2018*, 2018, accessed 23 Oct 23, p 5; OTA, *Donation and Transplantation Activity Report 2017*, 2017, accessed 27 Sep 23, p 4; OTA, *Donation and Transplantation Activity Report 2016*, 2016, accessed 23 Oct 23, p 4.

95 OTA, *Annual Report 2021-22*, 2022, accessed 2 Oct 23, p 26.

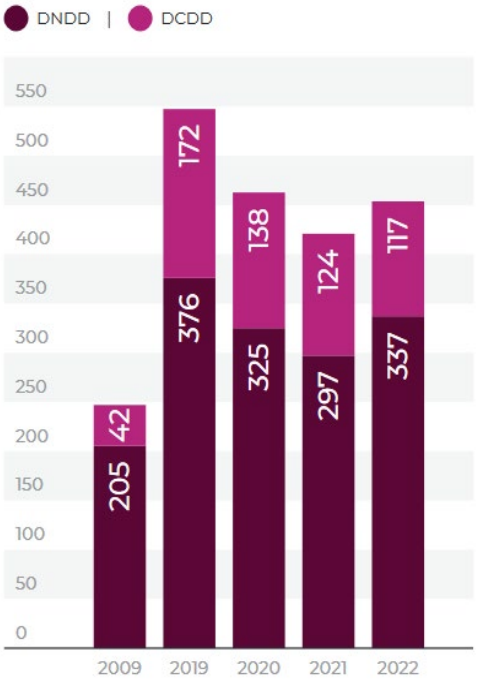
4.24 Australia has relatively low rates of Donation after Circulatory Death (DCD). In 2022, 74% of deceased donors came from the DBD pathway, and 26% came from the DCD pathway.[96]

4.25 In comparison, 40% of donors in the United Kingdom and 45% of donors in the Netherlands came from the DCD pathway.[97]

4.26 Western Australia does not currently transplant livers retrieved through the DCD pathway because they are more susceptible to damage before transplantation.

4.27 Australia's rates of DCD donors could increase with technology, as discussed in Chapter 11.

Figure 6. *National rates of donations after neurological or brain death (DNDD) compared to rates of donation after circulatory death (DCDD).*



[Source: Organ and Tissue Authority.[98]]

[96] OTA, *2022 Donation and Transplantation Activity Report*, 2022, accessed 23 Oct 23, p 16.

[97] J Reiling et al., 'The implications of the shift towards donation after circulatory death in Australia', *Transplant Direct*, 2017, 3(12):e226.

[98] Organ Tissue Authority, *2022 Donation and Transplantation Activity Report*, 2022, accessed 23 Oct 23, p 16.

CHAPTER 5
Australian organ donor registration rates

Chapter summary

5.1 In 2022, only 36% of eligible adults in Australia and 38% of Western Australians had registered on the Australian Organ Donor Register (AODR).[99]

5.2 The AODR is the national register for people (aged 16 years and older) to record their wishes about becoming an organ and tissue donor after death, including which organs and tissue the person wants to donate.

5.3 This chapter examines:

- the purpose of AODR;
- registration rates in Western Australia;
- myths that prevent people from registering on the AODR; and
- opportunities to increase registration rates, including but not limited to re-introducing driver's licences as a pathway to registration.

The Australian Organ Donor Register

5.4 The AODR is the national register for people (aged 16 years and older) to record their wishes about becoming an organ and tissue donor after death, including which organs and tissue the person wants to donate.[100]

5.5 Donation decisions recorded on the AODR can be updated or changed anytime.

Purpose of the register

5.6 If a person dies in circumstances that make them eligible to become an organ and tissue donor, DonateLife WA checks the AODR to ascertain the person's wishes.

5.7 Registering a decision on the AODR does not mean donation will automatically proceed, even if that person is eligible to donate. Families are consulted and must consent to donation. If the family does not consent, donation will not proceed, regardless of whether the person indicated their wish on the AODR.

5.8 Increasing registration rates is vital because the AODR:

- facilitates timely national access to a person's donation decision;
- provides families with the confidence to make a decision during an often distressing time;
- increases chances of families consenting to donation and fulfilling their loved one's wishes;[101]
- can act as a catalyst for having conversations with loved ones about organ donation; and
- provides data to measure current community attitudes towards organ and tissue donation.

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99 Submission 25 from Department of Health, 14 Apr 23, p 13.

100 Services Australia, *Australian Organ Donor Register: How to change your choices*, Australian Government, 2023, accessed 19 Sep 23.

101 See Chapter 6.

5.9 A person's registration status forms the basis of the conversation with families about whether they consent to their loved ones donating:

> The family discussion about organ donation is dramatically facilitated if donation specialist staff are advised in advance of the family donation conversation that the patient is registered on the AODR.[102]

5.10 The chance of families consenting if their loved one is on the donor register is around 90%. If the person has not registered their decision, or the decision is unknown, the chances of family consent dramatically decrease. This is discussed further in Chapter 6.

Current options to register a decision

5.11 Currently, Australians can register their decision on the AODR by:

- Registering through the DonateLife website ('yes' to donating all organs and tissue).
- Registering via My Gov[103] ('yes to donate all organs and tissue, 'yes to specific organs and tissue' or 'no').
- Hard copy register form ('yes to donate all organs and tissue, 'yes to specific organs and tissue' or 'no').
- Tick-box option on the Medicare app or the Medicare website.[104]

Registration rates

5.12 Despite studies showing that the majority of Australians support organ donation, only 38% of the eligible Western Australian population are registered.[105]

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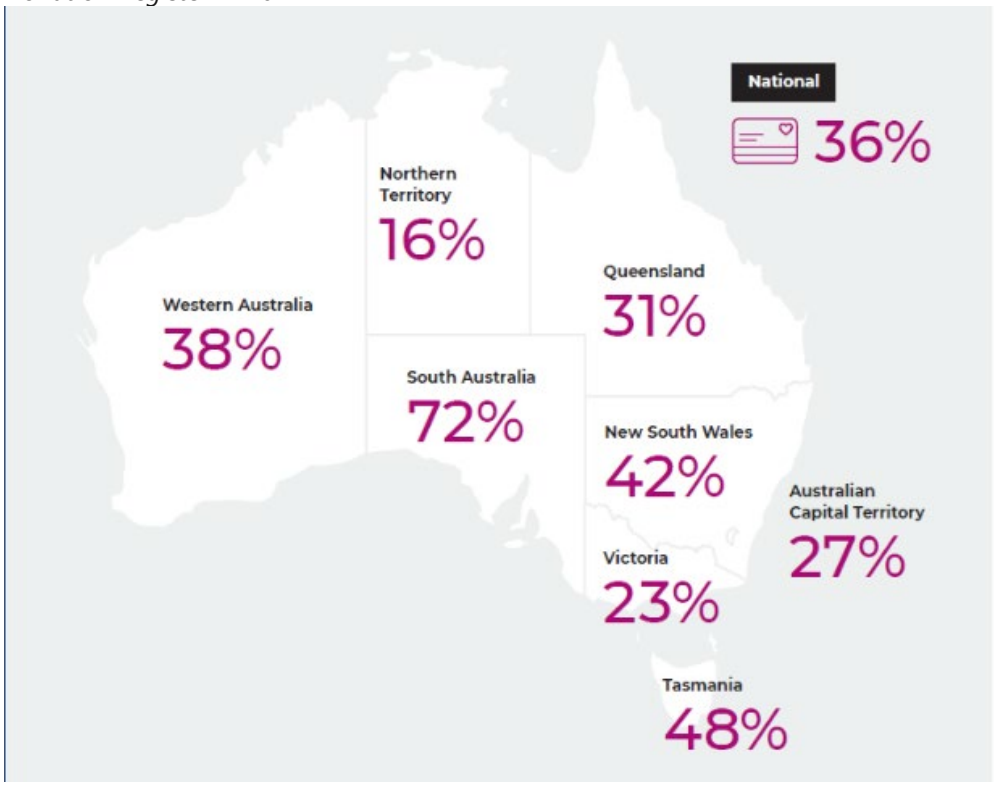
102 Submission 25 from Department of Health, 14 Apr 23, p 13.

103 The Australian Government Services website.

104 G Moloney et al., 'Respect, interaction, immediacy and the role community plays in registering an organ donation decision', *PLoS One*, 2022, 17(1): e0263096.

105 Organ and Tissue Authority, Strategic Plan 2021-22 to 2024-25, 2022, accessed 23 Oct 23, p 8.

Figure 7. *Percentage of population aged 16 years and over registered on the Australian Organ Donation Register in 2022*



[Source: Organ and Tissue Authority.[106]]

Opportunities to increase registration rates

5.13 Increasing registrations on the AODR does not automatically correlate to increasing numbers of transplantations because it is so rare for somebody to die in circumstances that would make them eligible to become an organ donor.[107]

5.14 The OTA advised the Committee that modelling shows 1 million registrations converts to approximately 11 donors. Therefore, mass registration is required.[108]

5.15 It is important for registration options to be quick and easily accessible. The OTA spoke about the benefit of a simple tick-box option, particularly with young people:

> We worked with the Behavioural Economics unit at the Department of the Prime Minister and Cabinet, and it was very clear the benefit of having a tick box. That was also seen last year, when people had to download their vaccination certificates off their Medicare app. We had 52 000 registrations in one month, because it sat underneath that and it was a simple tick-a-box. People can register on their Medicare app, they can register in their actual myGov account, and there are push notifications, but people do not tend to do it, I think, unless it is exceptionally simple.[109]

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106 Organ and Tissue Authority, Australian Donation and Transplantation Activity Report 2022, accessed 23 Oct 23, p 22.

107 See Appendix 3.

108 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 13.

109 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], p 14.

5.16 The Committee looked at the possibility of introducing additional pathways to register a decision on the AODR to translate favourable attitudes into actual registrations.

Driver's licence

5.17 In 2004, Western Australia abolished its system of being able to register for the AODR when applying for a driver's licence.[110]

5.18 The Committee heard evidence that many people are still under the assumption that AODR registration through driver's licences is possible. The Health Consumers' Council (HCC) noted that during their workshops for people from culturally and linguistically diverse backgrounds aged 50-plus and aged 16 to 25, participants:

> had no prior knowledge of DonateLife and little awareness of how to register for organ and tissue donation. Many believed it was through the driver's licence.[111]

5.19 The HCC also advised that driver's licences as a pathway to registration was viewed favourably:

> There were a lot of misconceptions about driver's licence registration and…broadly speaking, in both of the group conversations that I had, people were keen to see that as an option and thought that that would be a sensible way to increase the sign-ups, basically.[112]

South Australia

5.20 South Australia is the only jurisdiction in Australia that has retained the option to register on the AODR when applying for a driver's licence. The registration process begins with the driver's licence application and is then incorporated into the AODR.[113]

5.21 During its hearing with the Committee, the OTA noted that South Australia has maintained high registration and consent rates. The OTA contributed much of this success to their driver's licence registration scheme:

> I think the strength of South Australia is that they have maintained the drivers' licences; evidence shows that they have maintained and held a very high registration rate. As you will see from the trends, they also have quite a significantly high consent rate there…It would be a decision for the individual state and territory governments if they wanted to do that, but it is very clear that on a mass registration scale, drivers' licences have held up in South Australia.[114]

5.22 The use of driver's licences as a pathway to registration has proven to be particularly effective in engaging younger adults. South Australia has the highest proportion of young adults registered on the AODR.[115] Registration of young people is needed because:

> Sadly, a proportion of the people who are organ donors are younger people who have severe misadventure.[116]

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110 Government of Western Australia, *Supporting the community*, Department of Transport, accessed 11 Oct 23; Department of Health, *Becoming an organ and tissue donor*, Healthy WA, accessed 11 Oct 23.

111 N Laljee-Curran, Cultural Diversity Engagement Lead, Health Consumers' Council, [*transcript of evidence*], *Legislative Council,* 14 Jun 23, p 3.

112 N Laljee-Curran, Cultural Diversity Engagement Lead, Health Consumers' Council, [*transcript of evidence*], p 3.

113 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, accessed 6 Jun 23, p 16.

114 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, pp 13-14.

115 Submission 25 from Department of Health, 14 Apr 23, p 13.

5.23 WA Health advised that there has been some previous discussion about re-introducing registration via driver's licence, but it never came to fruition:

> The South Australian Minister for Health sponsored a proposal to have other jurisdictions reintroduce registration via the driver's licence, but this has not progressed...[117]

5.24 The evidence received by the Committee overwhelmingly supported the return to the option to register on the AODR when applying for or renewing a driver's licence.

5.25 Transplant Australia[118] advised the Committee:

> From Transplant Australia's point of view, we would return the "yes" option to all state-based driver's licence systems, with the data uploaded onto one register. It was removed in Western Australia… there are essentially a couple of generations of people who have never had that opportunity.
>
> …
>
> People will not go and find the Australian Organ Donor Register, whereas if it could be presented to you as part of one of your key life decisions at 16 and nine months…and then every five or 10 years you are able to reaffirm that decision. To us, that is the most logical way.[119]

5.26 Donor Mate, a charity that aims to increase awareness of organ and tissue donation amongst young people, also supports the return of driver's licence registration:

> Donor Mate would like the committee to prioritise the implementation of mass registration opportunities immediately, starting with linking registration to the application of a WA driver's licence.[120]

5.27 The option to re-affirm or change a decision registered on the AODR when renewing a driver's licence, which happens every 5 years, could give families more confidence that their loved ones recorded decision is current. Dr Simon Towler advised:

> It is a lot more enduring than knowing you registered 20 years ago. The *Human Tissue and Transplant Act* and the responsibilities it puts on the delegated or designated officer to try and be confident that the decision was enduring is, at the moment, totally dependent on the family's conversation.[121]

5.28 The concept of digital driver's licences is currently being explored in Western Australia and other jurisdictions.[122] This could provide an opportunity to introduce reform and an education campaign to the public.

5.29 Any registration pathway through driver's licences should offer the option to either register or make no decision. If the option to tick 'no' is provided, there is a risk that some people

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116 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, accessed 6 Jun 23, p 16.

117 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* p 7.

118 Transplant Australia is a leading charity supporting transplant recipients and their families; people on the waiting list, donor families, living donors and healthcare professionals.

119 C Thomas, Chief Executive Officer, Transplant Australia, [*transcript of evidence*], *Legislative Council,* 14 Jun 23, p 9.

120 Submission 11 from Donor Mate, 28 Mar 23, p 3.

121 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, accessed 6 Jun 23, p 24.

122 New South Wales launched a digital driver's licence in 2019. Queensland and Victoria are currently trialling digital licences.

would select it because they do not wish to decide at that time or require further information, rather than not consenting. If this 'no' decision is fed into the AODR, it could inaccurately reflect a person's intention.

FINDING 2

The South Australian experience indicates the option to join the organ donation registry when applying for a driver's licence increases registration rates, particularly among younger adults.

5.30 Providing the option to re-affirm a donation decision recorded on the AODR when renewing a driver's licence could provide next-of-kin with confidence about the currency of a decision.

Methods used in other jurisdictions to increase registration rates

United Kingdom

5.31 In the United Kingdom, individuals applying for a driver's licence must answer whether they wish to become an organ donor after death. The Driver and Vehicle Licencing Agency website produces the most significant number of registrations out of all methods, with 58% registered this way in 2016-2017.[123]

5.32 Other opportunities to join the Organ Donor Register involve prompted choice interventions, for example, inviting individuals to join the Organ Donor Register when registering for a Boots Advantage Care (a large chain of pharmacies rewards point shopping card) and when registering at a general practice.[124]

United States

5.33 In 2022, the United States, a system that works on an opt-in basis, achieved the highest deceased donor rate globally, exceeding Spain for the first time.

5.34 In the United States, over 90% of donor registrations occur through the driver's licence system.[125] For example, in Massachusetts, you can register by checking 'yes' on your licence application.[126] The website confirms:

> When you register as an organ and tissue donor, you will be entered into the Massachusetts Donor Registry. Though registration is legal consent for donation, you should also talk to your friends and family about your wishes.
>
> You must reconfirm your wish to be an organ donor each time you renew your Massachusetts driver's license [sic] or ID card, even if you were previously registered as a donor.
>
> If you change your mind about being an organ donor, you can unenroll at any time.[127]

123 A Sallis, H Harper and M Sanders, 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers', *Trials*, 2018, 19(1):513.

124 A Sallis, H Harper and M Sanders, 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers'.

125 DonateLife America, *Registering to be an organ donor at the DMV*, 2023, accessed 11 Oct 23.

126 Commonwealth of Massachusetts Registry of Motor Vehicles, *Register as an organ donor at the RMV*, 2023, accessed 19 Sep 23.

127 Commonwealth of Massachusetts Registry of Motor Vehicles, *Register as an organ donor at the RMV*.

5.35 The United States also offers the opportunity to register through the DonateLife websites, hunting licences and tax returns. As of 2021, there were 169 million registered organ donors in the United States.[128]

Tax returns

Canada

5.36 In November 2022, the Canadian government introduced an initiative to add a tick box on tax return forms to let taxpayers indicate if they wish to receive organ and tissue donation information from their provincial or territorial government. When taxpayers tick 'yes', the Canada Revenue Agency can share taxpayer's contact information with their province or territory of residence exclusively for this purpose.[129]

5.37 Residents in Ontario and Nunavut are the first jurisdictions to participate in the initiative, with the Canada Revenue Agency confirming that they will collaborate with any other provinces and territories that may be interested in participating.[130]

5.38 The Canada Revenue Agency website states:

> There is a new initiative to promote organ and tissue donation. If you want to receive information about the organ and tissue donation program, tick yes at the bottom of page 2 of your Income Tax and Benefit Return.[131]

5.39 Australia could utilise this method if future results reflect this initiatives success.

Other opportunities

5.40 The Committee has heard evidence that families are more likely to consent when they are confident in knowing the decision of their loved one. Retrieval of organs and tissue can only occur if it has been satisfied that a person has not withdrawn or revoked their wish or consent.[132]

5.41 Therefore, the Committee recommends having practical ways for people to re-visit and re-affirm their decision to donate regularly.

5.42 Options could include:

- Sending out correspondence to those registered on the AODR every 3 or 5 years asking them to re-visit and re-affirm their decision and discuss it with loved ones.
- Incorporating a decision when voting, registering, or updating details on the electoral roll. Registering to vote is compulsory for people 18 years and older. As federal elections occur every 3 years, it would provide an opportunity to revisit the decision without any additional burden.
- Registration pathways when completing a tax return.
- Registration pathways with a person's general practitioner.

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128 N Treacey, 'Australia: Organ donation and deemed consent: A new world order on the horizon?', Holding Redlich, 2020, accessed 20 Jun 23.

129 Government of Canada, *Minister of National Revenue announces the participation of Nunavut and Ontario in the organ and tissue donation service offering*, Canada Revenue Agency, 2022, accessed 19 Sep 23.

130 Government of Canada, *Minister of National Revenue announces the participation of Nunavut and Ontario in the organ and tissue donation service offering*.

131 Government of Canada, *Federal income tax and benefit guide*, Canada Revenue Agency, 2023, accessed 19 Sep 23.

132 *Human Tissue and Transplant Act 1982* s 22(2).

FINDING 3

Increasing the number of pathways to register a decision on the Australian Organ Donor Register can assist with turning favourable attitudes into action. Interactions between the public and government offer an opportunity to provide education about organ and tissue donation and encourage registration.

RECOMMENDATION 1

The Department of Transport and the Department of Health collaborate with the Organ and Tissue Authority to identify and implement methods for Western Australians to join the Australian Organ Donation Register when applying for and renewing a driver's licence and WA Photo Card. When identifying methods, the following should be considered:

- accommodating applications and renewals made via e-payment, online and in-person;
- feeding the information directly into the national Australian Organ Donor Register;
- a simple tick box option (the option to tick 'yes' or leave the box unticked, indicating the person does not wish to decide at that time); and
- planning for any future implementation of electronic licenses or identification documents.

RECOMMENDATION 2

DonateLife WA create an informational pamphlet on organ and tissue donation to be distributed by the Department of Transport in conjunction with driver's licence renewal communications.

RECOMMENDATION 3

The Department of Health advocate for the inclusion of an option to 'share' a registration decision through social media (such as Facebook messenger or Instagram direct message) or by electronic communication immediately after online registration on the Australian Organ Donor Register.

RECOMMENDATION 4

The Western Australian government advocate for the Commonwealth government to incorporate the ability to register as an organ and tissue donor when applying for or renewing a Medicare card.

Addressing myths

5.43 Educating the public about the organ and tissue donation process could help dispel myths that may prevent people from registering on the AODR.

5.44 One misbelief raised during the inquiry was that a medical practitioner may not 'try as hard to save' a person if it is known they are a registered organ donor.

5.45 This misconception or myth is addressed on the Australian DonateLife website, which explains:

> The doctor's first priority is always to save your life.
>
> Medical and nursing staff work incredibly hard to save lives.
>
> Organ and tissue donation will only be considered if you have died, or when death is expected. This is when the Australian Organ Donor Register is checked, and your

> family is asked about your wishes and to consent to donation before it proceeds.[133]

5.46 In 2018, an American survey of 766 respondents found that having concerns 'that paramedics and doctors will not try as hard to save me if they know I have agreed to be an organ donor' was the strongest independent predictor of unwillingness to register as a donor.[134]

5.47 Dr Towler addressed this myth during his hearing with the Committee. He noted that this is one of the reasons why decisions about end-of-life care and the discussion about organ donation is kept separate.

> we understand that trust is needed here…We would be very happy to speak with a person who has those concerns. I am more challenged at the moment by the sense that often the clinician in the intensive care unit is very, very focused on the care of the patient and a little less focused on the organ donation. It is more the other way around. I have no doubt of the ethical practice of my colleagues in terms of their responsibility is always to the patient in terms of optimising treatment and providing every opportunity for quality outcome, and the donations conversation comes later. This is one of those discussions that has featured internationally but is not demonstrable and is, in fact, dramatically covered off in the ethical framework. Australian and New Zealand Intensive Care Society produces the brain death and organ donation guidelines. The clinical community involved with these patients has set very high standards, and this is something for which I have absolute faith is not an issue.[135]

5.48 In 2010 an Australian study looked at the reasons influencing a person's decision whether or not to register as an organ donor. The study conducted 13 focus groups with participants in Sydney, Melbourne, Brisbane, and Adelaide, with 40% of participants from self-reported ethnic backgrounds. Most participants expressed an in-principle acceptance of organ donation. They supported its place in Australia, but there were differences when deciding to be an organ donor.

5.49 The study found the core beliefs likely to discourage donation included concerns about loss of dignity, quality of care, own organ viability, organ allocation, religion, grief and fear. Some relevant quotes from the workshops included:

> *There's no dignity there, I guess, or there's no sewing up afterwards. It's probably thrown in the bin 'cause it's all cut up. (Female, 50+ years group, Melbourne)*
>
> *I'm not officially a donor … just because I've heard stories about if you die in a car accident they don't save you 'cause they want your organs. But if you're not a donor then they'll try and save you. (Female, 18–25 years group, Sydney)*
>
> *The only thing I think about—probably as you get older—whether they [organs] are good enough. (Female, 50+ years group, Sydney).*[136]

5.50 Whilst this study was conducted some years ago, these same fears and misconceptions persist in contemporary society.

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133 Organ and Tissue Authority, *Myths about donation*, DonateLife, n.d, accessed 9 Oct 23.

134 M Sellers, 'Deterrents to organ donation: A multivariate analysis of 766 survey respondents', *Journal of the American College of Surgeons*, 2018, 226(4):414-422.

135 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, accessed 6 Jun 23, p 18.

136 M Irving et al., 'Community attitudes to deceased organ donation: A focus group study', *Transplantation Journal*, 2012, 93(10):1064-1069.

5.51 Increasing the general public's knowledge of the organ and tissue donation process may assist in dispelling these myths and ultimately increase registration rates. Education is discussed further in Chapter 14.

FINDING 4

Lack of education about organ and tissue donation can lead to enduring misunderstandings within the community, which discourages registration. Educational efforts should focus on areas of misconceptions and myths and provide information on the following facts:

- Organ retrieval is performed the same way as any other surgery, in a hospital theatre room by trained professionals.
- The deceased will have no visible injury after donation, and an open casket funeral is possible.
- Organ donation is only raised as an option after doctors reach a medical consensus that the patient has no chance of recovery (circulatory death or brain death).
- All major religions permit organ donation.
- Families will be asked to make the final decision about donation, even if a person has registered to be a donor on the Australian Organ Donor Register.

CHAPTER 6
Consent rates

Chapter summary

6.1 Very few people die in circumstances where organ transplantation is possible. Only about 2% of patients who die in Australian hospitals are eligible to be considered for organ donation. For organs to be viable for donation, a person must die in an ICU or ED.

6.2 Given the limited circumstances for potential organ donation, it is crucial to maximise all potential donation opportunities. One way of maximising this pool is having more families consent to the donation of their loved ones' organs and tissue.

6.3 Consent from a deceased's family is required before donation, regardless of whether the individual had registered as a donor on the AODR.

6.4 The consent rate is the percentage of people who, when asked, agree to donate their deceased relatives' organs and tissue. Western Australia has a low consent rate compared to other Australian jurisdictions.

6.5 This chapter examines the current consent rate in Western Australia and the factors which can influence a family's decision, such as:

- whether a loved one's wishes are known;
- the extent of previous knowledge about the organ and tissue donation process;
- the involvement of DonateLife WA specialist staff in family conversations; and
- whether hospital staff have followed the clinical best practice guidelines for offering organ and tissue donation.

6.6 To increase consent rates, efforts should focus on:

- increasing understanding within the community about organ and tissue donation, when it can occur, and the process involved. Learning the intricacies of organ donation for the first time in a hospital setting is overwhelming and not conducive to consent. Both formal studies and the experiences of donation specialists confirm this.
- Encourage individuals to register on the AODR and discuss their preferences with their loved ones. The chances of a loved one consenting to organ and tissue donation increase from 40% to 90% when wishes are known. The myths that may prevent people from registering on the AODR should be dispelled.
- Ensure clinical staff in the ICU and ED notify DonateLife WA staff early in the end-of-life process and involve them in 100% of family donor conversations. The involvement of DonateLife WA staff has consistently been proven to increase consent rates.

6.7 In summary, increasing awareness, addressing myths, and ensuring early involvement of DonateLife WA staff is vital to improving organ and tissue donation rates in Western Australia. Overcoming challenges in clinician willingness and enforcing best practices is essential for sustained progress.

6.8 Issues that relate specifically to Aboriginal and Torres Strait Islanders and culturally and linguistically diverse communities are discussed in Chapters 8 and 9, respectively.

Consent in Western Australia

6.9 Before retrieval of any organs or tissue takes place, the authorising designated officers must be satisfied that:

- For deceased persons' who indicated their wish to donate organs and tissue during their lifetime: that the deceased had not since withdrawn or revoked this wish or consent.[137]
- For deceased persons' who did not indicate their wishes during their lifetime: after making enquiries, there is no reason to believe that the deceased person had expressed an objection to donation and the next of kin consents.[138]

6.10 The process that occurs in practice and the decision-making role of loved ones was explained by the Department of Health:

> An attempt is made to identify and confirm the wishes of the patient. If the patient is registered on the [AODR] it is clear that at some time they had expressed a wish to donate organs and or tissues. The interview is then, in effect, to ascertain whether there is evidence to determine that this is an enduring request, and it can be considered the person at the time of their death would still wish to donate.
>
> The challenge is that registration on the AODR is not considered sufficient to confirm there is an enduring wish. The family become the surrogate decision maker by virtue of having to affirm they believe the person would have maintained the wish to be a donor. It is for this reason that the best practice approach to holding this conversation is to have specialist donation staff hold a family meeting. Their approach is to explore with the family whether the person had maintained a desire to donate. This is a materially different discussion than asking the family about their attitude to the donation.[139]

6.11 The Department of Health further summarised the practical clinical position as follows:

> when a loved one has died unexpectedly, and often tragically, the expressed wish of any family member at the time of death not to support the decision to donate becomes the defining position, and donation does not proceed.[140]

Consent rates

6.12 Consent rate is the percentage of people who are asked and agree to donate their deceased relatives' organs and tissue.

6.13 Western Australia has a consistently low consent rate compared to other Australian jurisdictions, second last only to the Northern Territory in 2017, 2018, 2020 and 2022.

FINDING 5

In 2022, Western Australia had the lowest rate of families consenting to donate their deceased relatives' organs and tissue of all Australian states.

6.14 The Committee acknowledges that the COVID-19 pandemic had a negative effect on consent rates in 2022.

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137 *Human Tissue and Transplant Act 1982* (HTTA Act) s 22(2)(a).

138 HTTA Act s 22(2)(b).

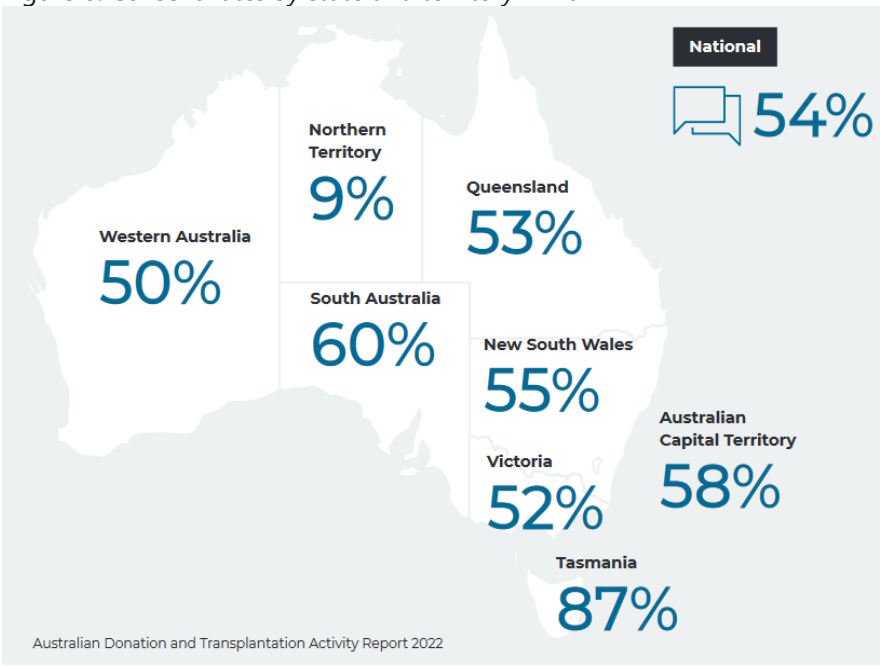
139 Submission 25 from Department of Health, 14 Apr 23, pp 4-5.

140 Submission 25 from Department of Health, p 5.

Table 8. *Consent rates in Western Australia in the years 2017 to 2022*

Year	Consent rate
2017	51%[141]
2018	53%[142]
2019	56%[143]
2020	54%[144]
2021	58%[145]
2022	50%[146]

Figure 8. *Consent rates by state and territory in 2022*



[Source: Organ and Tissue Authority.[147]]

141 Organ and Tissue Authority (OTA), *Australian Donation and Transplantation Activity Report 2017*, 2017, accessed 20 Oct 23, p 6.

142 OTA, *Australian Donation and Transplantation Activity Report 2018*, 2018, accessed 20 Oct 23, p 6.

143 OTA, *Australian Donation and Transplantation Activity Report 2019*, 2019, accessed 20 Oct 23, p 6.

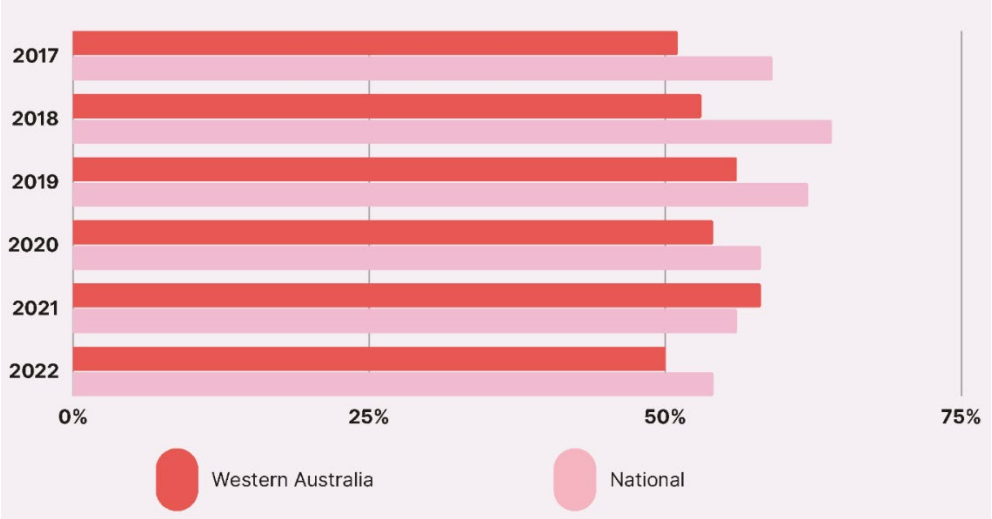
144 OTA, *Australian Donation and Transplantation Activity Report 2020*, 2020, accessed 20 Oct 23.

145 OTA, *Australian Donation and Transplantation Activity Report 2021*, 2021, accessed 20 Oct 23, p 6.

146 OTA, *Australian Donation and Transplantation Activity Report 2022*, 2022, accessed 20 Oct 23, p 19.

147 OTA, *Australian Donation and Transplantation Activity Report 2022*, 2022, accessed 20 Oct 23, p 19.

Figure 9. *Consent rates in Western Australia compared to the national average*



[Source: Adapted from Donation and Transplantation Activity Report data.[148]]

Factors that influence the likelihood of next-of-kin consent

6.15 Rates of organ and tissue donation are primarily limited by rates of consent by family members. Therefore, it is important to understand the reasons why families give consent or decline to provide consent to the donation of their loved one's organs and tissue.

The experience of donor families and the context of the requests

6.16 The discussion of organ and tissue donation occurs when families have just experienced the death of a loved one, usually in shocking and unexpected circumstances.

6.17 In 2020, a review was conducted of relatives' experiences during the donation process and found that relatives:

- Described the sudden and unexpected occurrence of illness as a surreal situation from which they wanted to escape.
- Experienced feelings of shock and distrust and sometimes had difficulty understanding information, with a feeling that their loss was overwhelming.
- Experienced feelings of denial, guilt, fear, helplessness, anger, and confusion when they understood the seriousness of the situation. They thought and hoped that recovery was possible, especially if their loved one was young. Hearing that recovery was not possible often came as a shock.[149]

[148] Organ and Tissue Authority (OTA), *Australian Donation and Transplantation Activity Report 2017*, 2017, accessed 20 Oct 23, p 6; OTA, *Australian Donation and Transplantation Activity Report 2018*, 2018, accessed 20 Oct 23, p 6; OTA, *Australian Donation and Transplantation Activity Report 2019*, 2019, accessed 20 Oct 23, p 6; OTA, *Australian Donation and Transplantation Activity Report 2020*, 2020, accessed 20 Oct 23; OTA, *Australian Donation and Transplantation Activity Report 2021*, 2021, accessed 20 Oct 23, p 6; OTA, *Australian Donation and Transplantation Activity Report 2022*, 2022, accessed 20 Oct 23, p 19.

[149] B Kerstis and M Widarsson, '*When Life Ceases-Relatives' Experiences When a Family Member Is Confirmed Brain Dead and Becomes a Potential Organ Donor-A Literature Review*', *Open Nurs.*, 2020, doi:10.1177/2377960820922031.

6.18 This is consistent with the experiences described by DonateLife WA staff:

> The donor coordinators and those who are approaching a family to discuss donation are going into a space where it is literally the worst day of [that families] lives and the amount of information coming in is overwhelming.[150]

[150] Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 11.

6.19 In relation to brain death of a loved one, relatives described that:

- It was difficult to understand the concept of brain death and distinguish it from a coma, particularly as their loved one was warm, looked the same, and usually lacked visible bodily injury.
- Being present at the hospital and seeing that the care provided did not produce results facilitated their understanding of the gravity of the situation.
- Information must be based on individual needs, and mistrust arose when too little information was given.
- An understanding of brain death was facilitated for relatives if graphic illustrations such as a computed tomography scan of the brain was shown or if the relatives were present during neurological tests.
- It facilitated the relatives' consent to donation when they experienced the request as empathetic.[151]

6.20 DonateLife WA staff reiterated that people are often learning about the organ donation process for the first time upon the death of a loved one:

> We need to help them understand what donation is. It is an education process, so we are dealing with so many of the myths that people bring into the space.
>
> …
>
> For most people…their only understanding or concept of organ donation is what they have seen in the media, what they have read in books or in fiction. [152]

Children as potential donors

6.21 All children who die in intensive care should be considered for potential organ donation.[153] Many families are unaware that organ donation by children is possible. Parents learning of this possibility for the first time during a traumatic event is not conducive to family consent.

6.22 Child donors and recipients are people under 16, the general age cut-off for admission to a paediatric intensive care unit.

6.23 The overall rate of organ donation in children is like that in adults; however, this rate declines below 2 years of age due to a combination of factors, primarily medical unsuitability and weight limits for retrieval and transplantation.[154]

6.24 The 2019 National Child Health Poll on Organ Donation, conducted by The Royal Children's Hospital Melbourne, surveyed parents and found that:

- many were unaware that young children can be organ donors, with 42% holding the misbelief that toddlers and pre-schoolers who have died are too young to donate organs;
- 31% of parents were unaware that not all children who need a transplant receive one; and

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151 B Kerstis and M Widarsson, '*When Life Ceases*-Relatives' Experiences When a Family Member Is Confirmed Brain Dead and Becomes a Potential Organ Donor-A Literature Review', *Open Nurs.*, 2020, doi:10.1177/2377960820922031.

152 Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 12.

153 The Transplantation Society of Australia and New Zealand (TSANZ), Clinical Guidelines for Organ Transplantation from Deceased Donors, 2023, accessed 22 Sep 23, p 163.

154 TSANZ, Clinical Guidelines for Organ Transplantation from Deceased Donors, p 163.

- some held misbeliefs about organ donation, believing that a child might suffer in the donation process (32%) or that a child might not receive all life-saving options if they were identified as a potential donor (36%).[155]

Themes for agreeing or denying donation

6.25 An Australian study interviewed potential organ donor families in 4 Melbourne hospitals to understand reasons for consent decisions. Participants included 49 people from 40 families (23 consenting and 17 non-consenting). The study found the main reasons for families consenting to organ and tissue donation of their loved one included:

- donation was consistent with the deceased's explicit wishes or known values;
- the desire to help others or self-including themes of altruism;
- pragmatism;
- wanting to prevent others from being in the same position;
- receiving some consolation from donation; and
- aspects of the donation conversation and care that led families to believe donation was right for them.[156]

6.26 The same study found that themes for refusing to consent to organ or tissue donation included:

- lack of knowledge of wishes;
- social, cultural and religious beliefs;
- being surprised by the donation request;
- lack of understanding or comfort with the concept of brain death;
- factors related to the donation process and family exhaustion; and
- healthcare provider comments that were perceived to be insensitive.[157]

6.27 While reasons for consent were like those described in international literature, reasons for non-consent differed in that there was little emphasis on lack of trust in the medical profession, fears of body invasion or organ allocation fairness.[158]

6.28 Therefore, efforts to increase consent rates should focus on:

- increasing conversations with loved ones about donation preferences;
- engaging with religious and culturally and linguistically diverse communities to educate them about how organ donation can align with their faith and cultural beliefs; and
- public education on the concept of brain death and the organ donation process.

Whether loved ones' wishes are known

6.29 When families know their loved one was a registered donor, there is a significantly higher chance they will consent to organ donation.

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155 The Royal Children's Hospital Melbourne, 'National Child Health Poll – Organ Donation: Do families know the facts?', *Poll 16*, 2019, accessed 27 Jul 23.

156 S Neate et al., 'Understanding Australian families' organ donation decisions', *Anaesth Intensive Care*, 2015, 43(1):42-50.

157 S Neate et al., 'Understanding Australian families' organ donation decisions'.

158 S Neate et al., 'Understanding Australian families' organ donation decisions'.

6.30 Nationally, consent rates when the patient was registered on the AODR were around:

- 90%, pre-pandemic; and
- 83% during 2021 and 2022.[159]

6.31 DonateLife WA staff noted that many families are relieved that their loved one registered their wishes on the AODR.[160]

Table 9. *Impact of registration on consent rates*

Circumstances	Rate of consent (%)
Loved one a registered donor	90%
Loved one's wishes known, but not registered	60%
Loved one's wishes unknown and not registered	40%

[Source: Organ and Tissue Authority.[161]]

6.32 It is often young people who suffer severe misadventures, leading to death in circumstances making them eligible for organ donation. However, most parents have not discussed organ donation with their children.

6.33 The Royal Children's Hospital Melbourne advises providing developmentally appropriate information about organ donation, targeted to individual children based on their maturity level, previous exposure to the concept of death and their ability to understand abstract concepts. They note that the concept of organ donation can be explored with school-age children. With adolescents, it is recommended parents share their own beliefs and wishes for their end-of-life care and explore their teenagers' views on the topic.[162]

6.34 Mr Turner of Zaidee's Rainbow Foundation explained that knowing the wishes of his young daughter made the decision easier for his family after his daughter died suddenly from an aneurysm:

> It was a lot easier for us, as a family, to have that discussion prior to going into any situation, because we never thought that one of our children would be an organ and tissue donor.[163]

6.35 The importance of registration on the AODR is discussed in Chapter 5.

159 Submission 25 from Department of Health, 14 Apr 23, p 5.

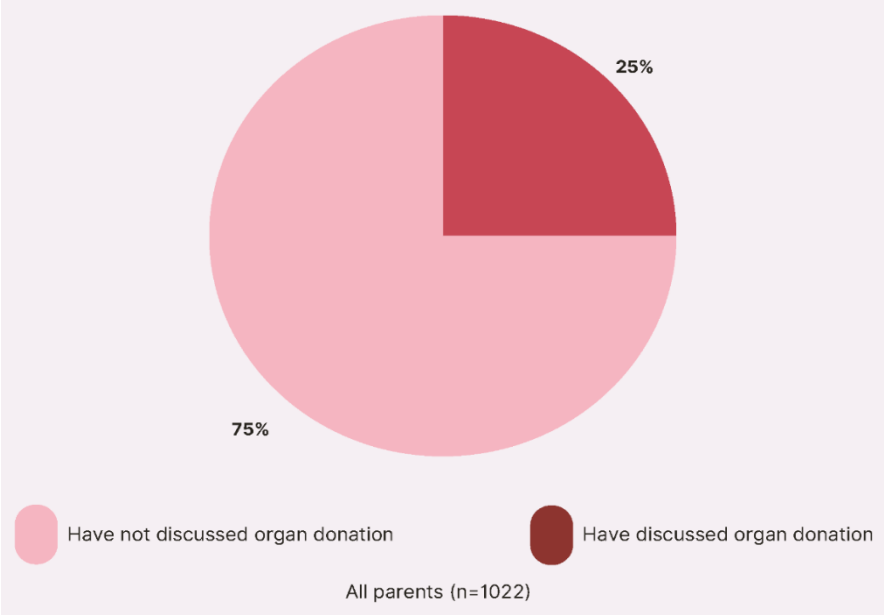
160 Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 12.

161 Organ and Tissue Authority, Annual Report 2021-22, 2022, p 30.

162 The Royal Children's Hospital Melbourne, *Kids health information: Organ donation*, 2019, accessed 19 Oct 23. This information was developed by The Royal Children's Hospital Paediatric Intensive Care Unit.

163 A Turner, Managing Director, Zaidee's Rainbow Foundation, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 4.

Figure 10. *The proportion of parents who have discussed organ donation with their teen*



[Source: Adapted from the Royal Children's Hospital Melbourne National Child Health Poll.[164]]

The involvement of DonateLife WA staff

6.36 DonateLife WA staff are highly skilled staff trained in organ and tissue donation and discussing options with families.

6.37 The role of the Donation Specialist Nurse is described in the clinical guidelines as follows:

> The Donation Specialist Nurse role is central to the family donation conversation. They provide detailed and accurate information about donation and have the skills to sensitively introduce the topic of donation and openly explore what donation may mean for a family, thereby assisting them in making a fully informed decision.[165]

6.38 The national guidelines for the best practice approach to offering organ and tissue donation recommend involving DonateLife WA staff in 100% of donor family conversations. However, as demonstrated by the evidence in Figure 12, Western Australian intensivists are involving DonateLife WA staff less often than is recommended.

6.39 During the Committee's hearing with WA Health, it was noted:

> WA still has room to improve on the practice elements of the best-practice model. We do need to ensure that all patients being considered for withdrawal of supportive treatment in the ICU and ED are notified to DonateLife staff and the registry is checked…We can do better. This suggests that the first option to increase organ and tissue donation in WA is to improve our performance in the clinical areas to reach the targets set by the Organ and Tissue Authority[166]
>
> …

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[164] The Royal Children's Hospital Melbourne, 'National Child Health Poll – Organ Donation: Do families know the facts?', *Poll 16*, 2019, accessed 27 Jul 23.

[165] Organ and Tissue Authority, *Best practice guideline for offering organ and tissue donation in Australia*, Australian Government, accessed 9 Oct 23, p 5.

[166] Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 6.

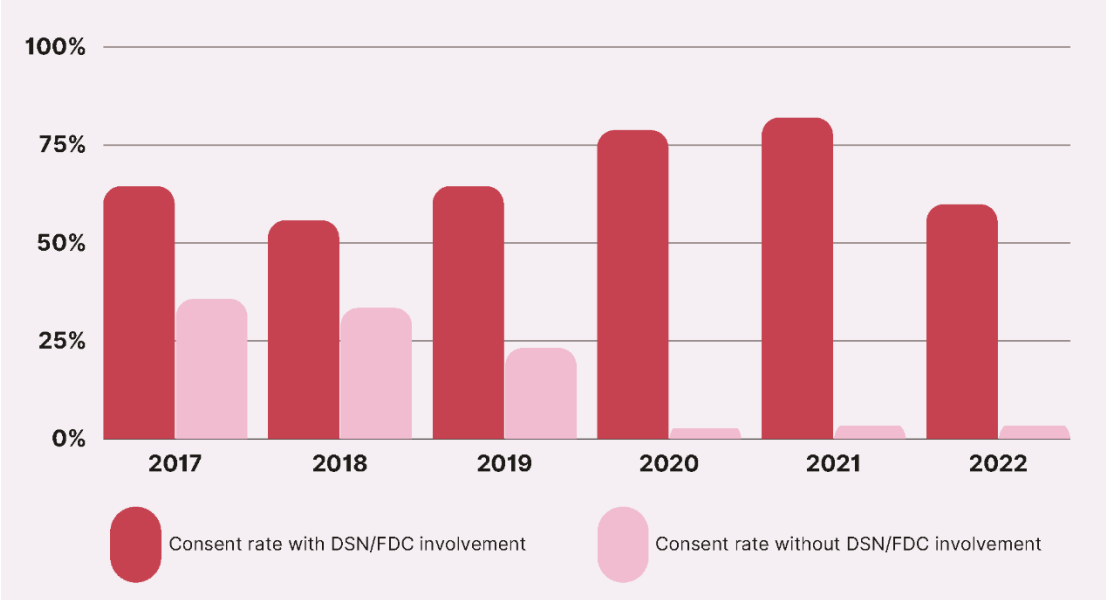
> More work is needed…to ensure that donation specialist nurses are included in discussions with families as a routine part of the end-of-life care decision in these settings.[167]

6.40 In 2021, 59% of Australian families agreed to donate when DonateLife WA staff supported them. This consent rate dropped to 19% when there was no Donation Specialist Nurse involved.

6.41 Research conducted for the OTA found that:

> 93% of donor families recall meeting with the DonateLife coordinator, nurse or doctor. Significantly fewer families who went on to decline donation recall meeting with a donor coordinator, donation nurse or doctor (30%). This may indicate that families who decline donation have not had the opportunity to talk with donation specialist staff before making their decision.[168]

Figure 11. *Consent rate percentage with the involvement of Donation Specialist Nurses (DSN) or Family Donor Coordinators (FDC) compared to the consent rate percentages without in Western Australia*



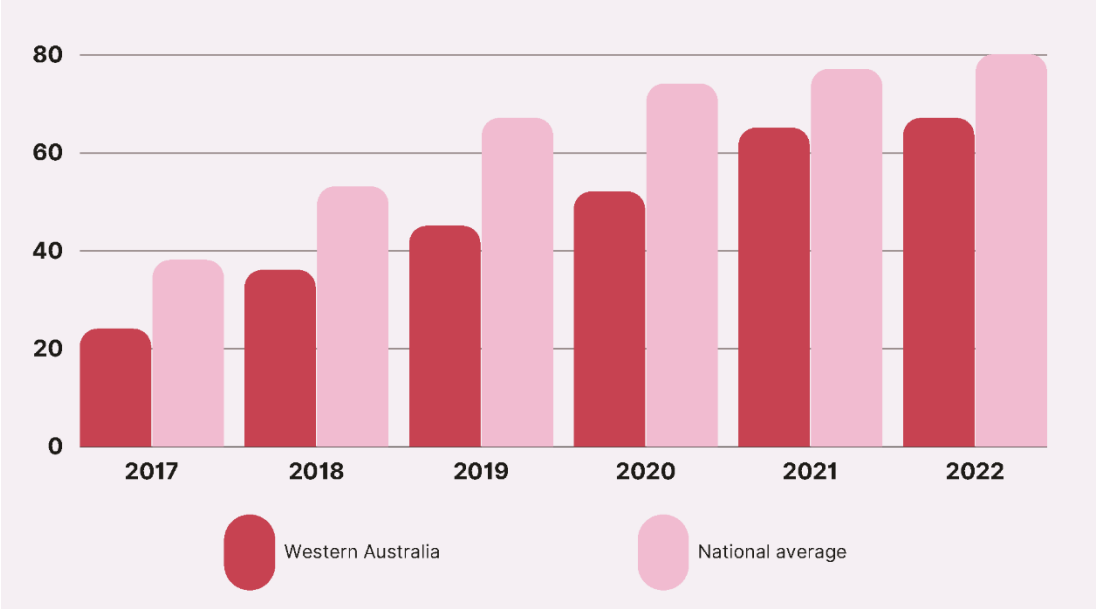
[Source: Adapted from data supplied by the Organ and Tissue Authority.[169]]

[167] Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 7.

[168] Organ and Tissue Authority, *National study of family experiences of organ and tissue donation: Wave 3 research report*, Commonwealth Government, 2019, accessed 5 Oct 23, p 2.

[169] Email from Mark McDonald, National Manager, Analytics and Technology, Organ and Tissue Authority, 5 Sep 23.

Figure 12. *The percentage of involvement of Donation Specialist Nurses (DSN) or Family Donor Coordinators (FDC) in family donor conversations in Western Australia compared to the national average*



[Source: Adapted from data supplied by the Organ and Tissue Authority.[170]]

6.42 When comparing the performance between Western Australia and the national average, profound differences can be observed.

6.43 In the written submission from DonateLife WA, one clinical staff member provided an example of the best practice guidelines not being followed with a potential donor who had suffered a traumatic brain injury:

> The doctor explained that their loved one would not survive from his injuries and the family were devastated. During this conversation the doctor decided to inform the family that the patient had registered his intent to be an organ donor.
>
> The doctor gave them a couple of hours to consider what they wished to do, and in the meantime called DonateLife WA. I am a donor coordinator and attended the hospital to be with the doctor for the next meeting with the family. When I arrived, the doctor said that I could not be part of the conversation as the family had not been advised that I would be coming. I waited outside and after 15 minutes, the doctor returned and advised me that the family said, "they were overwhelmed with events and unable to consider donation despite knowing he is registered on the Australian Organ Donor Register". They declined to meet with DonateLife staff, despite the doctor explaining that it would be helpful to meet with me…I feel this was a lost opportunity…[171]

6.44 Another example was provided by a clinical staff member as follows:

> The Intensivist opened the donation conversation by stating he was not a donor, and he doesn't recommend registering on the AODR because he did not want to put the pressure on his own family to make that 'difficult decision' if it was him…
>
> As the donor specialist nurse, I sat in the meeting for 45 minutes and had no opportunity to speak. However, when the intensivist shared some wrong

[170] Email from Mark McDonald, National Manager, Analytics and Technology, Organ and Tissue Authority, 5 Sep 23.

[171] Submission 26 from DonateLife WA (North Metropolitan Health Service), 17 Apr 23, pp 3-4.

> information, I did interrupt to say I will provide information about organ donation…[172]

6.45 WA Health, during its hearing, noted:

> [Intensivists] are very committed to their responsibility to the patient. I believe for some of them they would prefer that there is not a donor conversation if they believe the patient is not eligible.[173]

6.46 Routine incorporation of organ donation discussions at the time of a person's death is essential to increasing donation rates.

FINDING 6

When intensivists involve DonateLife WA specialist staff during conversations about donation, family consent rates increase significantly.

FINDING 7

Western Australia has consistently lower rates of involvement by donation specialist nurses in donor conversations than the national average.

FINDING 8

Some intensivists choose not to prioritise engagement with DonateLife WA specialists in donor family conversations, and this is having a detrimental effect on consent rates in Western Australia.

The unwillingness of clinicians to follow the best practice approach

6.47 The Committee acknowledges the highly challenging and unique environment that intensivists and other ICU staff work in. The organ donation process is complex and is stressful for the family of the potential donor and the clinical staff. It also brings the risk of ethical dilemmas, vicarious trauma and compassion fatigue.

6.48 Dr Towler discussed the complexity of the situation during the Department of Health's hearing:

> Hospital systems are very complicated. The change takes time. Uptake of these practices in WA has not been as quick as it has in some of the other jurisdictions. The uptake is still improving.
>
> We probably still have some intensivists who like to manage these conversations themselves and are still reluctant to invite the nurse early enough into the process and the conversation. It is a process of change. The positive engagement between the donation services and the intensive care staff is vital for this change to be effective. It is still a work in progress.[174]

6.49 Former Chief Medical Officer of DonateLife WA, Dr Powell, also explained the unique dynamic in intensive care settings:

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172 Submission 26 from DonateLife WA (North Metropolitan Health Service), p 6.

173 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 21.

174 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 10.

> intensive care is a deeply committed group of people, highly skilled, it is not that easy to invite people in, particularly when you think about your intensive care patients where there has been a long struggle. We come to know their relatives; we come to know them personally. That is part of the process, and it is a painful one giving a little bit of yourself. When you are then told "Well, actually, the evidence is that you should invite these people in to talk about end-of-life care and organ donation", that is a really difficult thing to do. As I said, I have the luxury of not being in that space now, not being in medicine, not being in charge of organ donation, so I am able to say that I think one of the significant barriers is what is also a strength in WA. As I said, these are highly skilled groups, world-class results in terms of critical care, and yet when you look at the numbers around invitations into donor conversations and outcomes from those consents, we are not as good as some.[175]

6.50 The requirement of routine notification to DonateLife WA and involvement of DonateLife WA nurses was implemented around 'five or six years ago':

> This requirement for routine notification of patients approaching end of life to donation services was only agreed and its implementation began, I think, probably about five or six years ago. The involvement of nurses earlier in the process at the point where there is communication with families about end of life being likely, that their relative is going to die and for nurses to be there for when donation is raised, has also been a new best practice that has been agreed and has been implemented, probably over the last six years.[176]

6.51 Other Australian jurisdictions have now embedded the best practice approach in their hospitals, despite the challenging ICU environments:

> We have seen, particularly through my role as state director and being able to attend the national clinical governance committee, that in other jurisdictions these are now routine practices and are deeply embedded.[177]

6.52 The OTA advised that efforts have been made to address the issue with Western Australian hospitals:

> DonateLife WA reached out to us. Helen, myself and Mark, in fact, were here in November and met with your three major metropolitan hospitals here—both executive staff and the leadership within the intensive care unit—to show where they were compared to other hospitals here in WA but also nationally, and to really put a highlight focus on having it accepted that the nurse should be a part of the conversation.[178]

6.53 WA Health, during its hearing with the Committee, noted:

> We have now medical donation specialists in all of the tertiary hospitals who are in intensive care practice. We are supporting them to support their colleagues in

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175 Dr B Powell, Retired former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 17 May 23, pp 3-4

176 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 10.

177 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 21.

178 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 11.

> really embracing the program. That is in fact where we are focusing most of our efforts at the moment.[179]

6.54 The Committee wrote to the College of Intensive Care Medicine of Australia and New Zealand inviting its fellows to contribute to the inquiry but received no response.[180]

Experiences of donor families

6.55 The reluctance of some intensivists to raise organ donation due to the family already being distressed and exhausted is well-meaning but potentially misplaced. While every family is different, the Committee received evidence that many find comfort in their loved one's organs and tissue being donated.

6.56 Staff from DonateLife WA advised the Committee:

> the families that were given the opportunity to consider donation and chose that path told me that it bought them some comfort to have something positive come at the end of their loved ones [life].[181]

6.57 Research conducted for the OTA[182] also supported this notion:

> For 96% of families who consented to donation, the decision about donation made in 2018 and 2019 still sits well with them [in 2023], 86% very much so. When reflecting, families not comfortable with their decision cite not knowing their family member's donation wishes and difficulty coming to terms with their death as the two predominant reasons.
>
> One quarter (24%) of families who declined donation are not very comfortable with their decision about donation today; 6% are very uncomfortable with their decision. Some of these family members wanted to donate but there were other members of the family who didn't, and in the absence of knowledge of what their family member would have wanted, the family opted to decline. On reflection, some feel that they may have made a different decision if they had more time.[183]

6.58 Dr Powell explained as follows:

> we know from the data…families are glad they were asked, not at the time, but they are overwhelmingly glad that they were asked and glad that their relatives became a donor. I make no mistake; it is not a consolation for the loss they have suffered, but somewhere down the line—a long way down the line—…they are proud about that and they are glad about that. If they could turn it around, of course they would, but they cannot so it is a good thing. As I said at the very beginning, I think it is a remarkable demonstration of humanity.[184]

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179 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 21.

180 On 22 Aug 23.

181 Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 2.

182 The Organ and Tissue Authority commissioned the National Donor Family Study to obtain information on family experiences of organ and tissue donation for transplantation. The study sought to learn from and understand the family's experience, from early interactions with hospital and DonateLife staff and initial donation conversations, to the follow-up contact and support provided to families after a donation decision was made.

183 Organ and Tissue Authority, *National study of family experiences of organ and tissue donation: Wave 5 Experiences in 2018 and 2019*, *research report*, Commonwealth Government, 2023, accessed 5 Oct 23, p 2.

184 Dr B Powell, Retired, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 5.

CHAPTER 7
Enduring consent

Chapter summary

7.1 Registration on the AODR is not considered enduring consent, and families must re-affirm their loved one's wishes before donation can proceed.

7.2 In Western Australia, a person with legal capacity can make an Advance Health Directive (AHD) containing their wishes for future medical treatment. However, unlike other Australian jurisdictions, an AHD cannot record organ and tissue donation decisions in Western Australia.

7.3 There is scope to consider amending the *Guardianship and Administration Act 1990* to allow individuals to record an enduring wish about their organ and tissue donation preferences.

7.4 In England, Wales, Northern Ireland, and Nova Scotia, an individual can nominate up to 2 representatives to decide on organ and tissue donation on their behalf. Western Australia could implement a similar option.

Advance Health Directive

7.5 A person over the age of 18 with legal capacity can make an AHD specifying treatment decisions in respect of the person's future treatment.[185] AHDs must be freely and voluntarily made and be substantially in the form prescribed by regulations.[186]

7.6 If it is known that the patient made an AHD containing a treatment decision, it must be adhered to.[187]

7.7 In Western Australia, an AHD cannot be used to register intent to be an organ or tissue donor[188] or instructions relating to Voluntary Assisted Dying.[189]

Table 10. *The ability to include organ and tissue donation preferences in an Advance Health Directive by Australian jurisdiction*

Jurisdiction	Whether an advance health directive can contain donation preferences
Western Australia[190]	No
New South Wales[191]	Yes
Victoria[192]	Yes

185 *Guardianship and Administration Act 1990* (GA Act) s 110P.

186 GA Act s 110Q.

187 GA Act s 110ZJ(2). There is no penalty attached to failure to comply with a treatment decision.

188 Department of Health, *A guide to making an Advance Health Directive in Western Australia*, 2023, accessed 16 Oct 23.

189 *Guardianship and Administration Act 1990* s 3B.

190 Department of Health (Health), *Advance Health Directives: What Cannot be included in an Advance Health Directive?*, accessed 4 Oct 23; Health, *A Guide to Making an Advance Health Directive in Western Australia*, accessed 4 Oct 23, p 28.

191 New South Wales Ministry of Health, *Making an advance care directive*, New South Wales Government, 2022, accessed 19 Oct 23, p 5. In New South Wales, Advance Care Directives are made pursuant to common law and legally binding.

Jurisdiction	Whether an advance health directive can contain donation preferences
South Australia[193]	Yes
Tasmania[194]	Yes
Australian Capital Territory[195]	Yes
Northern Territory[196]	Yes

7.8 Whilst families will still need to consent to organ and tissue donation, the ability to include donation preferences on an AHD:

- offers an opportunity for people to consider their wishes; and
- allows loved ones to feel more confident in the decision and increases the likelihood of consent.

FINDING 9

Western Australia is the only Australian jurisdiction which does not give the option for a person to specify their organ donation preferences in a prescribed advance health care planning document.

FINDING 10

The *Guardianship and Administration Act 1990* pre-dates organ and tissue donation and transplantation advancements and is now outdated.

RECOMMENDATION 5

The Western Australian Government amend the *Guardianship and Administration Act 1990* to provide the ability for an individual to record a decision on organ and tissue donation in an Advance Health Directive.

Substitute decision makers

United Kingdom

7.9 The *Human Tissue Act 2004* (Uniting Kingdom) permits an individual to nominate up to 2 representatives to decide on organ and tissue donation on their behalf in England, Wales and Northern Ireland. Section 4 of this Act provides:

> (1) An adult may appoint one or more persons to represent him after his death in relation to consent for the purposes of [organ and tissue transplantation].

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192 *Medical Treatment Planning and Decisions Act 2016* (VIC) s 12; Department of Health and Human Service, *Advance care directives for adults*, Victorian Government, 2022, accessed 19 Oct 23, p 3.

193 *Advance Care Directives Act 2013* (SA) s 11; South Australia Health, *Advance Care Directive DIY kit*, Government of South Australia, 2016, accessed 19 Oct 23, p 3.

194 *Guardianship and Administration Act 1995* (TAS) s 35G; Department of Health Tasmania, *Advance Care Directive*, Government of Tasmania, 2020, accessed 19 Oct 23, p 4.

195 Department of Health (ACT), *Advance Care Planning in the ACT*, Government of Australian Capital Territory, 2023, accessed 19 Oct 23, p 15.

196 *Advance Personal Planning Act 2013* (NT) s 8; Northern Territory Department of Attorney-General and Justice, Advance Personal Plan, Government of Northern Territory, 2023, accessed 19 Oct 23, p 7.

(2) An appointment under this section may be general or limited to consent in relation to such one or more activities as may be specified in the appointment.

7.10 An appointment can be made verbally (in the presence of at least 2 witnesses at the same time) or in writing (signed in the presence of a witness or contained in a valid will).[197] An appointment can be revoked at any time by the same methods as it can be made.

7.11 Crown dependencies, Guernsey,[198] Jersey[199] and Isle of Man[200] also authorise the appointment or nomination of a representative to provide appropriate consent for the purposes of organ donation.

7.12 The United Kingdom's National Health Service website provides a form to be completed. A copy of this form is at Appendix 4.

FINDING 11

In England, Wales and Northern Ireland, a person can appoint a representative, known as a substitute decision maker, to make decisions about organ and tissue donation after their death.

RECOMMENDATION 6

The Western Australian Government investigate amending the *Human Tissue and Transplant Act 1982* to incorporate provision for a person to appoint a substitute decision maker, including but not limited to amendments providing that an:

- adult may appoint one or more persons to represent them after death for the purpose of consent to organ and/or tissue donation;
- appointment may be made verbally (in the presence of 2 witnesses) or in writing (signed by the person making the appointment in the presence of at least one witness who attests the signature); and
- appointment can be revoked in the same manner as it was made.

197 *Human Tissue Act 2004* (UK) s 4(3).

198 The official website for the States of Guernsey, *Organ donation*, Government of Guernsey, accessed 4 Oct 23.

199 Government of Jersey, *Organ donation: Have the conversation*, Information and public services for the Island of Jersey, Jersey, United Kingdom, accessed 4 Oct 23, p 8.

200 *Human Tissue and Organ Donation Act 2021* (Isle of Man) s 11.

CHAPTER 8
Issues impacting Aboriginal and Torres Strait Islanders

Chapter summary

8.1 This chapter looks at the barriers to organ and tissue donation faced by Aboriginal and Torres Strait Islander Australians (hereafter respectfully referred to as Indigenous Australians).

8.2 Indigenous Australians face higher rates of organ failure, particularly kidney failure, compared to non-Indigenous Australians. However, they receive disproportionately fewer transplants. The reasons for this are complex and can be attributed to several factors including:

- greater comorbid illness leading to fewer patients being judged medically suitable;
- challenges of remote locations;
- higher complication rates; and
- shortage of suitable donors.

8.3 A person can only receive a kidney transplant if the donor is a compatible genetic or tissue match (Human Leukocyte Antigens (HLA) compatible); otherwise, there is a strong chance of organ rejection and complications. Indigenous Australians have dissimilar HLA types to non-Indigenous Australians and therefore are less likely to receive a HLA-compatible donor kidney from a non-Indigenous Australian.

8.4 There are very few living kidney donors in Indigenous Australian communities due to the burden of disease and comorbidities. Indigenous Australians are also less likely to consent to deceased donation than non-Indigenous Australians.[201]

8.5 Addressing health disparities, improving education, and fostering respectful community engagement are crucial to overcoming barriers in organ donation for Indigenous Australians. Collaborative efforts involving government, non-government organisations, and communities are essential for positive change.

8.6 Indigenous Australians also suffer disparity in bone marrow transplants, as they depend on HLA-compatible donors. Addressing inequalities in bone marrow transplants for Indigenous Australians also requires sustained efforts to diversify the donor pool, enhance awareness, and secure ongoing support for initiatives like the Strength-to-Give campaign.

Issues impacting Indigenous Australians

8.7 Indigenous Australians more commonly suffer organ failures, particularly kidney failure, compared with the non-Indigenous population of Australia.

Higher rates of kidney disease

8.8 As of 2019, Indigenous Australians' risk of having kidney disease was 3.1 times greater than that of non-Indigenous Australians, with a mortality rate 2.5 higher.

8.9 Western Australia has the highest disparity of any state or territory, with Indigenous Australians being 6.6 times more likely to experience chronic kidney disease than non-Indigenous Australians.

[201] See Figure 14.

Table 11. *Comparison between Indigenous and non-Indigenous Australians' experience with kidney disease*

	Indigenous Australians (per 100,000)	**Non-Indigenous Australians (per 100,000)**
Prevalence of chronic kidney disease 2018 to 2019 (National)	3.4	1.1
Prevalence of chronic kidney disease 2018 to 2019 (WA)	6.6	1.0
Deaths due to kidney disease in 2019 (National)	20.4	8.3

[Source: Australian Institute of Health and Welfare.[202]]

8.10 At the end of 2021, 2,568 Indigenous and 24,774 non-Indigenous Australians were receiving kidney disease treatment, either through dialysis or having previously received a transplant.

- Among the Indigenous patients:
  - 85% were on dialysis, and 15% had received a transplant.
- Among the non-Indigenous patients:
  - 51% were on dialysis, and 49% had received a transplant.[203]

8.11 At the end of 2022, there were 2,213 Indigenous Australians on dialysis nationwide, 70 of which were on the active transplant waitlist. In Western Australia, there were 519 Indigenous Australians on dialysis, with 9 of these on the active waitlist.[204]

8.12 One of the reasons Indigenous Australians are receiving disproportionately fewer transplants is because consent rates amongst Indigenous Australians are substantially lower than the national average:

> We know that Aboriginal and Torres Strait Islander people carry a higher burden of disease and we also know that the rates of donation in our community is low.[205]

8.13 In 2016, the consent rate of Indigenous Australians was 20%, compared to a consent rate of 69% amongst the non-Indigenous Australian population.[206]

8.14 The Australian Medical Association explained that poor access to transplantation experienced by Indigenous Australians is complex and can be attributed to:

- The greater burden of comorbid illness amongst Indigenous Australian dialysis patients leads to fewer patients being judged medically suitable.
- The shortage of living and deceased donors from within Australian Indigenous communities.

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202 Australian Institute of Health and Welfare (AIHW), Aboriginal and Torres Strait Islander Health Performance Framework. Data visualisation: Measure 1.10 Kidney disease, AIHW, 2020, accessed 18 Sep 23.

203 AIHW, *Aboriginal and Torres Strait Islander Health Performance Framework. Measure 1.10 Kidney disease*, AIHW, 2020, accessed 18 Sep 23.

204 Letter from Organ and Tissue Authority dated 20 Oct 23, p 1.

205 Tania Harris, Aboriginal and Disability Engagement Lead, Health Consumers' Council, [*transcript of evidence*], *Legislative Council,* 14 Jun 23, p 2.

206 Federation of Ethnic Communities' Councils of Australia, *Engaging CALD communities in organ and tissue donation discussions*, Spring 2017, accessed 14 Sep 23, p 6; Organ and Tissue Authority, *Australia Donation and Transplantation Activity Report 2016*, accessed 2 Oct 23, p 6.

- The challenges in delivering appropriate health services to people living in remote areas who might also have low health literacy and language barriers.
- The dislocation that follows from moving to transplant centres in distant capital cities.
- Before transplantation, there is a need for significant tests and assessments, which require visits to major centres. After transplantation, there is the prospect of a post-operative stay away from home and support. The number of medications usually increases, and there is an increased risk of infections and cancers.[207]
- The poorer outcomes among those who receive transplants are due to higher rates of rejection, less well-matched kidneys, higher rates of infection and infection-related deaths.

Organ matching

8.15 With fewer donations from Indigenous Australians, fewer matching kidneys are available for Indigenous Australians who require a transplant.

8.16 Unlike other types of donations, which merely require blood type matching, kidney (and bone marrow) transplants require a degree of HLA matching to minimise recipient rejection:

> HLA are proteins found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not.
>
> A close match between a donor's and a patient's HLA markers is essential for a successful transplant outcome. HLA matching promotes the growth and development of new healthy blood cells…and reduces the risk of a post-transplant complication…[208]

8.17 Among other factors, donors closely related to the recipient and those with a similar genetic or ethnic background are most likely to share HLA markers.[209]

8.18 As a result, there have been calls to increase the representation of genetically and ethnically diverse groups on the AODR and the Australian Bone Marrow Donor Registry.[210]

Table 12. *Ethnic origin of actual deceased donors, 2018 to 2022*

Donor racial/ethnic origin	2018	2019	2020	2021	2022
Australian Non-indigenous	412 (74%)	405 (74%)	335 (72%)	312 (74%)	333 (73%)
Australian indigenous	18 (3%)	16 (3%)	16 (3%)	17 (4%)	13 (3%)
New Zealand European	9 (2%)	15 (3%)	7 (2%)	5 (1%)	12 (3%)
New Zealand Māori	2 (0%)	2 (0%)	3 (1%)	2 (0%)	2 (0%)
European	49 (9%)	57 (10%)	34 (7%)	31 (7%)	35 (8%)
North African and Middle Eastern	6 (1%)	2 (0%)	13 (3%)	2 (0%)	7 (2%)
Asian	48 (9%)	40 (7%)	36 (8%)	41 (10%)	44 (10%)
American	5 (1%)	3 (1%)	6 (1%)	6 (1%)	1 (0%)

207 C Johnson and L Toy, *Unacceptable kidney transplant rate for Indigenous Australians*, media statement, Australia Medical Association, 15 Dec 17, accessed 9 Oct 23.

208 National Marrow Donor Program, *HLA basics*, Be the match, accessed 21 September 2023.

209 National Marrow Donor Program, *HLA basics*.

210 Submission 24 from Leukaemia Foundation, 12 April 2023, p 4.

Donor racial/ethnic origin	2018	2019	2020	2021	2022
Sub-Saharan African	3 (1%)	6 (1%)	9 (2%)	3 (1%)	4 (1%)

[Source: Australia and New Zealand Organ Donation Registry[211]]

Cultural barriers and perceptions regarding organ and tissue donation among Indigenous Australians

8.19 In 2013, researchers undertook a project to understand the cultural barriers and perceptions regarding organ and tissue donation among Indigenous people in Western Australia. The researchers conducted consultations and workshops in a 'yarning' approach in Perth, Warralong and Port Headland.[212]

8.20 The project's main findings were:

- A notable lack of understanding and limited knowledge about donating and registering to donate among Indigenous Australians consulted. There is also a real lack of awareness of the emphasis on discussing the issue with family and current campaigns regarding donation, despite many of the people consulted knowing of an organ recipient.
- Different cultural groups have differing ideas and beliefs influencing their views about donation.
- A high level of mistrust and fear of medical professions, institutions and procedures among Indigenous Australians, directly related to the historical treatment of Indigenous people in Australia and people's personal experiences of the medical profession. These issues are impacting people's views about donation.
- Discussion about organ and tissue donation is contingent on Indigenous Australians feeling comfortable thinking about their eventual death and the death of close family members, young and old. Using an appropriate educational aid can direct the attention away from sad personal thoughts and direct the flow of the discussion.
- Despite a lack of knowledge about organ and tissue donation and an acknowledgement that it is a difficult issue to raise with family, there was a general level of agreement that Indigenous Australians need to start thinking about it and talking to each other about organ and tissue donation.[213]

8.21 The researchers recommended:

- Educational materials should be visual and include images of Indigenous Australians. They should use plain English and Indigenous languages where possible.
- Health promotion needs to be undertaken in direct consultation with Aboriginal community-controlled health services and other relevant agencies and services to ensure a collaborative approach and improve communication and knowledge about donation and processes.
- Address people's beliefs that they are unsuitable donors because of their lifestyle, health or other issues.

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211 Australia and New Zealand Organ Donation Registry, *Annual Report 2023: Deceased donor profile*, 2023, accessed 23 Oct 23, ch 3, p 6.

212 Dr C Scrine and R Murray, 'Report on the Community Awareness Grant: Addressing Aboriginal rates of organ donation in WA', *Kulunga Research Network*, 2013, accessed 9 Oct 23.

213 Dr C Scrine and R Murray, 'Report on the Community Awareness Grant: Addressing Aboriginal rates of organ donation in WA.

- Identify ways of accessing Indigenous young people and ways of approaching the topic of donation in a safely. Social media offers an access point to many young people across the state.
- Identify suitable and appropriate people who are linked into community organisations and services that are available to be informed/trained and resourced with information about donation…Aboriginal Health Workers are well placed to undertake such a role.
- Ensure anyone dealing with Indigenous Australians about donation is culturally competent and aware.
- Promote discussion about donation for Indigenous Australians with a greater focus on collective responsibility rather than the individual and an acknowledgment of the role and authority of elders in a family group.[214]

8.22 Since this study in 2013, the OTA has produced several culturally specific resources for Indigenous Australians. However, lack of awareness of these resources remains an issue. A 2019 study facilitated group discussions in community settings in Western Australia to explore wishes and concerns about end-of-life. The study noted:

> Although the DonateLife (Australian Government Organ and Tissue Authority) website has a range of resources designed for Aboriginal communities, these were not known to the participants.[215]

8.23 In 2021, the OTA granted the Health Consumers' Council WA funding to engage in community conversations with Indigenous Australians and other culturally and ethnically diverse groups. The workshops were for:

- Collecting feedback and developing insights into these communities' information needs, to provide the basis for the video and printed resources that were later developed.
- Raising community awareness, encouraging discussion among families and communities, and promoting key DonateLife messaging, including about how to register.[216]

8.24 The Health Consumers' Council WA advised the Committee:

> What we learnt is that this is a topic that the community really do want to talk about. They want to be asked. They want to understand the process. They want to hear people's stories. They have ideas about how to increase awareness. They understand the barriers and they can help us find the solution. We need to partner with our consumers and communities and with NGOs and government. It needs to be done in a way that is respectful of the donor and the donor family and of culture and personal beliefs. We also learnt the importance of human connection, and the stories of people who have been both donors and recipients cannot be overestimated.
>
> …
>
> we need to have more education, more of the conversations in schools, obviously with the permission of parents and families. It just needs to be talked about more.[217]

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214 Dr C Scrine and R Murray, 'Report on the Community Awareness Grant: Addressing Aboriginal rates of organ donation in WA.

215 S Thompson et al., 'Passing on wisdom: exploring the end-of-life wishes of Aboriginal people from the Midwest of Western Australia', *Rural and Remote Health*, 2019, 19(4):5444, accessed 9 Oct 23.

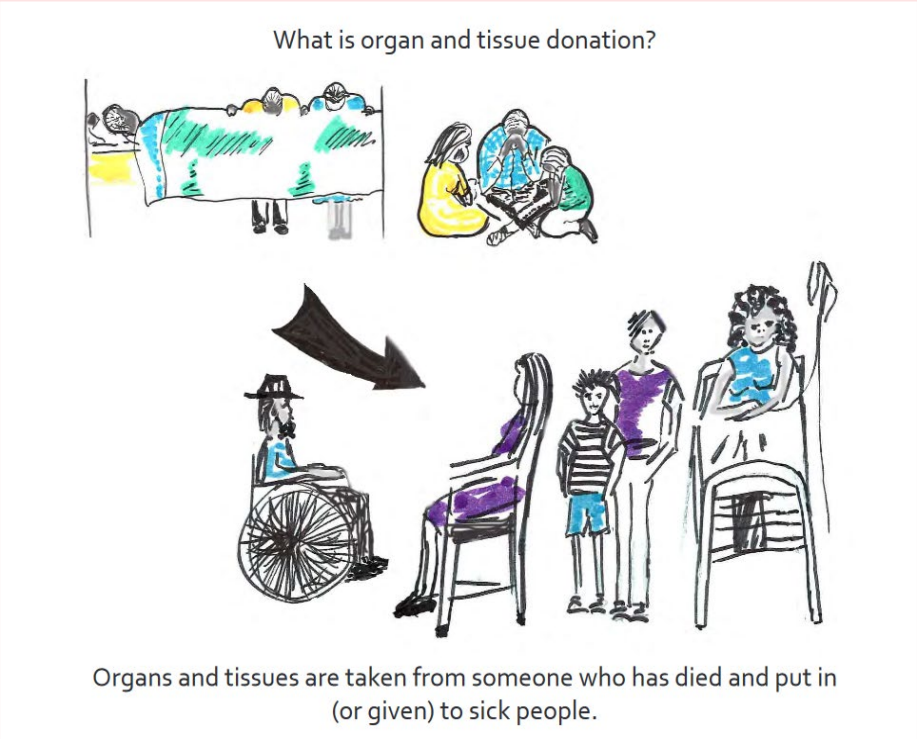
216 Submission 12 from Health Consumers' Council, 29 Mar 23, p 2.

217 Tania Harris, Aboriginal and Disability Engagement Lead, Health Consumers' Council, [*transcript of evidence*], *Legislative Council,* 14 Jun 23, p 3-4.

8.25 Tania Harris, Aboriginal Engagement Lead at Health Consumers' Council noted:

> In my community … no-one knows anything about this. No-one is talking about this. This branding is nowhere.
>
> …
>
> There [is] an absolute lack of resources into this, particularly marketing organ donation to Aboriginal communities and First Nations communities.[218]

Figure 13. *Excerpt from flip book utilised for discussion about organ and tissue donation with Indigenous Australians*



[Source: Dr C Scrine and R Murray.[219]]

FINDING 12

Consent rates among Indigenous Australians are substantially lower than the national average.

FINDING 13

Culturally appropriate engagement is required to improve organ and tissue donation rates amongst Indigenous Australians.

[218] Tania Harris, Aboriginal and Disability Engagement Lead, Health Consumers' Council, [*transcript of evidence*], *Legislative Council,* 14 Jun 23, p 3.

[219] Dr C Scrine and R Murray, 'Report on the Community Awareness Grant: Addressing Aboriginal rates of organ donation in WA', *Kulunga Research Network*, 2013, accessed 9 Oct 23.

RECOMMENDATION 7

The Western Australian government, in collaboration with Indigenous Australian Elders, academics and medical practitioners, facilitate comprehensive research into the cultural sensitivities and geographical challenges around organ and tissue donation within Western Australian Indigenous communities.

RECOMMENDATION 8

The Western Australian government advocate for the Commonwealth government and the Organ and Tissue Authority to provide additional grants for 'grassroots' tailored education about organ and tissue donation in Indigenous communities. This consultation should be undertaken in collaboration with Indigenous Australian Elders, Aboriginal community-controlled health services and other relevant bodies to ensure a culturally appropriate approach.

Bone marrow transplants

8.26 Indigenous Australians also suffer inequity in access to bone marrow or stem cell donors.

8.27 The Australian Bone Marrow Donation Registry (ABMDR) maintains a registry of volunteer donors willing to donate hematopoietic progenitor cells (HPC) and manages searches for compatible donors for patients.

8.28 HPCs can form red blood cells, platelets and white blood cells. HPCs are used to treat many diseases to replace or rebuild a patient's blood production system.[220] This is called bone marrow or stem cell transplant.

8.29 Every year, more than 600 Australians with blood cancer will need donated stem cells.[221] More than half of these people are unable to find a matched donor in their family and must find a match from an unrelated individual.[222]

8.30 Across Australia, 135,000 people live with blood cancer, with approximately 20,000 new diagnoses each year.

8.31 Treatment options are often complex, aggressive, highly toxic, and can cause debilitating lifelong side effects. Similarly, stem cell transplants are associated with serious mortality and morbidity risks. However, as a last resort for patients, a transplant can be potentially curative therapy:

> When stem cells in someone's bone marrow get damaged or destroyed because of blood cancer, a life-saving stem cell transplant from a healthy donor is often necessary to rebuild the body's blood and immune systems.[223]

8.32 Due to a lack of registered donors in Australia, 8 out of 10 Australian patients rely on overseas donors to find a compatible match.[224] Unlike other major transplanting nations, who have on average halved their dependency on foreign donors in the last decade, Australia's dependency has steadily increased.[225]

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220 Association for the Advancement of Blood and Biotherapies, *Hematopoietic Stem Cells*, 2023, accessed 16 Oct 23.

221 Submission 24 from Leukaemia Foundation, 06 Apr 23, p 2.

222 Submission 24 from Leukaemia Foundation, p 2.

223 Submission 24 from Leukaemia Foundation, 06 Apr 23, p 1.

224 Australian Bone Marrow Donor Registry (ABMDR), *Donor registry status report*, 2022, accessed 10 Oct 23.

225 ABMDR, *Donor registry status report*, 2022, accessed 10 Oct 23.

8.33 Transporting stem cells from overseas can impact their viability and increase complications.[226] Relying on overseas donors also makes it more difficult for people from ethnicities not well-represented internationally, such as Indigenous Australians, Māori's and Pacific Islanders.[227] It is also not cost effective, as importing international cells costs $30,000-$50,000, in comparison to $1,500-$3,500 for Australian donor collections.[228]

8.34 To achieve meaningful improvement, ABMDR has identified that Australia's donor pool should contain 3% of Australia's population of 18 to 35 year olds (preferably male and ethnically diverse).[229] The ABMDR estimates that 100,000 new HPC donors must be recruited within the next 5 years.[230]

The Strength-to-Give campaign

8.35 In 2019, the ABMDR initiated the 'Strength to Give' campaign to recruit more donors. The campaign involved registering online for a cheek swab kit. The website explains as follows:

> Once you get your kit, simply swab your cheek and return the sample for free (we'll send you full step-by-step instructions in the kit). We'll then add you – and your swab results – onto our registry and you'll join the millions of donors around the world, ready and willing to save a life.[231]

8.36 This initiative was modelled on similar campaigns that have been successful internationally. It allows the ABMDR to target ideal donors and demographics not well represented on the ABMDR. The campaign recruited 5,000 donors in its first year and another 6,000 in the year after before government funding ceased in mid-2021.[232]

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226 Submission 24 from Leukaemia Foundation, 06 Apr 23, p 3.

227 Submission 24 from Leukaemia Foundation, p 3; Joseph Guenzler, 'Tackling Leukaemia is working with grassroots clubs to help boost the Bone Marrow Donor List Registry', *National Indigenous Times,* 6 Jan 23, accessed 21 Sep 23.

228 Australian Bone Marrow Donor Registry, *Donor registry status report,* 2022, accessed 10 Oct 23.

229 Medical research shows that younger, male donors are best for patients and provide the greatest chance for transplant success.

230 Submission 24 from Leukaemia Foundation, 06 Apr 23, p 3.

231 Australian Bone Marrow Donor Registry, *Strength to Give*, n.d., accessed 16 Oct 23.

232 Shelby Traynor, 'Bone marrow registry to fund cheek swab collection as families seek donors overseas', *ABC News,* 27 Mar 23, accessed 21 Sep 23.

CHAPTER 9
Issues impacting culturally and linguistically diverse Australians

Chapter summary

9.1 Culturally and linguistically diverse (CALD) Australians exhibit higher prevalence rates of certain health conditions, increasing the potential need for transplants. However, CALD communities have low rates of consent to organ donation.

9.2 Religious and cultural beliefs of potential donors and their loved ones can influence the decision-making process. Despite all major religions in Australia supporting organ donation, many people are unaware of their religion's view on the issue.

9.3 The OTA website contains a collection of published statements of support for organ and tissue donation, as well as translated videos and brochures. However, current resources on the DonateLife website lack visibility. Recommendations include updating resources and providing intuitive navigation.

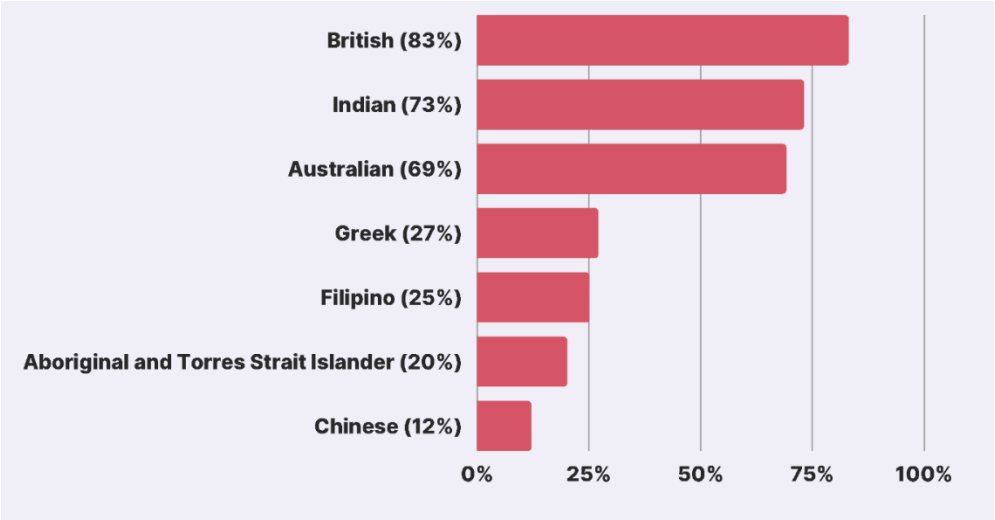
9.4 Grassroots community engagement and targeted consultation is essential to address concerns related to organ donation's impact on burial, religious principles and dispelling myths. The United Kingdom's example demonstrates the effectiveness of involving religious leaders in educational forums to address concerns.

Culturally and linguistically diverse Australians

9.5 As of 2021, more than 7 million people (28%) in Australia were born overseas, and around 6 million (23%) people speak a language other than English at home.[233]

9.6 Data from the OTA has consistently shown that Australians from CALD backgrounds are less likely to have discussed organ donation and less likely to consent to their loved ones donating organs and tissue.

Figure 14. *Consent rates amongst various cultural groups that Australians self-identified as (data from 2016)*



[Source: Federation of Ethnic Communities' Councils of Australia.[234]]

[233] Australian Bureau of Statistics, Cultural diversity: Census, 2021, accessed 21 Sep 23.

9.7 Australians born overseas, particularly those born in the regions of Polynesia, South Asia and the Middle East, have higher rates of heart disease, diabetes and kidney disease than the Australian-born population.[235] This may result in a greater need for transplants.

9.8 Diabetes is also experienced more prevalently by people who speak languages other than English at home.

Table 13. *Rate of diabetes by language used at home, 2021*

Language spoken at home	Diabetes
English only	3.95
Arabic	7.87
Filipino	7.62
Punjabi	6.55
Hindi	9.28
Tagalog	7.98
Vietnamese	5.21
Malayalam	10.26
Sinhalese	9.32
Tamil	10.49

[Source: Australian Institute of Health and Welfare.[236]]

9.9 Kidney donors and recipients are matched by blood group and tissue type. People from the same ethnic background are more likely to have matching tissue types.

9.10 If more people with these ethnic backgrounds donated their organs after death or as living donors, transplant waiting times would decrease and transplant rates would increase.

Reasons for lower consent rates amongst CALD communities

9.11 The ethnic and cultural background of a potential donor and their family can impact the likelihood of consent for donation. The reasons for this include:

- lack of awareness of their religion's position about organ and tissue donation or assumption that their cultural beliefs do not allow it;[237]
- cultural taboos surrounding death and dying, which may limit organ and tissue donation conversations, leading to a lack of open dialogue about the topic;[238]
- people of faith may have concerns about the observance of funeral and burial customs; and

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234 Federation of Ethnic Communities' Councils of Australia, *Engaging CALD communities in organ and tissue donation discussions*, Spring 2017, accessed 14 Sep 23, p 6; Organ and Tissue Authority, Australia Donation and Transplantation Activity Report 2016, accessed 2 Oct 23, p 6.

235 Australian Institute of Health and Welfare (AIHW), *Chronic health conditions among culturally and linguistically diverse Australians 2021*, 2023, accessed 20 Sep 23, based on Census data 2021.

236 AIHW, *Chronic health conditions among culturally and linguistically diverse Australians 2021*, 2023, accessed 20 Sep 23, based on Census data 2021.

237 Federation of Ethnic Communities' Councils of Australia (FECCA), *Engaging CALD communities in organ and tissue donation discussions*, Spring 2017, accessed 14 Sep 23, p 7.

238 FECCA, *Engaging CALD communities in organ and tissue donation discussions*, Spring 2017, accessed 14 Sep 23, p 7.

- suspicion about the process and the possibility of exploitation or coercion.

9.12 Religious leaders from various faiths in Australia, such as Buddhism, Catholicism, Greek Orthodox, Hinduism, Islam and Judaism, have expressed support for organ and tissue donation and have issued official position statements, encyclicals, fatwas or rulings.

9.13 Medical professionals respect individuals' wishes and religious practices. Organ donation does not usually alter a person's physical appearance, and family members may still view the body and have an open-casket funeral if desired.

9.14 In 2016, a research project was conducted on attitudes and beliefs about deceased organ and tissue donation in the Australian Arabic-speaking community. The research found that:

> although organ donation is considered a generous life-saving 'gift' [by faith leaders]…members of the Arabic-speaking community in Australia were unfamiliar with, unnerved by and sceptical about the donation process.[239]

Initiatives in the United Kingdom

9.15 The United Kingdom has taken steps to acknowledge the importance of religious beliefs in relation to organ and tissue donation.

9.16 The United Kingdom's National Health System (NHS) publishes comprehensive electronic booklets for each of the main religions. The booklets contain faith-specific information made in cooperation with faith leaders. The booklets contain current information, including direct quotes, from respected faith leaders.[240] Spain publishes a similar comprehensive document.

9.17 Another initiative provided by the United Kingdom is the 'personal statement developed for the Jewish community'.[241] The United Kingdom's donor register offers the opportunity for people to register to donate, but specify they wish for staff to speak to their family and any other appropriate people about how it can occur in line with their faith or beliefs. The NHS website explains:

> The statement has been agreed between the Office of the Chief Rabbi, Board of Deputies and NHS Blood and Transplant, to provide reassurance to Jewish people who want to be organ or tissue donors around the processes that can be put in place to ensure that donation proceeds in line with their faith.[242]

9.18 In 2019-2020, the British Islamic Medical Association held a series of public forums to discuss the procedures, experience and Islamic ethical and legal rulings on organ donation. Health professionals and Imams ran the forums. Participants completed a questionnaire before and after the forums. Before the forum, 50% of respondents were unsure of the permissibility of organ donation in Islam, of which 72% changed their opinion to 'deeming it permissible' after the forum, and 60% towards a willingness to register.[243] This demonstrates the effectiveness of education incorporating faith leaders alongside healthcare professionals to address religious or cultural concerns.

9.19 In 2013, NHS Blood and Transplant hosted a Faith & Organ Donation Summit, inviting prominent faith leaders from all faiths. It was one of the first times that faith leaders from all

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239 A Ralph et al., Attitudes and beliefs about deceased organ donation in the Arabic speaking community in Australia: a focus group, 2016, BMJ Open, 6(1):3.

240 Scottish Government, *Organ donation and religious beliefs: A guide to organ and tissue donation and Muslim beliefs*, 2021, accessed 21 Sep 23.

241 National Health Service Blood and Transplant (NHSBT), *A Jewish perspective on organ donation*, accessed 6 Sep 23.

242 NHSBT, *A Jewish perspective on organ donation*, accessed 6 Sep 23.

243 O Ali et al., 'Informing the UK Muslim community on organ donation: Evaluating the effect of a national public health programme by health professionals and faith leaders', *J Relig Health*, 2023, 62(3):1716-1730.

the leading United Kingdom faith organisations had come together to discuss a significant health issue and contribute to developing an action plan. One of the recommendations that came out of the Summit was the need to engage at a local level:

> It was felt that engaging with people at a local level via events and meetings would be most effective. It was suggested that religious centres such as churches, mosques, and gurdwaras would be a good route for engagement and using major festivals such as Diwali, Eid, Vsant Navrati and Vaisakhi as an opportunity to promote organ donation to vast gatherings of followers. Local faith leaders would require educational training and support. The potential for working with Donation Committees was mentioned by many of the attendees as a means to progress local level action.[244]

9.20 In 2016, a United Kingdom study looked to identify barriers to organ donor registration and family consent among the United Kingdom's minority ethnic population. The study facilitated focus groups in community and hospital settings. The study found that national campaigns focusing on ethnic minorities had little impact and the most effective educational interventions were those that:

- were conducted in a familiar environment;
- addressed the group's particular concerns;
- were delivered by trained members of the lay community; and
- provided immediate access to registration.[245]

9.21 The following concerns felt by members of religious and ethnic communities should be addressed in collaboration with community and faith leaders:

- organ donation and its impact on burial or cremation, or funeral arrangements;
- organ donation and its impact on religious principles;
- transplantation and the 'sanctity of the body'; and
- myths such as that medical staff will not try as hard to save you if they know you are an organ donor.

Current resources

9.22 The DonateLife website contains religious support statements for Islam (2015), Greek Orthodox (2013), Hindu (undated), Serbian Orthodox (undated), United Vietnamese Buddhism (undated), Canonical Orthodox (2014) and from the Sydney Beth Din (undated). The website also has resources in 18 different languages.[246]

9.23 However, these resources are not prominently or intuitively located on the website, which risks rendering them ineffective. The DonateLife website should be updated to ensure accessibility and intuitive and logical navigation.

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244 Prof G Randhawa, *Faith engagement and organ donation action plan*, University of Bedfordshire in collaboration with NHS Blood and Transplant, 2013, accessed 20 Oct 23.

245 M Morgan et al., 'Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on Donation, Transplantation and Ethnicity', Southampton (UK): National Institute for Health and Care Research Journals Library, 2016, doi: 10.3310/pgfar04040.

246 Organ and Tissue Authority, *Community resources library*, DonateLife, n.d., accessed 20 Oct 23.

FINDING 14

Engaging with community and faith leaders is likely to have a positive impact on registration and consent rates amongst culturally and linguistically diverse communities.

RECOMMENDATION 9

The Western Australian Government advocate for the Organ and Tissue Authority to update and review the DonateLife website to ensure that:

- all statements of religious and cultural support contain up-to-date information and are clearly marked with the date they were last reviewed;
- the content meets accessibility standards; and
- there are prominent options to translate key information into various languages.

RECOMMENDATION 10

The Department of Health and DonateLife WA ensure all staff involved with organ and tissue donation are provided with appropriate training in understanding religious and cultural aspects of organ donation.

RECOMMENDATION 11

The Western Australian government and the Organ and Tissue Authority provide grants for 'grassroots' tailored consultation with culturally and linguistically diverse communities. This consultation should address specific concerns of the relevant community and should occur in:

- collaboration with community and faith leaders; and
- environments familiar to the relevant community.

CHAPTER 10
Opt-in and opt-out consent models

Chapter summary

10.1 Two main consent models are used globally for organ and tissue donation: 'opt-in' and 'opt-out'. Opt-in requires active consent on a registry, while opt-out presumes consent unless an individual registers an objection during their lifetime. However, in practice, families are the ultimate decision-makers in both systems, and donation will not proceed in the face of family objection.

10.2 Australia's legislative framework is based on an 'opt-in' model. Individuals are encouraged to register their organ and tissue donation preferences on the AODR. Registration is not legally binding; family consent is sought in practice. Families will be approached about organ donation, whether somebody has registered a decision to donate on the AODR or not.

10.3 Community debate continues over whether an opt-out system would yield higher transplantation rates than our current opt-in system. All jurisdictions in the United Kingdom have recently transitioned from an opt-in to an opt-out system. It is still too early to ascertain the true impact of this change, and the United Kingdom is facing current difficulties with consent and registration rates.

10.4 England's legislative change coincided with the COVID-19 pandemic, making it difficult to assess the actual impact of the legislation. The pandemic affected the rates of organ donation throughout the world.

10.5 Arguments favouring an opt-out system include shifting the default position within the community to an assumption of consent and that a legislative change would offer a mandate for mass-media coverage and campaigns.

10.6 Arguments against a legislative change from the current model to an opt-out model include the lack of clear evidence that one system is better, the risk of disengagement and a potential decline in registration and consent rates.

10.7 Only 36% of Australians and 38% of eligible Western Australians are registered on the AODR.

10.8 The AODR registration rate does not necessarily reflect the current level of support for organ donation within the community. Australian attitudes and perspectives of an opt-out system should be ascertained.

10.9 Any legislative change must avoid damaging public trust and would require thorough communication with the public, including cultural and religiously sensitive outreach. Any change should only take place with public support.

10.10 Regardless of the consent model used, a nationally consistent approach is preferable.

Opt-in and opt-out models

10.11 There are 2 main consent systems for organ donation: the 'opt-in' model and the 'opt-out' model.[247]

- Opt-in systems of organ donation require individuals to actively consent on a registry to their organs and tissue being donated.

[247] Within each of these models, there are varying degrees of how strictly these models are enforced, and as such, a model will usually be described as a 'soft' or 'hard' model.

- Opt-out systems of organ donation presume that all individuals consent to their organs and tissue being donated after their death unless the individual registered their dissent during their lifetime.

10.12 There are only a limited number of patients who die in circumstances that make them eligible to be organ donors each year. Regardless of the consent model, families are still consulted in the donation process. The size of the donor pool effectively remains the same irrespective of the consent model used.[248]

The Australian consent model

10.13 The legislative framework in all Australian jurisdictions is based on the opt-in model. Individuals can choose to consent to their organs being donated after their death by recording their decision on the AODR.

10.14 However, registration is not a legally binding directive. In practice, even if an individual has recorded their wishes to donate their organs after death, no retrieval will occur without obtaining consent from the deceased's family.[249]

10.15 If a person does not 'opt-in', it is assumed either they were not aware of how to register, they were not motivated enough to register, or they do not wish to consent to be an organ donor.[250]

Table 14. *Impact of registration on what happens in practice*

Registration status	In practice	Result
Registered 'yes' on the donation registry for some or all organs and tissue	The deceased's family are consulted and must provide consent before any retrieval.[251]	Donation will not occur where family members are opposed to such a procedure, even when the deceased person's consent has been registered on AODR.
No decision registered on the donation registry	The deceased's family are consulted and must provide consent before any retrieval.[252]	Donation will not occur where family members are opposed to such a procedure.
Register a 'no' decision on the donation registry	The deceased's family are not consulted.[253]	Donation will not occur regardless of the families wishes.

248 Organ and Tissue Authority, *Organ and tissue donation opt-in and opt-out consent systems,* Australian Government, n.d., accessed 17 Nov 23.

249 National Health and Medical Research Council, Organ and Tissue Donation After Death, For Transplantation: Guidelines for Ethical Practice for Health Professionals, Australian Government, 2007, pp 33-34.

250 L Delriviere and H Boronovskis, 'Adopting an opt-out registration system for organ and tissue donation in Western Australia: A discussion paper', 2011, accessed 23 May 23.

251 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 26.

252 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 26.

253 *Human Tissue and Transplant Act 1982* s 22(2)(b).

Family consultation

10.16 It is important to note that in the majority of opt-in and opt-out systems internationally, families are approached about donation when their family member dies. If the family objects, donation will not proceed.

10.17 One study collected data from 54 nations to compare the authority of next-of-kin in explicit and presumed consent systems for deceased organ donation. It found:

> Organ procurement systems are complex with key differences between what is legislated and what is done in practice. We found that many nations with presumed consent legislation follow a much softer system of consent in reality, which almost always includes next-of-kin in the decision making.[254]

10.18 The difference between what is legislated and what happens in practice within opt-out systems was also highlighted by the Organ and Tissue Authority:

> Countries with opt-out will not proceed in the face of family objection, and even those countries said to have a hard opt-out system, such as Singapore and Austria, will not proceed in the face of family objection; in fact, the systems, in practice, operate very similarly.[255]

10.19 In practice, the difference between the 2 systems is the framing of the conversations with the families when consent is sought. In an opt-out system, if a person has not registered a decision, the conversation is framed with a presumption that the person did want to donate their organs and tissue. In an opt-in system, the conversation explores whether the persons' wishes would have been to donate.

Table 15. *The role of family wishes in opt-in and opt-out systems*

	Opt-in	Opt-out
The family will be asked to consent to organ donation before retrieval happens.[256]	✓	✓
The family's wishes will be almost uniformly respected, including overriding the deceased's express decision to donate.[257]	✓	✓

[Source: Various.]

10.20 Families are involved in the decision about organ donation of a loved one for the following reasons:

- Trust needs to be maintained and there is an expected duty to the living as well as the deceased.
- Australian legislation requires the designated officer to be aware of the current wishes of the deceased.
- Health information, including the donor's medical and social history, is needed before donation can proceed. This information usually can only be ascertained with family support.[258]

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254 A Rosenblum, 'The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations', *Nephrol Dial Transplant*, 2012, 27(6):2533-2546, doi: 10.1093/ndt/gfr619, accessed 13 Oct 23.

255 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 5.

256 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], p 5.

257 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], p 5.

10.21 The OTA described the situation as follows:

> The family go through quite a process; [the donor assessment process can] often takes 24 hours or more…and the family provide much vital information that makes the safety of the donation and transplantation at a higher level. They provide health information about their family member; lifestyle factors. The cooperation of the family is important for the safety of the system, and I think those of us who care for people at end of life, the whole idea that one would proceed with donation when you have a family by the bedside just totally objecting to it, I think many people would feel very uncomfortable with that. There is a concern that it could hit the media and cause a backlash against donation.[259]

International perspectives

Spain

10.22 Spain has the highest rate of organ transplantation worldwide, with 48.9 dpmp in 2019, well above international averages.

10.23 The country has a presumed consent or 'opt-out' model; however, the family is always asked about the deceased's preferences and family opposition is always respected. If family members of the deceased cannot be located, donation will not proceed:

> Emulating [Spain's] success at achieving 40 deceased organ donors and 100 transplant procedures per million population should lead to emulation of their investment in education and infrastructure rather than tinkering with organ registration methodology.[260]

10.24 WA Health noted:

> [Spain] is frequently referred to as the exemplar country for the opt-out approach. However, the Spanish approach is an opt-out model with family consent required, but they have no registry at all. The Spanish also suggest the real change occurred with the introduction of hospital donation specialist teams and a major public campaign.[261]

10.25 The OTA, in commenting on the Spanish system, stated:

> Spain, for instance, is notionally opt-out, but there is no register for people to opt-out on. In fact, it functions more like an opt-in system, where families are approached and it is the family decision about donation which determines the outcome.
>
> …
>
> [Spain] introduced their [opt-out] legislation in 1979. There was no change in consent or donation rates, and it was only when they properly invested in and

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258 Organ Donation Scotland, *The role of your family*, n.d., accessed 11 Oct 23.

259 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 15.

260 A Sharif, 'Presumed consent will not automatically lead to increased organ donation', *Kidney International*, 2018, 94:249-251.

261 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 8.

> started to organise their system, much like we began in 2009, that their rates improved.[262]

10.26 This is consistent with advice received by Spanish stakeholders during the Committee's international meetings in Spain. The Spanish attribute their success not to their legislative system but to decades-long investment in specific infrastructure for organ donation, such as:

- a national transplant coordination system;
- staffing all hospitals with transplant coordinators who are usually intensivists;
- routine identification and notification at the end of life; and
- organ donation is considered a routine part of end-of-life care.

Nova Scotia

10.27 Nova Scotia is a province within the Commonwealth of Canada and the first Canadian province to shift from an opt-in to an opt-out consent model of organ donation. The legislative change came into effect in January 2021.

10.28 It is observed that:

> Nova Scotia, on the back of the extensive community engagement program implemented in the lead-up to the passage of the legislation, noted a substantial increase in organ donation prior to the legislation being proclaimed.[263]

10.29 The Committee notes that in addition to the legislation, Nova Scotia simultaneously adopted other elements of health system transformation, including:

- mandatory notification for all patient deaths;
- approaching the families of all medically suitable potential donors;
- centre reporting of donor performance; and
- provision for a substitute decision-maker to grant consent or refusal for organ donation.

10.30 The Committee accepts that the effectiveness of Nova Scotia's reforms should be assessed when more data becomes available to inform discussion about whether Australia should adopt similar changes.

10.31 Nevertheless, it is the Committee's observation that the current state of donation and transplantation was related to the fact that Nova Scotia's change in legislation occurred in conjunction with other significant reforms and community engagement.

United Kingdom

10.32 All jurisdictions in the United Kingdom have recently moved from an 'opt-in' system to an 'opt-out' system. Adults are considered to have agreed to be organ donors when they die unless they have recorded a decision not to donate or are in an excluded group. The legislation varies between jurisdictions but has a similar overall effect. The changes were implemented at different times:

- Wales: December 2015
- England: May 2020

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262 Dr H Opham, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 5.

263 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 8.

- Scotland: March 2021
- Northern Ireland: June 2023.

10.33 The legislative changes in the United Kingdom provide a legal basis for deeming (presuming) consent, but the family is still asked to support the deemed consent. This system is known as soft opt-out. Family opposition will stop donation proceeding.

10.34 Implementing the new opt-out system had 3 components: the legislation, public media campaign and retraining specialist nurses and other key healthcare staff.

10.35 In Wales, before implementing the opt-out legislation, an intensive media promotion campaign was held over 2 years. The campaign achieved 74% population awareness of the legislative change before implementation. Specialist Donation Nurses undertook training to become accustomed to the change in style and language of the family approach under the new legislation.[264]

10.36 The OTA noted:

> Wales, with the introduction of opt-out, saw an early increase in consent rates, but they have since decreased. The issue with Wales, it has three million people, 90 per cent of the population identify as white, and there was a lot of public awareness raising and education when they introduced opt- out, so it is difficult to determine whether it was the change of legislation per se or the other activities in terms of community awareness raising that showed that early impact in consent rates.[265]

10.37 In England and Scotland, the legislative changes coincided with the COVID-19 pandemic, making it difficult to assess the actual impact of the legislation. The pandemic affected the rates of organ donation throughout the world.

Table 16. *Comparison between legislation models in Wales, England, Scotland and Australia*

	Options for registration	**Role of family**
Opt-out system in Wales	1. Register to opt-in. 2. Register to opt-out. 3. Appoint a representation on the organ donor register to make the decision for you. 4. Do nothing: You will be treated as having no objection to being a donor and your consent will be deemed.[266]	Donation will not proceed if the family do not consent.[267]

264 S Madden et al., 'The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system', *Anaesthesia*, 2020, 75(9):1146-1152.

265 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, pp 5-6.

266 J Noyes et al., 'Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study', *BMJ Open*, 2019, doi: 10.1136/bmjopen-2018-025159.

267 J Noyes et al., 'Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study'.

	Options for registration	Role of family
Opt-out system in England	1. Register to opt-in. 2. Register to opt-out. 3. Register with the option to state that your family and/or faith leader should be consulted to ensure that any religious considerations are observed. 4. Appoint someone to make the decision for you.[268]	Nurses will continue to have a conversation with the family to discuss their loved one's wishes, during which the family will be able to provide information if they know that their loved one would or would not have wanted to donate their organs. Even if there is a recorded decision on the Register, those close to the potential donor can still provide information if they know that what has been recorded is not the deceased's latest wish. Faith and the views of the family will form part of these discussions.[269]
Opt-out system in Scotland	1. Register to opt-in. 2. Register to opt-out. 3. Do not register a decision: It will be considered you agree to donate.	Loved ones are consulted about the deceased's latest views to ensure donation does not proceed if they would not have wanted it to.[270]
Opt-in system in Australia	1. Register to opt-in. 2. Register to opt-out. 3. Do nothing: Your family members will be asked about your wishes.	To give consent for organ donation.[271]

Opt-out: matters to be considered

10.38 The Committee acknowledges there are calls from some in the community for Australia to adopt an opt-out model.

10.39 One argument in favour of adopting an opt-out system is that it aims to shift the default position:

> It sort of shifts the default, and potentially, when one spoke with families…one would say, "Your relative has not opted out, they have not expressed an objection to donation, and I am now going to therefore explain how donation can proceed for your relative." One would explain it that way, with a more presumptive approach that donation would proceed. That is the argument in favour.[272]

10.40 Another argument is that adopting an opt-out system offers a mandate for mass-media coverage and information, which may then increase consent rates as greater awareness is raised:

> when you talk to the UK and you ask, "What do you think the benefit has been in moving to opt-out?", part of what the people in the sector view as the benefit is the additional resourcing that was provided to do public messaging, engage with a variety of community groups and spend more time educating healthcare staff as to

268 Department of Health and Social Care (DHSC), *The new approach to organ and tissue donation in England: Government response to public consultation*, United Kingdom Government, 2018, accessed 11 Oct 23, p 21.

269 DHSC, *The new approach to organ and tissue donation in England: Government response to public consultation*, p 21.

270 Scottish Government, *Register your decision*, Organ Donation Scotland, n.d., accessed 21 Oct 23.

271 See para 6.9.

272 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 7.

> how to approach families in what is now quite a complex system, given the four choices.[273]

10.41 The experience in the United Kingdom and Spain shows that for any legislative change to have a positive effect, it must be carried out in conjunction with other comprehensively integrated supporting measures.

FINDING 15

The experience in the United Kingdom and Spain shows that for any legislative change to the organ and tissue donation consent model to have a positive effect, it must be carried out in conjunction with other comprehensively integrated supporting measures.

Risk of disengagement

10.42 Implementing any change in the current consent system would need to maintain public trust and transparency, or the change might backfire and have long-term negative impacts on the organ donation system. An example of this occurred in Brazil, where opt-out legislation was introduced without sufficient community education or consultation in March 1997 and, as a result of the backlash, was repealed in October 1998.[274]

10.43 The OTA noted that any change in systems had the risk of disengaging people:

> in shifting to opt-out, there is a risk of disengaging people in the community. It may even cause people who have previously been willing to be donors to now object, because they are sensing it is no longer an altruistic gift but something that is being expected. One would need to manage a transition—a move to opt-out—very carefully, in a similar way to what the UK has done.[275]

10.44 The risk of misinformation, conspiratorial thinking and distrust would need to be managed in relation to any changes to legislation.

10.45 In 2023, academics from Western Sydney University considered themes of mistrust in Australia based on a national survey conducted in 2019. It compared online misinformation to a 'digital wildfire' and noted that:

> In recent 'crisis' times, the issue of trust has come to the fore regarding the relationship between distrust and conspiratorial thinking during the COVID-19 pandemic, particularly distrust in science.
>
> There are also indicators that the COVID-19 pandemic has seen a bifurcation in trust in public institutions (that is, some public institutions being more trusted than others), across different countries.[276]

10.46 The impact of misinformation in social media is a significant concern in public health. It would need to be anticipated and addressed as it can reduce the effectiveness of programs and campaigns.

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273 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 6.

274 C Csillag, 'Brazil abolishes "presumed consent" in organ donation', *Lancet*, 1998, 352(9137):1367, accessed 14 Oct 23.

275 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 7.

276 A Kamp et al., 'Understanding trust in contemporary Australia using latent class analysis', *Cosmopolitan Civil Societies: An Interdisciplinary Journal*, 2023, 15(2):84-104.

Public awareness campaign

10.47 Widespread public awareness and professional education would be required before any legislative change to ensure people are fully informed and to prevent misinformation dissemination.[277] Communication with historically underrepresented populations and communities with low donation rates would be particularly important.

10.48 During its hearing with the Committee, WA Health noted:

> there are many different cultural groups in WA and they would need to be fully informed and understand any proposal to change the consent process…This would be particularly significant for our Aboriginal citizens.[278]

10.49 It is noted that the United Kingdom has lower proportions of multicultural communities than Australia. The OTA noted:

> One of the challenges in Australia that we might have that is different to other countries, particularly the UK, is our high proportion and very heterogeneous multicultural community…there would need to be a lot of resources and effort in really explaining [any change in the system] appropriately to people in language and with appropriate cultural messaging, and this would require a significant amount of resource.[279]

Table 17. *Multi-cultural differences between Australia and England, Wales and Scotland*

	Percentage of people who speak a language other than English at home	**Percentage of the population born overseas**
Australia[280]	22.8%	27.6%
England/Wales[281]	12.5% (9.2% England, 3.3% Wales)	16.8%
Scotland[282]	7.4%	7.4

10.50 For any legislative change, the amount of time required to effectively deliver the change at an operational level must be considered to ensure there is adequate time to:

- build, test, and deliver training to clinicians and DonateLife WA staff who approach families to frame the conversation in compliance with the laws and policy;
- create and publish guidance documentation for clinicians;
- engage and involve stakeholders across the donation system to garner support for the changes; and
- develop necessary informational technology changes.

277 MJ Weiss, 'International Donation and Transplantation Legislative and Policy Forum: methods and purpose', *Transplant Direct*, 2023, May 9(5):e1351.

278 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 8.

279 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 6.

280 Australian Bureau of Statistics, *Cultural diversity of Australia*, 2022, accessed 11 Oct 23.

281 Office for National Statistics (ONS), *Language, England and Wales: Census 2021*, 2022, accessed 11 Oct 23; ONS, *International migration: Census 2021*, 2022, accessed 11 Oct 23.

282 Scotland's Census, *Languages*, 2021, accessed 11 Oct 23; National Records of Scotland, *Just over 7% of Scotland's population are non-British nationals*, media statement, National Records of Scotland, 25 Nov 21, accessed 11 Oct 23.

Risk of inaction

10.51 There is an argument that moving to an opt-out system may result in inaction, leading to fewer people registering a decision. When families are unaware of their loved ones' wishes, they are more likely to decline organ and tissue donation.

> There is nothing more valuable in terms of higher consent rates than someone saying they are willing to be a donor, and to let their family know, and to register. We know that within Australia and internationally.[283]

10.52 The OTA noted that:

> The risk with simply just having opt-out is, in effect, it may encourage inaction. Why bother, unless you want to say no? And it may risk leaving more families not actually knowing their relative's wish, and whether you have opt-in or opt-out, it may just leave families defaulting to a "no", because that is what they do when they are uncertain and they are making a decision in a stressful time. So it is certainly not clear.[284]

10.53 Lower registration rates have been seen in the United Kingdom following their move to an opt-out system, contributing to lower consent rates. In March 2023, a report was issued to the NHS Blood and Transplant Board noting that:

> Recent focus group research indicates the public believe the opt-out system should be sufficient to ensure donation goes ahead as it is assumed everyone is automatically registered. This is leading to public inertia to register an opt-in decision on organ donation…results show consent is declining and the new regulation is less effective than hoped.[285]

10.54 The same report noted that:

> Data evidence shows that the opt-in register plays an increasingly important role in informing the next of kin of a deceased donor's decision. Today, 89% of families support organ donation at the time of death if they knew what their loved one wanted. When the family is unaware of a decision, and therefore relying on deemed consent, the rate falls to 58%. Indecision has reduced with fewer families being unsure of what their loved one would have wanted but confirmation of an opt-out decision (verbally or on the [Organ Donor Register] has increased.
>
> The increased awareness of organ donation law, a larger [Organ Donor Register] and continuing support by families for expressed consent, is being offset by lower consent rates from families of donors who qualify for deemed consent. There are also a greater number of families who report their relative has expressed an opt-out decision verbally during their lifetime, as well as being guided by a recorded opt-out decision on the [Organ Donor Register].[286]

10.55 The Committee acknowledges that falling consent rates in the United Kingdom must also be considered in the context of the COVID-19 pandemic and current low satisfaction levels with the NHS generally. Overall satisfaction with the NHS is at the lowest recorded since 1983 for

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283 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 6.

284 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], p 6.

285 National Health Service Blood and Transplant (NHSBT), *Improving consent post law change: The role and health of the NHS Organ Donor Register*, board papers, 2023, accessed 13 Sep 23, p 1.

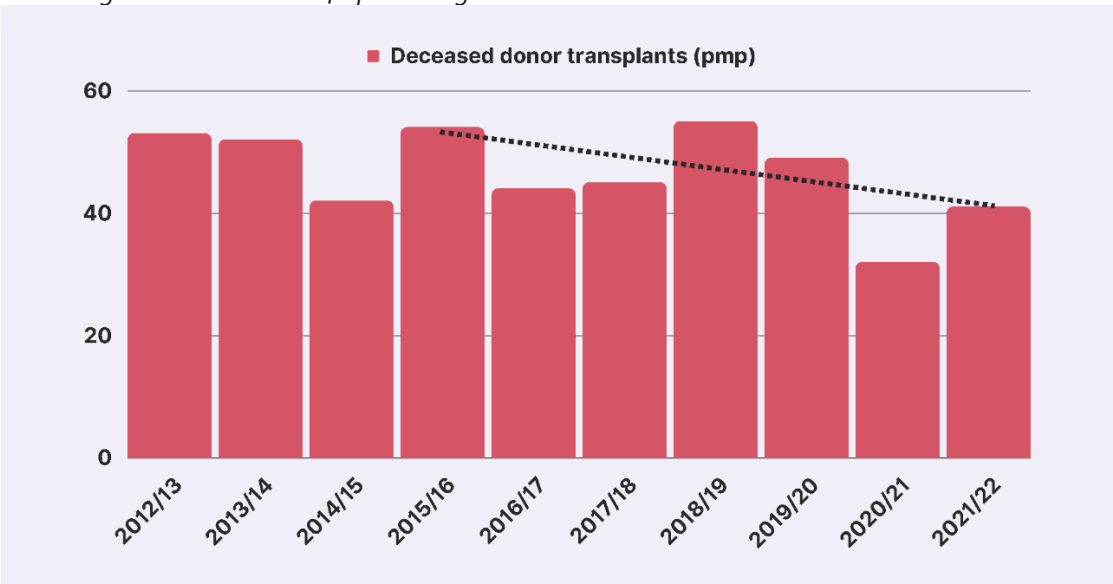
286 NHSBT, *Improving consent post law change: The role and health of the NHS organ donor register*, p 21.

reasons including long wait times, staff shortages and public perception of lack of investment. [287]

10.56 The United Kingdom experience shows that regardless of the consent model used, knowing the wishes of loved ones is essential to increasing consent rates and, therefore, donation rates.

10.57 The experience of implementing the legislative change differed between Wales and England. In contrast to Wales, England introduced its changes during the COVID-19 pandemic, which hindered the effectiveness of the implementation of the legislative change.

Figure 15. *Deceased donor transplants in Wales from 2012/13 to 2021/22, with the dotted line indicating the introduction of opt-out legislation*



[Source: Donation and Transplantation Plan for Wales.[288]]

Lack of current data about Australian views

10.58 Australians' views about moving to an 'opt-out' system have not been widely studied.

10.59 Dr Towler noted that the number of Australians who would choose to 'opt-out' may be as much as 30%:

> those countries that have introduced opt-out, part of the underlying recognition is that only a small proportion of the population have indicated a desire to opt-out. In fact, in Nova Scotia, interestingly, even with the introduction of the new registry, the opt-out numbers have been very low. Australia does not seem to be in quite that position. We believe from previous surveys the proportion of the population who may well choose to opt-out may be as much as 30 per cent, so there are challenges.[289]

10.60 Dr Powell further noted that with only 35% of the population on the AODR, it is difficult to ascertain current attitudes:

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287 J Morris et al., *Public satisfaction in the NHS and social care in 2022: Results from British Social Attitudes Survey*, The Kings' Fund, 2023, accessed 14 Oct 23, p 3.

288 Wales Transplantation Advisory Group, *Donation and Transplantation Plan for Wales 2022-2016*, National Health Service Wales, Government of Wales, June 2022, accessed 20 Oct 23, p 5.

289 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 13.

> once you have not 35 per cent of people on the organ donation register but 80 per cent, then maybe it is reasonable to assume that people kind of know and just did not get around to it.[290]

10.61 There would be a benefit to conducting large-scale studies to ascertain community perceptions about organ and tissue donation.

Coordinated national approach

10.62 In 2008, the National Clinical Taskforce on Organ and Tissue Donation (Taskforce) found the main attributer to Australia's inability to increase organ donation rates was the fragmented nature of the sector.[291] It recommended national coordination of all major aspects of the organ donation and transplantation system, including public communications, clinical guidelines, allocation protocols and data collection.[292]

10.63 On the advice of the Taskforce, a national program commenced in 2009 and resulted in Australia's organ donation rate more than doubling in the first decade (122% increase by 2019).[293]

10.64 All countries in the United Kingdom changed their legislation at different times. Nova Scotia, as a province of Canada, changed its legislation unilaterally. While it is possible for a state jurisdiction to adopt an opt-out model, an evidence-based nationally consistent approach is preferrable.

RECOMMENDATION 12

In 5 years, the Western Australian government conduct a review of organ and tissue donation.

FINDING 16

While it is possible for a state jurisdiction to adopt an opt-out model, an evidence-based nationally consistent approach is preferrable.

290 Dr B Powell, Retired former State Medical Director, DonateLife WA, [*transcript of evidence*], 17 May 23, p 4.

291 Department of Health and Ageing (DHA), *National clinical taskforce on organ and tissue donation final report: Think nationally, act locally*, Commonwealth Government, 2008, accessed 13 Oct 23, p 16.

292 DHA, *National clinical taskforce on organ and tissue donation final report: Think nationally, act locally*, p 16.

293 Organ and Tissue Authority, *Corporate Plan 2023-24*, Commonwealth Government, 2023, accessed 13 Oct 23, p 7.

CHAPTER 11
Increasing donation opportunities

Chapter summary

11.1 This chapter focuses on efforts that may increase the utilisation of donor organs and tissue.

11.2 Firstly, adequate and ongoing funding should be provided for the equipment and resources required for new technology. Machine perfusion provides the opportunity to observe and treat organs before transplantation, which can improve outcomes and reduce non-utilisation rates. Machine perfusion can result in the transplantation of organs previously considered non-viable and is a cost-effective alternative compared to dialysis.

11.3 Secondly, there should be a focus on increasing the uptake of OrganMatch, Australia's new state-of-the-art organ matching system. While widely operational, efforts are needed to educate clinicians and promote its adoption in Western Australia.

11.4 Third, guidelines should be developed to facilitate organ and tissue donation after Voluntary Assisted Dying (VAD). Victoria and international models in Belgium, the Netherlands, Spain, and Canada highlight the feasibility and benefits of organ donation following VAD.

11.5 Fourth, barriers to tissue donation such as delayed referrals to DonateLife WA and lack of local testing facilities should be addressed.

11.6 In conclusion, embracing technological advancements, expanding donor criteria, addressing funding challenges, and aligning legislative frameworks are crucial for enhancing organ donation and transplantation practices in Australia.

The cost-benefit of transplantation

11.7 In 2019-2020, $1.8 billion of health expenditure was attributed to chronic kidney disease.[294]

Dialysis

11.8 When kidneys fail to work properly, waste products and fluid can build up to dangerous levels in the body. Left untreated, it can lead to death.[295]

11.9 Dialysis is a procedure that performs the functions that the kidney usually does, such as:

- removing waste and extra fluid to prevent them from building up in the body;
- keeping safe levels of minerals in the body; and
- helping regulate blood pressure.[296]

11.10 There are 2 main types of dialysis:

- Haemodialysis: This involves cleaning blood by diverting it through a machine. [297] A typical dialysis schedule requires a patient to attend a hospital or health care service for 3 to 4 sessions a week, each taking around 4 hours. This equates to around 60 hours of connection to the dialysis machine a month.[298]

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294 Australian Institute for Health and Welfare, *Chronic kidney disease: Australian facts*, 2023, accessed 21 Sep 23.

295 National Health Service United Kingdom, *Dialysis overview*, 2021, accessed 10 Oct 23.

296 National Kidney Foundation (United States of America), *Dialysis*, 2023, accessed 12 Oct 23.

297 National Health Service United Kingdom (NHS UK), *Dialysis overview*, 2021, accessed 10 Oct 23.

298 NHS UK, *Dialysis overview*.

- Peritoneal: Peritoneal dialysis uses the inside lining of your abdomen (the peritoneum) as the filter rather than a machine. This can usually be done at home. [299]

11.11 Once commenced, regular dialysis sessions continue until a kidney transplant is performed. Without dialysis, people with kidney failure will die rapidly.[300]

11.12 Dialysis is time-consuming and draining on the patient. It affects the patients' quality of life and caregivers' quality of life. Life expectancy on dialysis varies depending on other medical conditions and adherence to treatment plans:

> The average life expectancy on dialysis is 5-10 years. However, many patients have lived well on dialysis for 20 or even 30 years.[301]

11.13 In 2020, an Australian study considered the cost-effectiveness of transplantation compared to dialysis. The study found:

> transplanting a kidney of any quality is cost-effective compared to remaining on dialysis. Transplanting higher-quality kidneys to younger patients and lower-quality kidneys to older patients is also cost-effective. Depending on dialysis in hopes of receiving a higher-quality kidney is not a cost-effective strategy for any age group or for any blood group.[302]

11.14 The Department of Health noted the 'win-win' outcome of successful transplants:

> Supporting a patient who has had a successful kidney transplant costs the health care system less than the provision of ongoing dialysis. It is a true win;win [sic] outcome. In Victoria, there are now more patients with end-stage kidney disease alive with a functioning transplant than being treated on dialysis. Every kidney failure patient who has a successful transplant makes available access to dialysis care for someone else.[303]

11.15 In 2020-2021, there were 1,617,723 dialysis-related hospitalisations, making it the leading cause of hospitalisations and accounting for around 14% of total hospitalisations.[304]

Table 18. *Costs of kidney transplant compared to hospital-based haemodialysis in 2021*

Key figures	Number/amount
Number of people with kidney failure receiving dialysis[305]	15,200
Number of kidney transplants performed[306]	857
Cost of kidney transplant per person (cost of surgery, hospital stay and post-transplant medications)[307]	$82,000

299 NHS UK, *Dialysis overview*.

300 R Kwok et al., *Change the future: Saving lives by better detecting diabetes-related kidney disease*, Diabetes Australia, 2023, p 13, accessed 21 Sep 23.

301 National Kidney Foundation (United States of America), *Dialysis*, 2023, accessed 12 Oct 23.

302 S Senanayake et al., 'Donor kidney quality and transplant outcome: An economic evaluation of contemporary practice', *Economic Evaluation*, 2020, 23(12):1561-1569.

303 Submission 25 from Department of Health, 14 Apr 23, p 2.

304 R Kwok et al., *Change the future: Saving lives by better detecting diabetes-related kidney disease*, Diabetes Australia, 2023, p 13, accessed 21 Sep 23.

305 Australian Institute for Health and Welfare (AIHW), *Chronic kidney disease: Australian facts*, 2023, accessed 11 Oct 23.

306 AIHW, *Chronic kidney disease: Australian facts*.

307 R Kwok et al., *Change the future: Saving lives by better detecting diabetes-related kidney disease*, Diabetes Australia, 2023, p 13, accessed 21 Sep 23.

Key figures	Number/amount
Cost of hospital haemodialysis per year per person[308]	Initial access: $12,752 Annual ongoing costs per person (including specialist consultations, medications and hospital admissions): $116,036
Average years on dialysis (assuming no transplant is available)[309]	10

11.16 Based on the figures in Table 18, if a patient remains on dialysis for 10 years, the treatment cost would be $1,160,360. In comparison, the average cost of kidney transplantation in the public hospital system is about $81,000. This includes the cost of the surgery, the patient's hospital stay and post-transplant medications.[310]

11.17 These figures do not include the additional cost of lost productivity (including absenteeism, informal care costs, reduced employment, increased need for financial government support, and premature mortality) associated with ongoing dialysis treatment.[311]

FINDING 17

Organ transplantation is a significantly more cost-effective option than hospital-based dialysis for patients with kidney failure.

Technology

Ex-vivo machine perfusion of donor organs

11.18 Ex-vivo machine perfusion of donor organs has evolved over the past 20 years, and many international transplanting teams have adopted this technology to increase the organ donor pool.

11.19 Machine perfusion allows the opportunity to observe and treat organs before transplantation, which can improve outcomes and reduce non-utilisation rates.[312]

11.20 Machine perfusion technology allows kidneys, livers, hearts and lungs to be kept in a state suitable for transplantation by continuously pumping blood through them. The machines maintain the temperature and oxygenation of organs. They can supply nutrients and medications to revive organs while in transit. The machine can also assess the function of an organ and predict its viability before it is transplanted. An example of one type of ex-vivo machine can be seen in Figure 17.

11.21 Western Australia utilises standard cold storage (SCS) of organs, placing them on ice until transplantation into a recipient:

> While this method is serviceable, it is far from ideal…as irreparable damage from a lack of oxygenated blood flow rapidly occurs. When a heart stops beating, or lungs

[308] Deloitte Access Economics, *Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment*, Kidney Health Australia, 2023, accessed 11 Oct 23, p 44.

[309] National Kidney Foundation (United States of America), *Dialysis*, 2023, accessed 12 Oct 23.

[310] R Kwok et al., *Change the future: Saving lives by better detecting diabetes-related kidney disease*, Diabetes Australia, 2023, p 13, accessed 21 Sep 23.

[311] Deloitte Access Economics, *Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment*, Kidney Health Australia, 2023, accessed 11 Oct 23, p 44.

[312] B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts', Transplant Journal of Australia, 2022, 31(2):5-9, doi:10.33235/tja.31.2.5-9.

stop breathing, the organ slowly dies. The cold slows down the deterioration process but not entirely, and this race against the clock severely limits organ availability.[313]

Figure 16. *Images of a liver in standard cold storage*

[Source: Professor Luc Delriviere.[314]]

11.22 Former State Medical Director of DonateLife WA, Dr Towler, advised:

> We know that clinicians in this state are enthusiastic to have access to perfusion systems to support organs that have been removed from the donor prior to being implanted in the recipients, and there is good evidence that allows for the recovery of the organ prior to implantation and leads to better clinical outcomes. At the moment there is not a clear funding model to support those activities, though.[315]

11.23 The advantages of machine perfusion compared to SCS can be summarised as follows:

- Significant reduction of 'cold ischemic time,' which means the organ spends much less time on ice without blood flow, which is better for the organ and reduces tissue damage.
- Quality assessment: while an organ is perfused in a machine, transplant experts can better assess its quality and function before being transplanted into a patient.
- Extended operating window: ex-vivo perfusion may allow organs to survive longer outside the body, making immediate transplant less urgent.[316]

11.24 In 2015, Ernst & Young conducted a review for the Australian Government on organ donation and transplantation. The review noted the emergence of ex-vivo perfusion technology and recommended supporting research and clinical programs.[317]

Perfusion machine technology and kidneys

11.25 More than 8% of retrieved kidneys in Australia annually are deemed unsuitable for transplant.[318]

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313 A Ciubotaru and A Haverich, 'Ex vivo approach to treat failing organs: Expanding the limits', *European Surgical Research*, 2014, 54(1):65-74.

314 Tabled Paper 1, tabled by Prof L Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, during hearing held 29 Nov 23, p 15.

315 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, pp 18-19.

316 John Hopkins Comprehensive Transplant Centre, *Ex Vivo Perfusion*, 2023, accessed 10 Oct 23.

317 Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, Australian Government, 2015, accessed 13 Sep 23, p 9.

318 The Westmead Institute for Medical Research, '*Australia's first 'revived' kidney transplant*', 18 Feb 21, accessed 13 Sep 23.

11.26 From 2014 to 2019, 15% of kidneys retrieved from donors after circulatory death were not used. Strategies to reduce organ damage and improve post-transplant recipient kidney function may reduce rates of non-utilisation.[319]

11.27 Two complementary machine perfusion technologies are now available to patients at Austin Health to improve access to and outcomes from kidney transplantation in Victoria and Tasmania.[320] The Kidney Machine Perfusion Program uses hypothermic (cold) and normothermic (body temperature) machine perfusion devices to improve transplant access and outcomes by restoring and protecting the organ during transport between the donor and the recipient.

> This will result in more kidneys that were previously thought to be non-viable being transplanted, transforming the lives of people who could otherwise be waiting years for a second chance.[321]

Perfusion machine technology and livers

11.28 SCS allows the preservation of many livers for 12 hours or more with minimal damage. Machine perfusion can preserve livers for up to 24 hours (and, in one reported case, for 3 days) before successful transplantation.[322]

11.29 Austin Health in Victoria has integrated liver machine perfusion for the past 4 years, enabling the transplant of livers that would otherwise be non-viable:

> Austin Health established a normothermic perfusion program for liver transplants in 2019 and has so far transplanted an additional 16 livers from organs thought to be non-viable.[323]

11.30 Livers donated from the DCD pathway are rarely used in Australia:

> Donation after circulatory death [DCD] livers are more susceptible to ischemia-reperfusion injury. Australia has taken a conservative approach to the use of DCD livers, with them rarely being considered for transplantation if they are older than 40 to 45 years, in an attempt to select more superior grafts. This is despite favourable outcomes of the use of older DCD donors reported in the United Kingdom and the Netherlands.[324]

11.31 Using organs donated from the DCD pathway would be a highly cost-effective way of reducing waiting list mortality in liver transplantation.

11.32 The use of alternative preservation methods, such as machine perfusion, could be the solution to facilitate the use of DCD donor livers for transplantation. Machine perfusion:

- reduces the preservation injury and therefore holds the potential to preserve organ quality and possibly even rescue marginal donors who are outside current criteria;
- opens up the possibility for organ sharing and use of marginal donors between geographically distant centres in Australia by extending preservation periods; and

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319 Y Lin et al., 'Non-utilisation of kidneys from donors after circulatory determinant of death', *Transplant Direct*, 2022, 8(6):e1331.

320 Austin Health, *Australia first to improve kidney transplant access and outcomes*, 28 Feb 23, accessed 13 Sep 23.

321 Austin Health, *Australia first to improve kidney transplant access and outcomes*.

322 B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts', Transplant Journal of Australia, 2022, 31(2):5-9, doi:10.33235/tja.31.2.5-9.

323 Austin Health, *Australia first to improve kidney transplant access and outcomes*, 28 Feb 23, accessed 13 Sep 23.

324 J Reiling et al., 'The implications of the shift toward donation after circulatory death in Australia', *Transplant Direct*, 2017, 3(12):e226.

- allows for assessment of viability, the ability to directly assess liver function may offer a rational alternative to the use of current empirical criteria for selection of DCD livers for transplantation. [325]

11.33 Perfusion technology is beneficial as more testing can be performed prior to transplantation to assess suitability:

> [One study] showed that approximately two-thirds of the [originally] rejected livers performed adequately and were successfully transplanted.[326]

11.34 Western Australia does not currently transplant livers from the DCD donor pathway.[327] Professor Delriviere advised the Committee that in 2022, 6 livers would have been available from the DCD pathway if machine perfusion was available. In addition, another 6 'marginal' livers could have been utilised.[328] This would equate to approximately 12 additional liver transplants per year.

Perfusion machine technology and hearts

11.35 The 'safe' ischaemic time for a 20-year-old donor heart is approximately 4-5 hours and approximately 3 hours for a 60-year-old donor heart.[329] Ischemia time is the time that blood flow (and thus oxygen) is restricted to the organ. The longer the organ goes without blood flow, the more damaged it becomes.

11.36 An Australian-New Zealand clinical trial with hypothermic ex-vivo machine perfusion using the 'XVIVO Heart Box' has increased successful donations:

> So far, 25 patients in centres in Australia and New Zealand have undergone cardiac transplantation with donor heart ischaemic times out to 8 hours…[with] no mortality.
>
> Donor hearts have been transported on the HMP system from New Zealand to Australia and over very long distances within Australia, which would have been inconceivable with SCS. Due to this trial, there is no donor heart in Australia or New Zealand that cannot be transplanted due to logistic reasons.
>
> HMP is an ideal strategy for Australia and New Zealand. The trial has convincingly demonstrated the cardiac transplant truism that the best chance of surviving a heart transplant is to leave the operating room with a normally functioning donor heart.[330]

Perfusion machine technology and lungs

11.37 The ex-vivo lung perfusion technique (EVLP) means the typical upper limit ischaemic time for lungs can safely increase from 8 hours to around 20 hours.

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325 J Reiling et al., 'The implications of the shift toward donation after circulatory death in Australia'.

326 B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts', Transplant Journal of Australia, 2022, 31(2):5-9; H Mergental et al., 'Transplantation of discarded livers following viability testing with normothermic machine perfusion', *Nat Commun.,* 2020, 11(1):2939.

327 Private hearing, Prof Luc Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, [*transcript of evidence*], *Legislative Council,* 29 Nov 23, p 5.

328 Private hearing, Prof Luc Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, [*transcript of evidence*], p 5.

329 B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts', Transplant Journal of Australia, 2022, 31(2):5-9.

330 B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts'.

11.38 EVLP would allow evaluation and assessment of lungs prior to acceptance for transplantation and improve suitability prior to transplantation.

11.39 Professor Greg Snell, lung transplant physician, wrote:

> Whilst all Australian lung transplant programs have access to an EVLP system, it is rarely utilised due to practical and significant staffing and consumable resource costs. Unfortunately, this has limited the number of additional transplants that could be done if EVLP could be used to further expand the Australian lung donor pool.[331]

Costs of machine perfusion

11.40 The machines used at Austin Health were purchased using philanthropic funding.[332]

> The consumable costs for the machine perfusion device are $7,000 per case, and the consumable costs for the normothermic machine perfusion device are about $10,000 per case…to put that in perspective, the hypothermic device costs the equivalent of one month on dialysis and the machine perfusion device consumables cost the equivalent of six weeks on dialysis, so these machines are expensive, but compared to the alternative, they are cost saving.[333]

11.41 It is also noted:

> Currently, funding for ex-vivo machine perfusion is covered by the retrieving transplant teams, not the donation sector. This means all the costs associated with purchasing the ex-vivo perfusion machines, consumables as well as staff to coordinate and manage the ex-vivo perfusion, and research programs to assess the effectiveness and benefits of this technology, are all borne by the transplant sector. To ensure ongoing utilisation of these technologies in the future, there must be a recognition that the funding for these expensive but obviously beneficial technologies must be covered as part of the overall donation and retrieval services costs. This will help ensure machine perfusion technology will become more widely adopted by the donation and transplant sectors in Australia, ultimately leading to more donor organs being utilised for transplantation.[334]

11.42 Prof Luc Delriviere advised the Committee that the OrganOx machine is available for lease, with the estimated costs is outlined in Table 19.

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331 S Okahara et al., 'A retrospective review of declined lung donors: estimating the potential of Ex Vivo Lung Perfusion', Ann Thorac Surg 2021;112:443-9; B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts'.

332 A/Prof J Whitlam, Medical Director, Kidney Transplant Service, Austin Health, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee,* Vic, 23 Jun 23, p 10.

333 A/Prof J Whitlam, Medical Director, Kidney Transplant Service, Austin Health, [*transcript of evidence*], p 10.

334 B Levvey et al., 'Ex-vivo machine perfusion of donor organs: an update from Australian experts', Transplant Journal of Australia, 2022, 31(2):5-9, doi:10.33235/tja.31.2.5-9.

Table 19. *Estimated costs of leasing an OrganOx machine*

Item	Cost
Training	$30,000
Lease of OrganOx machine for 1 year, including maintenance	$80,000
Consumables for 1 year (12 cases)	$300,000
Total	**$410,000**

[Source: Prof Luc Delriviere.[335]]

11.43 The Organ and Tissue Authority agree that machine perfusion is a cost-effective option:

> ensuring sufficient capacity in the transplantation sector, for example, so they can waitlist more people and provide access to new technologies, such as machine perfusion, is important for expanding donation and transplantation opportunities. Such an approach is cost effective, given the expanding practice results in increased kidney transplantation, and reduces the cost of dialysis on the health system.[336]

Figure 17. *The OrganOx System designed to transport and preserve donor livers prior to transplantation.*

[Source: US Food and Drug Administration.[337]]

FINDING 18

Machine perfusion technology can improve organ transplant outcomes and increase the utilisation rates of donor organs. Machine perfusion technology provides for extended transportation timeframes.

335 Private hearing, Prof Luc Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, *Paper tabled during Committee hearing, Legislative Council,* 29 Nov 23, p 12.

336 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 4.

337 United States of America Food and Drug Administration, Recently approved devices, 2022, accessed 18 Dec 23.

RECOMMENDATION 13

The Western Australian Government, after taking into consideration the cost and benefit of perfusion technology:

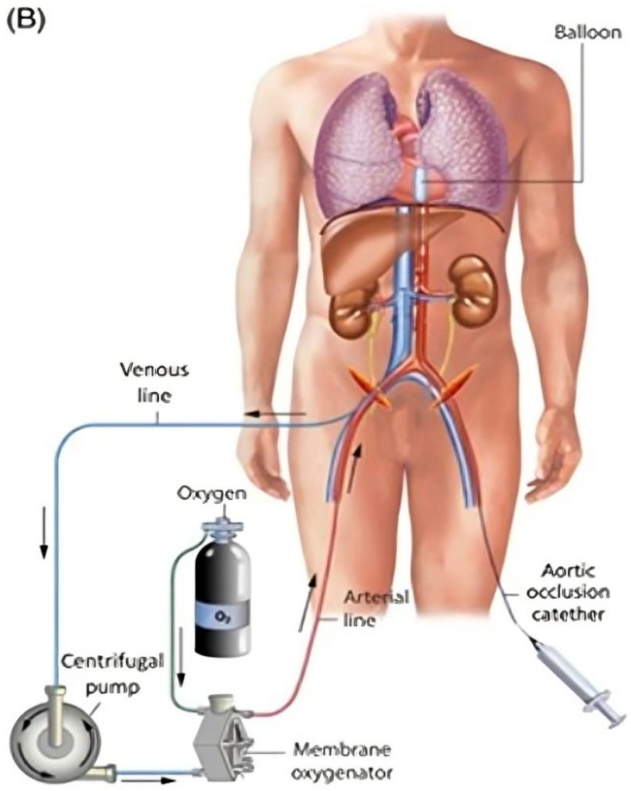
- obtain perfusion machines and related consumables for each major retrieval hospital; and
- ensure adequately trained staff to manage and coordinate perfusion.

Normothermic regional in-situ perfusion

11.44 Normothermic regional in-situ perfusion (NRP) is a medical technique used in organ transplantation to improve the quality and viability of organs before transplantation.

11.45 NRP involves maintaining an organ (usually the liver or kidneys) at or near normal body temperature while still inside the donor's body but disconnected from the donor's circulatory system. During this process, a solution is circulated through the organ's blood vessels to provide oxygen and nutrients and remove waste products. In practice, this involves using an Extracorporeal Membrane Oxygenation (ECMO) machine, which oxygenates blood at 37°C for around 2 hours.[338]

Figure 18. *Arrangements for abdominal normothermic regional perfusion in donation after circulatory death.*



[Source: C Fondevila et al.[339]]

[338] C Watson, *UK Protocol for Normothermic Regional Perfusion in controlled donation after circulatory determination of death version 1.10* , National Health Service Blood and Transplant, United Kingdom Government, 2023, accessed 18 Dec 23, p 6.

[339] C Fondevila et al., 'Practical considerations for implementation of abdominal normothermic regional perfusion', *Liver Transplantation*, 2023, 29(12):1255-1257.

11.46 This method is more favourable to organ preservation than the traditional SCS. It has demonstrated better outcomes for organ transplantation recipients by reducing organ damage, allowing for real-time organ viability assessment and enhancing graft survival.

11.47 Currently, NRP is mandatorily applied in DCD organ recovery in 3 European countries (Italy, France and Norway) and is permitted in 5 (Spain, the United Kingdom, Belgium, the Netherlands and Switzerland).[340]

11.48 The United Kingdom has a *Protocol for Normothermic Regional Perfusion in controlled Donation after Circulatory Determination of Death* (UK Protocol).[341]

11.49 The UK Protocol explains:

> NRP has been shown to increase the utilisation of all abdominal organs, and significantly improve the outcomes of liver and kidneys, with no adverse effects on the pancreas.
>
> This protocol details the technical aspects of the procedure. It is written with regard to the current legislation and observes the Academy of Royal Medical Colleges code of practice for the diagnosis and confirmation of death that forms the basis of organ donation from deceased donors.[342]

11.50 There are currently ethical and legislative barriers to using normothermic in-situ perfusion in Australia. The Department of Health advised the Committee:

> Recently, Health Ministers have requested of the Commonwealth Attorney General that priority be given to engage the ALRC to take once again take on the task of advising on harmonisation of the tissue and transplant legislation across the country. It is timely that this should happen. One example is the emerging problem of the definition of death. Other than death of the brain – or brain death – death is defined in legislation as the permanent cessation of the circulation. However, new techniques of organ support are predicated on artificially establishing local circulation to the donor organs while still in the body of the donor prior to organ retrieval. Currently in Australia, this approach is seen to be in conflict with the definition of death and therefore not able to be used. Research shows that this approach - normothermic in-situ perfusion - results in better recipient outcomes after transplantation.[343]

11.51 Prof Luc Delriviere, Head of Liver and Kidney Transplant Services, disagreed that abdominal normo-thermic perfusion was in conflict with the legal definition of death:

> We are asking for abdominal NRP…We are not reactivating the heart. It is just perfusion of the abdominal organ, so there is no contradiction with the death donor rule.
>
> …
>
> What we want to do, which is abdominal NRP, which is reanimation in the abdomen of the organs, does not interfere at all with the circulatory death or the

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340 R De Carlis et al., 'Abdominal normothermic regional perfusion in donation after circulatory death: Organ viability or organ preservation?', *European Journal of Transplantation*, 2023, Special Issue 2, August 2023.

341 C Watson, *National protocols, policies and reports*, National Health Service Blood and Transplant, 2023, accessed 18 Dec 23.

342 C Watson, *UK Protocol for Normothermic Regional Perfusion in controlled donation after circulatory determination of death version 1.10* , National Health Service Blood and Transplant, United Kingdom Government, 2023, accessed 18 Dec 23, p 6.

343 Submission 25 from Department of Health, 14 Apr 23, p 9.

> brain death of that patient. There is no reason why we should not be able to start now or we should not have been able to start three years ago. There are countries in Europe where it is now compulsory to have NRP for DCD donation.[344]

11.52 Western Australia has ECMO machines available in its ICU units and therefore the main costs would be consumables and trained staff:

> The cost of NRP in WA is low. It would probably bring us about six usable livers per year that currently we do not use. There are plenty of ECMO machines available because we bought quite a lot of them during the worst of COVID. They are mostly sitting in the corridors. The disposables are about $6 000 a case.[345]

11.53 In the Committee's opinion, research and clinical programs for normothermic in-situ perfusion should be supported and the removal of ethical and legislative barriers to using this technology in Western Australia be considered.

FINDING 19

Normothermic Regional Perfusion has been established as a procedure which allows longer total preservation times and could expand the donor pool by achieving higher organ utilisation rates.

RECOMMENDATION 14

The Department of Health advocate for the development of ethical and clinical guidelines for Normothermic Regional Perfusion to be incorporated into clinical practice.

RECOMMENDATION 15

In consultation with medical professionals, the Western Australian Government obtain legal advice about any legislative barriers to the use of Abdominal Normothermic Regional Perfusion and implement any necessary legislative amendments to remove identified barriers.

OrganMatch

11.54 OrganMatch is Australia's organ waitlisting and matching software system, and it was launched in 2019. [346]

11.55 OrganMatch enables clinicians to share time-critical information amongst tissue typing services, the DonateLife Network and transplant teams in all states.[347]

11.56 Transplant teams register a potential recipient's information, such as blood type, tissue type and medical conditions. This is then used to find a potential donor match. At the time of the organ retrieval surgery, the destination of the organ and what will be retrieved is known. If there is no suitable recipient, then the organs will not be retrieved.[348]

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344 Private hearing, Pr Luc Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, [*transcript of evidence*], *Legislative Council,* 29 Nov 23, pp 11-12.

345 Private hearing, Pr Luc Delriviere, Head of Liver and Kidney Transplant Services, Sir Charles Gairdner Hospital, [*transcript of evidence*], p 10.

346 Organ and Tissue Authority, *OrganMatch,* Donatelife, accessed 13 Sep 23. OrganMatch was developed in partnership with the Australian Red Cross Lifeblood.

347 Hon Dr David Gillespie, *Making matching more successful for people needing an organ transplant*, media statement, Former Minister for Regional Health, 31 January 2022; R Holdsworth, 'Implementation of a national organ matching and data system for Australian solid organ transplantation programs', *Transplantation*, 2020, 104(S3): S262.

348 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council,* 10 May 23, p 10.

11.57 In relation to the OrganMatch system, the OTA advised:

> OrganMatch…is fully operational now and really is able to drive better practices around allocation and matching in Australia. It is probably one of the best systems in the world at the moment.[349]

11.58 Some of the benefits of OrganMatch are:

- Shorter time frames to find recipients, as clinicians can share information in real time.
- Increased accuracy: OrganMatch can help increase organ matching accuracy by using a more sophisticated matching algorithm than previous systems, considering a more comprehensive range of factors.
- Improved communication: OrganMatch provides a single access point for clinicians to share live information about organ donors and recipients, improving communication between clinicians.[350]

11.59 Only 4.5% of OrganMatch users are Western Australian clinicians.[351]

11.60 The OTA explained this lack of uptake was due to a lack of education provided about the system:

> Numerous jurisdictions have taken up that option to waitlist into the system. WA has been a little bit behind in that uptake with clinicians, but that is about us educating. I have to say, we have not potentially been able to bring people in on the ground. Lifeblood runs OrganMatch, and they have a team that can do some education actually face-to-face on the ground. I am unsure whether WA has had that face-to-face, because it is much easier to learn the system if you are doing it together with that, but we would encourage all transplant clinicians to use OrganMatch as best practice. [352]

RECOMMENDATION 16

The Department of Health encourage the use of OrganMatch and facilitate face-to-face training on the OrganMatch system for all relevant healthcare professionals in Western Australia.

Expanding donor suitability criteria

11.61 Another option to expand the donor pool is to extend donor suitability criteria.

11.62 The Committee received evidence that Australia is conservative with the organs it uses for transplants and will often reject organs from older donors. Organs from older donors are not utilised because the aging process causes deterioration of organ function.[353]

11.63 The Organ and Tissue Authority advised the Committee that international jurisdictions will utilise donor organs that Australian clinicians typically reject:

> Countries like Spain and the UK have expanded donation practices so that they proceed with donation in circumstances that we do not necessarily in Australia.

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349 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, pp 12-13.

350 Organ and Tissue Authority, *OrganMatch,* Donatelife, accessed 13 Sep 23.

351 Submission 23 from Organ and Tissue Authority, 6 Apr 23, p 5.

352 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 13.

353 S Feng et al, 'Characteristics Associated with Liver Graft Failure: The Concept of a Donor Risk Index', *American Journal of Transplantation*, 2006, 6(4):783-790.

> They accept older donors and those with more health issues, and have also expanded practices to support the ability of people to donate via the circulatory death pathway to a greater extent than we have in Australia. With careful allocation of these organs, this can provide a benefit to those in need of transplant. For example, a kidney from a 70-year-old donor will enable a 70-year-old person to come off dialysis and have a good quality of life. Such a person in Australia may not currently get that opportunity and reduces the cost of dialysis on the health system. For the around 1 800 Australians currently on the organ transplant waitlist, it can be a matter of life and death.[354]

11.64 The OTA further noted:

> 57 per cent of donors in Spain are aged over 60, compared with approximately 30 per cent in Australia. One of the opportunities we would have in Australia, and this practice has been occurring, is to build our capacity to proceed with donating organs from older donors and those with other health conditions, and targeting the transplantation of those organs into perhaps older individuals who have the capacity to achieve a benefit. Certainly, that practice happens in Spain. It requires building transplant capacity. [355]

Spain

11.65 The Spanish coordination and transplantation system has progressively adopted more flexible criteria for donor selection. An 'old-for-old' allocation strategy has been devised, whereby older organs are preferentially allocated to older recipients.

11.66 Despite the definite risks that exist with older organs, the results in Spain have been acceptable and the practice confers survival benefits compared with patients on a waiting list.[356] In Catalonia, the probability of death for recipients of older organs is less than half of those receiving dialysis therapy and waitlisted for transplantation.[357]

11.67 In 2015, more than half of Spanish deceased donors were aged above 60 years: 30% were over the age of 70, and 10% were over 80.[358] These figures are far higher than the percentages recorded in most other countries in the same peer group.[359] The old-for-old system has resulted in a substantial number of donations. Donors over 60 are now contributing 41% of deceased kidney donations, 51% of liver donations, and 24% of lung transplants.[360]

FINDING 20

Expanding organ suitability criteria and adopting an 'old-for-old' approach to organ transplant can increase the donor pool and transplantation rates.

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354 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 4.

355 Dr H Opdam, National Medical Director, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Council,* 17 May 23, p 12.

356 R Matesanz et al, 'How Spain Reached 40 Deceased Organ Donors per Million Population', *American Journal of Transplantation*, 2017, 17(6):1447-1454.

357 MJ Pérez-Sáez et al, 'Survival Benefit From Kidney Transplantation Using Kidneys From Deceased Donors Aged ≥75 Years: A Time-Dependent Analysis', *American Journal of Transplantation*, 2016, 16(9):2724-2733.

358 R Matesanz et al, 'How Spain Reached 40 Deceased Organ Donors per Million Population', *American Journal of Transplantation*, 2017, 17(6):1447-1454.

359 Global Observatory on Donation and Transplantation, 2020 Activity Data Summary, 2022, accessed 10 Oct 23, p 5.

360 R Matesanz et al, 'How Spain Reached 40 Deceased Organ Donors per Million Population', *American Journal of Transplantation*, 2017, 17(6):1447-1454.

Licensed laboratories

11.68 The TGA sets certain standards for quality control of collected blood, cells and tissue. The TGA requires certain testing, such as nucleic acid testing (NAT)[361] and serology testing, to ensure diseases are not transmitted to recipients.

11.69 Currently, ocular tissue from donors that will be used solely for the purpose of corneal transplantation is exempt from certain NAT and serology testing requirements that apply to other human tissue. This is because corneal tissue is avascular.[362] However, the TGA is proposing amendments to require complete NAT and serology testing of corneal tissue from 2024.[363]

11.70 Lions Eye Bank advised the Committee that there are no TGA-accredited pathology services to perform NAT testing in Western Australia. Samples are sent to the National (Serology) Reference Laboratory (NRL) in Victoria,[364] which causes logistical issues, delays in results and a loss of some donors. Lions Eye noted this issue would continue growing as new testing requirements are implemented.

11.71 Establishing a TGA-approved pathology service for NAT testing in Western Australia would mitigate these issues and future-proof pathology services from unforeseen events or further pandemics. The biotechnologies sector in Western Australia would also be accelerated by improved access to NAT services.

FINDING 21

Using an interstate provider for nucleic acid testing (NAT) causes logistic issues and missed opportunities.

RECOMMENDATION 17

The Department of Health engage a Therapeutic Goods Administration-accredited pathology service for nucleic acid testing in Western Australia.

Notifications of death and the coronial system

Delays in referrals from the police

11.72 The Committee received evidence that the number of referrals and successful donation events occurring within the coronial system has declined.

11.73 Bone and tissue must be retrieved within 24 hours of the time the donor was 'last known to be alive'.[365]

11.74 PlusLife advised the Committee that the timeframe for police completing and lodging P98 forms has increased. The P98 form is an interim mortuary admission form, which triggers a

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361 Tests for infections that cannot be detected by routine screening or other diagnostic laboratories, such as HIV and hepatitis C.

362 The cornea has the unusual capacity to function without blood vessels. The lack of blood vessels keeps the eye clear for vision. As it had no blood vessels, its risk of carrying disease or infection is low.

363 Department of Health and Aged Care, Consultation: Remaking of standards and legislative instruments for human cell and tissue (HCT) products, blood and blood components, Australian Government, 2021, accessed 10 Oct 23.

364 NRL performs testing for blood-borne viruses for services and companies involved in cell and tissue banking for transplantation and cell therapies in Australia. Infection status of the blood product or tissue sample is confirmed via multiple assays (serology, NAT) prior to release for transfusion, transplantation and cell and tissue banking.

365 *Therapeutic Goods (Standard for Human Cell and Tissue Products—Donor Screening Requirements (TGO 108) Order 2021* s 4.

referral to DonateLife WA. In their submission, PlusLife explained that delays reduce the likelihood of donation:

> Delays in the lodgement of a P98 form dramatically reduce the likelihood of successful bone and tissue donation. Presently the median time between certification of life extinct and lodgement of the P98 form is 10.9 hours…This leaves little time to collect information to determine medical suitability, approach the family for consent and mobilise a retrieval team and perform the retrieval of bone and tissue from the donor.[366]

11.75 Some causes of death, such as motor vehicle accidents, are no longer represented in the donations sourced through the coronial system due to the time elapsed before submission of the P98.[367]

FINDING 22

Delays in the lodgement of a P98 form by police dramatically reduce the likelihood of successful bone and tissue donation.

RECOMMENDATION 18

Western Australia Police introduce and enforce minimum target times for the lodgement of a P98 form following certification of life extinct.

Authorisations from the coroner for organ and tissue donation

11.76 The State Coroner is responsible for investigating all reportable deaths and where appropriate, arranging autopsies, examinations and inquests. The Coroner carries out their functions under the *Coroners Act 1996*.

11.77 Reportable deaths include but are not limited to those:

- which appear to have been unexpected, unnatural or violent or to have resulted from injury;
- which occurs during an anaesthetic;
- of a person who immediately before death was a person held in care;[368]
- that appears to be caused or contributed to by any action of a member of the Police Force; and
- of a person of unknown identity.[369]

11.78 When a designated officer for a hospital believes a death is or may be a reportable death, they must obtain the Coroner's consent before any retrieval of organs or tissue takes place.[370]

11.79 The Committee heard anecdotal evidence that there has been an increase in the Coroner refusing consent for organ and tissue donation. However, this data is not formally collected.

11.80 Dr Simon Erickson, Head of Critical Care at Perth Children's Hospital advised:

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366 Submission 22 from PlusLife, 3 Apr 23, p 2.

367 Submission 22 from PlusLife, p 2.

368 For example, children in state care, people in custody and involuntary patients under the *Mental Health Act 1996*.

369 *Coroners Act 1996* s 3.

370 *Human Tissue and Transplant Act 1982* s 23.

> we need to discuss the cases with the coroner for all accidental or unexpected deaths. We are just finding over the last couple of years that we are being denied the possibility of the families donating because it is a coronial case and the Chief Pathologist has not allowed us to progress with organ donation…But this is a new thing which has happened over the last two or three years. On speaking to [other] intensivists, it is also a problem for them. We are just finding that that has been at bit of a difficulty for us and there have been moments when families have wanted their child to donate organs where we have been unable to do that, and obviously potential organ recipients miss out on that.[371]

11.81 Dr David Blythe, State Medical Director, DonateLife WA noted:

> we do not routinely collect complete data on the number of Coronial refusals as it has been a fairly unusual event. The records we have indicate between zero and two refusals a year. This year so far there have been at least eight. I have spoken to my colleagues interstate and this seems to be an unusually high rate of refusal. However, I would emphasise that the data should be treated with caution, and it may be that the Coroner has more systematically collected and reliable numbers to guide the Inquiry.[372]

11.82 Principal Registrar of the Coroner's Court, Kelly Niclair, advised that data on the number of times a coroner's authorisation has been requested, and the times a coroner's authorisation has been declined, cannot be extracted from the Integrated Court Management System.[373]

RECOMMENDATION 19

The Department of Health and DonateLife WA collect data on the number of requests made for Coroner's authorisation for organ donation, the outcome of each request and the reason given for any refusals.

Post-mortems as a barrier

11.83 The Coroner may authorise a post-mortem examination to determine the cause of death or factors which contributed to death.

11.84 A full post-mortem examination (or autopsy) involves an internal and external examination of the body. During the internal examination of the body, organs, tissues and bodily fluids are examined for any abnormalities, such as blood clots or tumours. Small samples may be taken for laboratory analysis. After being examined, the organs are returned to the body.

11.85 For non-contentious cases, a limited post-mortem examination is usually conducted, with only the outside of the body being examined. A limited (or external-only) post-mortem examination does not inspect inside a deceased's body.

11.86 A full post-mortem examination of a deceased is required before a deceased's tissue and bone can be transplanted. This is to ensure no undetected potentially transmissible diseases are present.

11.87 PlusLife explained:

> The State Coroner has aligned its processes with the Law Reform Commission of Western Australia – Review of Coronial Practice in Western Australia Final Report recommendation 101. For cases that appear non-contentious, if data can be

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371 Dr S Erickson, Head of Department, Critical Care, Perth Children's Hospital, private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 2.

372 Email from Dr David Blythe, State Medical Director, DonateLife WA, 4 Dec 23, p 1.

373 Letter from Kelly Niclair, Principal Registrar, Coroner's Court of Western Australia, 23 Oct 23, p 3.

provided by a limited examination for coronial purpose then the least-invasive procedure should be considered. In practice this has seen an increasing use of external post mortem examinations supported by the use of a CT scanner.

PlusLife requires an internal post mortem examination to remove the risk of undetected potentially transmissible occult diseases being present in the donor at the time of death. These diseases cannot be detected by external examination and the use of a CT scanner.

As a consequence of the increasing trend towards external post mortem examinations the pool of otherwise potential bone and tissue donors has decreased.[374]

11.88 Section 34(1) of the *Coroners Act 1996* provides power for the Coroner to request a post-mortem examination if they reasonably believe that it is necessary to investigate a death. This means a Coroner cannot authorise an internal post-mortem examination solely to facilitate tissue and bone donation, even if there is family consent and the deceased expressed a wish to donate.

11.89 The Committee considers it appropriate to provide discretionary power for the Coroner to authorise internal post-mortem examinations to facilitate bone and tissue donation, with the consent of the next-of-kin. This power could be used in circumstances of high demand for tissue and bone.

FINDING 23

Under the current legislation, the Coroner is unable to conduct internal post-mortem examinations for the purpose of tissue and bone donation, and this limits the potential donor pool.

RECOMMENDATION 20

The Western Australian Government investigate amending the *Coroner's Act 1996* to provide the Coroner with a discretionary power, with the consent of the next-of-kin, to conduct an internal post-mortem examination for the purpose of tissue and bone donation.

Voluntary assisted dying

Summary

11.90 All Australian states have VAD legislation. VAD legislation is still relatively new in Western Australia and the current legislation does not make any provision for organ donation.

11.91 In Western Australia, a person is eligible for VAD when they have been diagnosed with an incurable disease that is advanced and progressive and they are experiencing suffering that cannot be relieved in a manner they deem tolerable.[375]

11.92 There is an opportunity to offer and facilitate organ and tissue donation from VAD patients in Western Australia.

11.93 Victoria is the only state which has facilitated organ donation after VAD. In 2023, Victorian woman Marlene Bevern, who had an aggressive form of Motor Neurone Disease, became the first Australian to become an organ donor after VAD, having donated her lungs, liver and kidneys.[376]

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374 Submission 22 from PlusLife, 31 Mar 23, pp 2-3.

375 *Voluntary Assisted Dying Act 2019*, s 16.

376 Organ and Tissue Authority, *Australian first – Victorian woman donates organs after Voluntary Assisted Dying*, media statement, 2023, accessed 2 Oct 23.

The opportunity

11.94 About 10% of patients who undergo VAD are potentially eligible to donate organs. Most of these patients have neuro-degenerative disease.[377]

11.95 Patients who undergo VAD may be potential donors due to:

- control/predictability over time of death;
- death occurs in a similar way to the circulatory death pathway after withdrawal of life-sustaining treatment;[378] and
- the patient can provide first-person, contemporaneous consent.

11.96 It is acknowledged that organ donation will not be suitable for some patients because it will have implications on the place and mechanism of death, which may not otherwise be appealing to VAD patients. Patients who wish to donate organs would be required to utilise VAD in a hospital setting. This would not be necessary for eye and tissue donation, as this has a longer retrieval window.

11.97 The practical and ethical considerations of organ donation after VAD, and the risk of 'contamination' of organ donation with the decision to access VAD were discussed in one journal as follows:

> This risk will be minimised by the objective and strict eligibility criteria for VAD as well as by delaying any discussions about donation until after eligibility is confirmed. Finally, there is a possibility that someone deemed eligible for VAD will end their lives prematurely purely in order to support a wish to be a donor. This may be seen as a legitimate part of the decision making of the person or as a risk that will, at least in part, be reduced by continuing to disallow directed donation.[379]

11.98 The Department of Health supported the opportunity for VAD patients to donate at the end of their life, should they wish to do so:

> This situation provides unequivocal first-person consent and in the presence of the family. We need to be ready to support those generous people facing their own death who wish to consider organ and tissue donation. WA has been a leader in Australia in end-of-life care over recent years. There is another opportunity here whilst we continue to respect the choice of people and professionals not to participate in VAD. From the publication of the VAD Board about VAD in WA from July 2021 to June 2022, of the 190 people who died by administration of the VAD substance, 77% died by injection of the VAD substance which, if it occurs in a hospital that can support DCD, would allow for safe and effective organ donation. Based on the data in the VAD report we surmise that possibly 25-35 persons in that year would likely have been eligible to be organ donors.[380]

11.99 During the Committee's site visits to the Lions' Eye Bank and PlusLife, both called for the opportunity for VAD patients to donate eye and tissue after death. PlusLife, in their written submission, advised:

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377 S Philpot, 'Organ donation after circulatory death following voluntary assisted dying: practical and ethical considerations for Victoria', *Critical Care and Resuscitation*, Dec 2018, 20(4):254-257.

378 S Philpot, 'Organ donation after circulatory death following voluntary assisted dying: practical and ethical considerations for Victoria'.

379 S Philpot, 'Organ donation after circulatory death following voluntary assisted dying: practical and ethical considerations for Victoria'.

380 Submission 25 from Department of Health, 14 Apr 23, p 20.

> Adding the option of donation within this pathway will increase the pool of potential donors and support consenting Western Australians to donate organs and tissue after death.[381]

International approach

11.100 Currently, organ donation after VAD is available in Belgium, the Netherlands, Spain and Canada.

11.101 From 2012 to January 2022, the number of organ donations after VAD[382] by country was:

- The Netherlands: 85;
- Spain: 49 (7 in 2021 and 42 in 2022);
- Canada: 136; and
- Belgium: 50.[383]

11.102 DCD following VAD in Australia appears both legally and clinically feasible.

Table 20. *Countries with voluntary assisted dying legislation which facilitate organ donation*

Country	VAD Legislation
The Netherlands[384]	Symptom state: Unbearable suffering with no prospect of improvement. Specific medical conditions: N/A Life expectancy requirement: N/A
Spain[385]	Symptom state: Constant and unbearable physical or psychological suffering. Specific medical conditions: Severe and incurable illness or severe, chronic, and disabling condition. Life expectancy requirement: N/A
Canada[386]	Symptom state: Intolerable physical or psychological suffering that cannot be relieved in a manner the person considers acceptable. Specific medical conditions: A serious and incurable illness, disease, or disability, not solely psychiatric. Life expectancy requirement: N/A
Belgium[387]	Symptom state: Unbearable physical or psychological suffering. Specific medical conditions: N/A Life expectancy requirement: Terminal or nonterminal.

FINDING 24

There is a need to identify and support the potential for organ donation as part of the Voluntary

[381] Submission 22 from PlusLife 3 Apr 23, p 5; Discussions during the Committee's site visits on 4 May 23.

[382] Although the Australian legal term is 'voluntary assisted dying', it is internationally known as assisted suicide when medication is self-administered and euthanasia when administered intravenously by a physician.

[383] J Bollen et al., 'Feasibility of organ donation following voluntary assisted dying in Australia: lessons from international practice', *Medical Journal of Australia*, 2023, doi: 10.5694/mja2.52016.

[384] *Termination of Life on Request and Assisted Suicide Act 2000* (Netherlands) article 2(1).

[385] *Organic Law 3/2021 of the Regulation of Euthanasia in Spain 2021* (Spain) article 3(c).

[386] *Bill C-14 2016* (Canada) s 241.

[387] *The Belgian Act on Euthanasia 2002* (Belgium) s 3.

Assisted Dying process. All eligible patients accessing Voluntary Assisted Dying should be offered the opportunity to receive information and make an autonomous decision about organ donation.

RECOMMENDATION 21

The Department of Health advocate for ethical and clinical guidelines to be developed by the National Health and Medical Research Council and The Transplantation Society of Australia and New Zealand for organ and tissue donation after Voluntary Assisted Dying.

As soon as possible after these guidelines are developed, the Western Australian Government amend the *Voluntary Assisted Dying Act 2019* and the *Human Tissue and Transplant Act 1982* to incorporate provisions to legislate:

- the right of patients accessing Voluntary Assisted Dying to become organ and tissue donors; and
- record-keeping and reporting requirements for patients donating organs and tissue after accessing Voluntary Assisted Dying.

CHAPTER 12
Funding

Chapter summary

12.1 This chapter summarises the funding structure for organ and tissue donation in Western Australia.

12.2 The OTA administers financial grants to states/territories for organ donation services, staffing, infrastructure, family support, and data reporting. Grants aim to implement a nationally coordinated approach to organ and tissue donation for transplantation.

12.3 Funding is provided to the Department of Health through funding agreements, which typically span 3 years. The current funding agreement is from 1 July 2023 to 30 June 2026.

12.4 The current funding agreement provides the following:

- a maximum amount of $3.3 million, which supports 18.1 FTE DonateLife WA agency staff positions; and
- contribution towards the costs associated with organ donation activity, paid on an activity basis. In 2022-23, this amounted to $670,000.

12.5 All future funding agreements are subject to negotiations between the Commonwealth and the Western Australian Government.

12.6 DonateLife WA staff express concerns about inadequate staffing levels affecting various aspects of their work, noting:

- lack of administrative support hampers effective use of staff time; and
- there is a need for more managerial support.

Funding provided by the Organ and Tissue Authority to the states and territories

12.7 The OTA administers grants of financial support to state and territory governments for the delivery of organ donation services:[388]

> The CEO may, for example, make a grant to:
>
> - employ medical specialists and other hospital staff who are dedicated to increasing organ and tissue donation for transplantation;
> - meet the additional staffing, bed and infrastructure costs associated with organ donation;
> - provide a national program of support for families of deceased donors; and
> - provide activity data and other performance indicators.
>
> These grants will assist in the implementation and maintenance of a world's best practice, nationally coordinated approach to organ and tissue donation for transplantation.[389]

[388] *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth) ss 54-55.

12.8 The OTA receives around $54 million in funding annually from the Commonwealth Government, of which around $48 million is distributed onwards through grants to the states and territories.[390]

12.9 The grant terms and conditions must be set out in a written agreement between the Commonwealth and the state or territory.[391]

12.10 There are 2 types of funding agreements entered into between the Commonwealth and each state and territory:

- DonateLife Network state and territory grants (S&T grants); and
- organ donation hospital support funding (ODHSF).

Organ donation hospital support funding

12.11 ODHSF grants contribute towards the costs associated with organ donation activity up to the point of the commencement of the donation procedure. The funding agreement is entered into with jurisdictional health departments.[392]

12.12 The dollar value of the grant is based on the number of actual and intended organ donors and the cost of transferring an intended donor from a regional hospital to a larger hospital solely for organ donation. The number of actual and intended organ donors is calculated pursuant to data provided by the Australian and New Zealand Organ Donation Registry (ANZOD).[393]

12.13 The OTA provided a total of $6.7 million of ODHSF to states and territories for the 2022-2023 financial year.[394]

12.14 During its hearing with the Victorian Legal and Social Issues Committee, the OTA explained:

> The organ donation hospital funding is activity based. It is payment for jurisdictions to help support the extra care required for donation to proceed.[395]

State and territory grants

12.15 In addition to ODHSF grants, the OTA provides funding to states and territories through multi-year head agreements and funding schedules. These grants are known as S&T grants.

12.16 The purpose of S&T grants is to support each state and territory in implementing the national organ and tissue service delivery model in the public hospital sector (and where mutually agreed, in the private hospital sector).

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389 Australian Organ and Tissue Donation and Transplantation Authority Bill 2008, *Explanatory Memorandum*, House of Representatives, p 24.

390 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee Victoria,* 23 Jun 23, p 16.

391 *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (Cth) ss 54-55.

392 Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, Australian Government, 2015, accessed 13 Sep 23, p 47; Legal and Social Issues Committee, answer to question on notice, Inquiry into increasing the number of registered organ and tissue donors, Victoria, Legislative Assembly, June 2023, p 1.

393 Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, p 47; Legal and Social Issues Committee, answer to question on notice, Inquiry into increasing the number of registered organ and tissue donors, p 1.

394 Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority, Answer to Question on Notice no. 1, asked at hearing held 23 Jun 23, dated Jun 23, p 1.

395 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee Victoria,* 23 Jun 23, p 16.

12.17 In practice, S&T grants provide funding to operate the DonateLife agencies of each state and territory and dedicated donation specialist staff in hospitals.

12.18 The OTA contributed a total of $31.2 million in funding to states and territories for S&T grants in 2022-2023.[396]

12.19 S&T grants meet the definition of 'grant' under the Commonwealth Grant Rules and Guidelines. The OTA must publicly report certain details (such as value, term and recipient) of all grants within 14 days of agreement execution. These grants are published on the Australian Government Grant Connect database.

Funding received by Western Australia

12.20 The current funding agreement between the Department of Health and the OTA is for the period 1 July 2023 to 30 June 2026.[397]

12.21 The current funding agreement provides the following:

- an S&T grant to a maximum amount of $3.3 million, which supports 18.1 FTE DonateLife WA agency staff positions; and
- ODHSF contribution towards the costs associated with organ donation, which is paid on an activity basis. In 2022-2023, this amounted to $670,000.[398]

12.22 Table 21 itemises the funds that may be paid by the OTA to the Department of Health pursuant to the OHDSF funding agreement.

Table 21. *Funds payable by the Organ and Tissue Authority to the Department of Health for organ donation hospital support funding pursuant to the current funding agreement*

Payment type	Funds payable (GST exclusive)
Actual organ donor	$10,000 per actual organ donor
Intended organ donor	$10,000 per intended organ donor
Regional transfer for the purpose of donation	$8,000 per regional transfer

[Source: Organ and Tissue Authority.[399]]

12.23 The funding for states and territories was originally based on a population-based formula. However, the OTA is working towards activity-based funding, with consideration of factors such as the number of:

- intended donors and actual donors within the state; and
- hospitals, their location and regional services.[400]

396 Legal and Social Issues Committee, answer to question on notice, Inquiry into increasing the number of registered organ and tissue donors, Victoria, Legislative Assembly, June 2023, p 1.

397 Letter from Lucinda Barry, Chief Executive Officer, Organ and Tissue Authority dated 15 Nov 23, p 3.

398 Letter from Organ and Tissue Authority, p 3.

399 Letter from Organ and Tissue Authority, p 3.

400 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee Victoria,* 23 Jun 23, p 17.

12.24 Funding distribution for staffing is normally determined by the particular state or territory based on where the main donation activity occurs:

> Part of that funding [funds] a DonateLife agency in each state and territory, which includes a DonateLife manager, a state medical director which is a fractional position. It includes specialist nursing staff…donor family support, education, community awareness programs and data analytics.[401]

12.25 The OTA advised the Committee that if Western Australia adopted a significant policy change that departed from the national program, the existing funding arrangement would need to be reviewed:

> All future funding agreements are subject to negotiations between the Commonwealth and the Western Australian governments. A significant policy change in Western Australia would require a review of the existing funding arrangements.[402]

FINDING 25

If Western Australia adopted a significant policy change departing from the national program, the existing finding arrangement between the Western Australian Government and the Organ and Tissue Authority would need reviewing.

12.26 In relation to the funding agreements between the OTA and states and territories, the 2015 review of the national implementation process noted:

> Some jurisdictions expressed concern that they were not receiving their fair share of the State and Territory funding. The Review noted that this State and Territory funding was allocated on the basis of long standing arrangements between the Commonwealth, states and territories in 2014/15 but it is difficult to ascertain this from the mandatory reports published on the OTA web site. It would assist all states and territories to understand the fairness of the allocation of the State and Territory Funding if it was clearly published on the OTA web site as a consolidated table indicating the funding share by jurisdiction including the 2015/16 allocation.[403]

12.27 In comparison, Victoria currently has funding in place for 38.8 FTE for the DonateLife network.[404]

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401 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee Victoria,* 23 Jun 23, p 17.

402 B Small, Acting Chief Executive Officer, Letter of correction to transcript for hearing held 24 May 23, dated 31 May 23, p 1.

403 Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, Australian Government, 2015, accessed 13 Sep 23, p 47.

404 L Barry, Chief Executive Officer, Organ and Tissue Authority, [*transcript of evidence*], *Legislative Assembly Legal and Social Issues Committee Victoria,* 23 Jun 23, p 17.

Figure 19. *Funding provided from the Organ and Tissue Authority to each state and territory for 2018 to 2022.*

Year	Funding ($m)	VIC	ACT	NSW	QLD	SA	WA	TAS	NT	Total
2022-23	S&T Grants	7.682	1.151	8.398	5.282	2.989	3.156	1.374	1.211	**31.243**
	ODHSF	1.890	0.110	1.750	1.350	0.638	0.670	0.240	0.020	**6.668**
	Total	**9.572**	**1.261**	**10.148**	**6.632**	**3.627**	**3.826**	**1.614**	**1.231**	**37.911**
2021-22	S&T Grants	7.495	1.124	7.837	5.019	2.926	2.926	1.341	1.181	**29.849**
	ODHSF	1.680	0.100	1.470	1.130	0.580	0.648	0.160	0.020	**5.788**
	Total	**9.175**	**1.224**	**9.307**	**6.149**	**3.506**	**3.574**	**1.501**	**1.201**	**35.637**
2020-21	S&T Grants	7.045	1.117	7.729	4.932	2.894	2.955	1.260	1.293	**29.225**
	ODHSF	1.770	0.110	1.530	1.330	0.660	0.600	0.148	0.030	**6.178**
	Total	**8.815**	**1.227**	**9.259**	**6.262**	**3.554**	**3.555**	**1.408**	**1.323**	**35.403**
2019-20	S&T Grants	7.663	1.181	8.260	5.176	3.026	3.281	1.472	1.187	**31.247**
	ODHSF	2.000	0.180	1.600	1.360	0.620	0.584	0.188	0.020	**6.552**
	Total	**9.663**	**1.361**	**9.860**	**6.536**	**3.646**	**3.865**	**1.660**	**1.207**	**37.799**
2018-19	S&T Grants	7.280	1.142	6.125	4.905	2.899	3.129	1.301	1.026	**27.809**
	ODHSF	2.590	0.140	1.900	1.210	0.680	0.712	0.190	0.050	**7.472**
	Total	**9.870**	**1.282**	**8.025**	**6.115**	**3.579**	**3.841**	**1.491**	**1.076**	**35.281**

[Source: Organ and Tissue Authority.[405]]

DonateLife WA

12.28 DonateLife WA staff told the Committee they do not have adequate staffing levels.

12.29 Staff explained the following situation to the Committee:

> We are impeded by not having adequate staffing, I believe, not only from clinical, as in the nursing and the donation side, but also administratively.
>
> …
>
> With the structure itself, we need more help in the management field so that the manager can get stuff done.[406]

12.30 Another staff member agreed to this assessment and advised:

> I think the way that we manage our staffing within the ICU and the on-call system works well for the Perth metro area, but compared to our eastern states colleagues, I think we are very under resourced. We are the poor state in that regard.[407]

12.31 The importance of the role of DonateLife WA staff, particularly in relation to increasing family consent rates, is discussed in Chapter 6.

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[405] Organ and Tissue Authority, Answer to question on notice 1 asked at hearing held by Legislative Assembly Legal and Social Issues Committee, 23 Jun 23, p 2.

[406] Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, pp 6-7.

[407] Private hearing [*transcript of evidence*], *Legislative Council,* 20 Sep 23, p 7.

FINDING 26

Involvement of DonateLife WA staff in the organ donation process has proven to increase family consent rates and increase deceased transplantation rates. DonateLife WA should be adequately resourced to implement the National Organ and Tissue Donation strategy.

RECOMMENDATION 22

The Department of Health and DonateLife WA in collaboration with DonateLife staff and management, review the staff funding requirements of DonateLife WA and re-negotiate additional funding from the Organ and Tissue Authority.

CHAPTER 13
Data, measuring and reporting

Chapter summary

13.1 The chapter summarises the available data on the ANZOD and OTA websites and existing gaps in reported information.

13.2 Donation rates and adherence to best practice guidelines vary across hospitals. Hospital-specific data is not currently published. NHS Blood and Transplant publishes regional reports with hospital-specific datasets.

13.3 This chapter ultimately recommends improved data transparency by publishing specific benchmarks on the OTA website, such as family authorisation rates, DonateLife WA staff presence during donor family conversations and detailed AODR statistics.

13.4 Overall, the benefits of increased data access include removing data silos, promoting research, empowering communities and enhancing public accountability.

Data relating to organ donation

Australian and New Zealand Organ Donation Registry

13.5 Data is crucial to identifying opportunities for improving the organ and tissue donation and transplantation system.

13.6 The ANZOD collects and records data on deceased donors and a wide range of statistics about organ donation and transplant activities.

13.7 ANZOD operates a website that produces annual reports, monthly data summaries and transplant waitlisting activity. ANZOD's monthly reports contain data on the total amount of:

- deceased organ donations;
- transplant recipients from deceased organ donors;
- organs transplanted from deceased organ donors;
- organs transplanted by organ type;
- transplantation procedures from deceased organ donors; and
- transplantation following circulatory death.

13.8 ANZOD also produces information about the organ donation waitlist.[408]

13.9 However, ANZOD data is not well known and can be difficult to find. It is recommended that links be provided on the OTA website directing users to the ANZOD website, especially for waitlist information.

Organ and Tissue Authority

13.10 The OTA produces an annual 'Australian Donation and Transplantation Activity Report' in collaboration with the donation and transplantation sector. The data provided in the Activity

[408] See para 4.7 to 4.12.

Report contains a snapshot of key metrics on organ, eye and tissue donation from living and deceased donors. It also provides data on consent rates and registration rates.[409]

13.11 The OTA also publishes an annual report, which is used to report progress in delivering the national program and inform future direction.

13.12 The OTA collects data about all organ donation events from deceased donors through an electronic registry called the Electronic Donor Record (EDR). The EDR was launched in 2014 and is an online medical record platform used to collect and document information about potential donors. Once this information is collected, referrals to transplant centres can be made, potential donor recipients identified, and retrieval surgeries planned.[410]

Audits of transplantation and retrieval activity in Western Australia

13.13 The OTA provides regular performance reports to states and territories. These reports capture key metrics for donation activity. They identify processes that can be improved at the individual hospital level to achieve best-practice organ and tissue donation.

13.14 The Department of Health advised the Committee that:

> At the state level, there is a regular audit of all cases where a patient has died in the intensive care unit or the emergency department of one of our donation hospitals. When a decision is made to withdraw life-sustaining treatments, the audit captures whether the patient was notified to the DonateLife team and whether the Australian Organ Donor Registry was checked to determine if the person was registered. If a family discussion is initiated about organ and tissue donation, the audit records whether a trained donation specialist nurse participated in the discussion. From the data that includes a demographic profile of every patient, a prospective estimate of the likely consent rate for each hospital can now be modelled on the whole national dataset.[411]

13.15 The performance reports are not publicly available.

FINDING 27

The Organ and Tissue Authority's regular performance reports are not publicly available.

Gaps in the data reported

13.16 The information that is published is silent on several key issues.

13.17 Increasing the availability and type of data available is important to maintaining trust, accountability, and transparency in the organ donation sector.

13.18 The following data is not readily available, nor is it easily accessible to the public:

- referral rate (number of patients who met referral criteria, number of patients actually referred) by jurisdiction;
- waitlist data broken down by ethnicity, including specific waitlist data for Aboriginal and Torres Strait Islanders;
- consent/authorisation rate:

409 Queensland Health, *Organ and tissue donation for transplantation*, Queensland Government, 2023, accessed 10 Oct 23.

410 New South Wales Government, *Reducing the timeframe to complete the electronic donor record*, NSW Organ and Tissue Donation Service, 2018, accessed 20 Oct 23.

411 Dr S Towler, Former State Medical Director, DonateLife WA, [*transcript of evidence*], *Legislative Council*, 10 May 2023, p 4.

- DonateLife WA staff present; and
- DonateLife WA not present;

- unit where the patient was referred from (ICU, ER, coroner, other);
- primary reason why the family did not give consent for organ donation;
- consent (authorisation) rates for each jurisdiction and each hospital; and
- in relation to the AODR:
  - number of opt-in and opt-out registrations by jurisdiction;
  - information on the types of organs the potential donor has nominated to donate ('all' or specific);
  - source or pathway to registration on AODR (DonateLife website, MyGov, etc.);
  - age and gender at registration on the AODR; and
  - breakdown of registration by ethnicity and age group.

FINDING 28

Australia could collect and publish more comprehensive data on organ and tissue donation and transplantation.

RECOMMENDATION 23

The Western Australian Government advocate for the Organ and Tissue Authority to:

- collect further data relating to:
  - the demographics of individuals on the organ and tissue donor waitlist;
  - the Australian Organ Donor Register, including the demographics of registered persons and the number of opt-out registrations; and
- publish this information in a central location.

Hospital data

13.19 Donation rates and adherence to the best practice guidelines for offering organ donation differ between hospitals. Reports on hospital performance are not published.

13.20 The 2015 review of the national reform agenda considered whether hospital data should be published.[412] The review noted there were concerns that the variable nature of each hospital (size, ethnicity of patients, location) would impact the accuracy or meaningfulness of performance data. Those in favour of publishing hospital donation performance believed greater transparency would enable a greater understanding of national performance and benchmarking to encourage improvement.[413]

13.21 The Committee considers publishing hospital data appropriate, for example, the number of conversations taking place in collaboration with donation specialist staff.

[412] Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*, Australian Government, 2015, accessed 13 Sep 23, p 48.

[413] Department of Health, *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation*.

13.22 The NHS Blood and Transplant publishes regional reports with hospital-specific datasets. The NHS Blood and Transplant publish reports annually on the performance benchmarks of referral of potential deceased organ donors, presence of specialist nurses during organ donation discussions with families, neurological death testing, consent/authorisation rates and the registration status of the donor.[414] Similar data should be published by the OTA.

Canadian data

13.23 Canada has an interactive online platform that reports national performance data for organ donation and transplantation in Canada. Data for each province is also provided.[415]

13.24 In 2019, Health Canada approved multi-year funding for the Pan-Canadian Organ Donation and Transplantation (ODT) Data and Performance Reporting System Project (Project), co-executed by the Canadian Institute for Health Information (CIHI) and Canada Health Infoway.

13.25 The Project objectives include developing and reporting performance indicators and measures and designing and developing data access capability and services for decision-making, policy development, research, and innovation.

13.26 The Project is currently underway, and several indicators have been prioritised, such as missed referral rates and approach rates.[416]

Spanish data

13.27 The Spanish National Transplant Organisation publishes extensive donation and transplant activity data. Data is provided for each region in Spain, and deceased donation activity by hospital is published.[417]

FINDING 29

The United Kingdom and Spain record and publish detailed hospital-specific data relating to organ and tissue donation and transplantation performance benchmarks.

13.28 The benefits of increased access to data include:

- removal of data silos;
- fewer requests or queries about specific datasets;
- promoting further research;
- providing easy-to-access preliminary information for pilot studies and grant applications;
- empowering local communities to see which issues affect them and to take action;
- various uses for the general public, health departments, community groups, journalists and researchers; and
- public accountability and transparency.

414 National Health Service Blood and Transplant, *Regional Reports*, Organ Donation and Transplantation Clinical, 2023, accessed 21 Oct 23.

415 Canadian Blood Services, *System Progress Data Dashboard*, 2021, accessed 17 Nov 23.

416 Canadian Institute for Health Information, *Pan-Canadian Organ Donation and Transplantation Prioritized Indicators*, 2023, accessed 17 Nov 23, p 10.

417 National Transplant Organisation (Spain), *Donation and Transplant Activity in Spain 2022*, 2022, accessed 17 Nov 23.

FINDING 30

Recording and publishing hospital-specific data relating to organ and tissue donation and transplantation performance benchmarks is appropriate.

RECOMMENDATION 24

The Western Australian Government advocate for jurisdiction and hospital-specific data to be published on the Organ and Tissue Authority website in an easily accessible and user-friendly format, relating to the following performance benchmarks:

- referral of potential deceased organ donors;
- the presence of DonateLife staff during organ donation discussions with families;
- neurological death testing; and
- family consent rates and the registration status of the potential donor.

CHAPTER 14
Education, campaigns and the media

Chapter summary

14.1 This chapter focuses on education opportunities and media engagement, such as:

- providing education to school students;
- including organ and tissue donation in all medical school curriculums; and
- developing communication policies to assist the media in handling information about donation and transplantation accurately and appropriately.

14.2 The OTA coordinates ongoing professional development for clinicians involved in donation and offers various professional training courses about organ and tissue donation.

14.3 Increasing curriculum content about organ and tissue donation for medical and allied health workers would be beneficial.

14.4 Education in schools corrects misconceptions and promotes organ and tissue donation.

14.5 This chapter outlines strategies for improving organ donation, focusing on communication, education for healthcare professionals and schools, cultural competency, OTA training and community education through media strategies.

Education of healthcare works

14.6 Emergency physicians, intensivists, nurses, social workers and other allied health staff are essential in providing information and supporting families through the donation process.

14.7 Healthcare professionals need accurate and current knowledge about organ and tissue donation to provide optimal support for a patient's family. Understanding the ethnic, cultural, and religious context in which such attitudes are formed and held is also essential.[418]

Nurses

14.8 In 2019, an Australian study examined the self-reported knowledge, attitudes, education and support of perioperative nurses in relation to their participation in organ donation and procurement surgery.[419] Responses from 4000 members of the Australian College of Perioperative Nurses found that:

- Education was often lacking or brief and limited to attendance at day-long seminars or workshops on donation and transplantation. There was no emphasis on preparing health professionals adequately for their participation in these procedures.
- Uncertainty about their professional role in procurement surgery, the surgical procedure itself and the surgical requirements necessary to undertake these procedures.

[418] R Jenkin et al., 'Altruism in death: Attitudes to body and organ donation in Australian students', *Anatomical Sciences Education*, 2023, 16(1):27-46.

[419] Dr Z Smith, 'Australian perioperative nurses' attitudes, levels of knowledge, education and support needs related to organ donation and procurement surgery: A national survey', *Journal of Perioperative Nursing*, 2019, 32(2):2.

- The study suggested that health services support implementing a national OTA perioperative nursing education program. The Committee understands this has since been implemented.[420]

Medical schools

14.9 Three universities offer medical degrees in Western Australia, and the extent to which they incorporate organ and tissue donation into their curriculum is outlined below.

14.10 Training of medical students is important to:

- integrate organ and tissue donation as a natural extension of end-of-life care in Australia;
- help students become disseminators of information about the topic to their friends, family and the general community; and
- implement culture change.

University of Notre Dame Australia

14.11 Organ and tissue donation education and training is incorporated into the curriculum for medical students (Doctor of Medicine program) at the University of Notre Dame Australia, Fremantle.

14.12 Professor Gervase Chaney, National Head, School of Medicine, advised the committee:

- In the first year, the concept of organ donation is introduced, but not explored in detail.
- In the second year, organ transplant is discussed:
  - in the context of chronic kidney disease;
  - in a lecture that covers transplantation from a clinical and basic clinical science perspective;
  - as a topic for a clinical briefing tutorial, with discussion of barriers to organ donation including, religious, cultural and psychological; and
  - dedicated bioethics panel sessions on organ transplantation and bodily integrity.
- In the clinical years:
  - ICU teaching covers the practicalities of the clinical aspects of organ and tissue donation such as, talking to families, consent, brain death and ethics around this; and
  - the medical aspects around transplants are covered in surgery and general medicine (so the students see renal and some bone marrow, lung and liver transplants) and these are addressed within the relevant disciplines.[421]

Curtin University

14.13 Organ and tissue donation education and training is incorporated into the curriculum for medical students at Curtin University as follows in 2023:

- In the second year, there is some discussion during renal block teaching.

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420 Organ and Tissue Authority, *Perioperative workshop*, Australian Government, n.d., accessed 21 Oct 23.

421 Letter from Professor Gervase Chaney, National Head, School of Medicine, The University of Notre Dame Australia, 24 Aug 23, p 1.

- In the third year, informally addressed through immunology seminars, with visiting specialists answering student questions about transplantation.
- In the fifth year, Dr Bruce Powell will discuss organ and tissue donation during the pre-internship program.[422]

University of Western Australia

14.14 The University of Western Australia did not respond to the Committee's request for information.

Increasing curriculum content

14.15 In 2022, the Australian Medical Students' Association, the peak representative body for medical students in Australia, called for increased curriculum content regarding organ and tissue donation for medical and allied health workers. Specifically, they called for education on ethical issues, cultural concerns, transplant legislation and present Australian systems.[423] The Committee supports this call.

FINDING 31

Training future healthcare professionals will enable them to intelligibly disseminate organ and tissue donation information to families and the wider community and provide confidence to advise future patients.

Education in schools

14.16 It is known that misconceptions and lack of understanding surrounding organ and tissue donation can have an impact on consent rates and registration rates. Education can play an important role in promoting organ and tissue donation, increasing basic knowledge of the population and promoting ethical values.[424]

14.17 Education provided to school students may correct misconceptions about organ donation and transplantation to promote personal and collective motivation, leading to an eventual cultural shift. Education in schools will also likely encourage conversations between students and their families.

14.18 The OTA partnered with an online education resource provider to develop lessons about organ and tissue donation for year 9 and 10 students.[425] The OTA website confirms all resources are aligned with the Australian curriculum and were reviewed by a child and adolescent psychologist.[426] The extent to which these resources are utilised is not reported.

14.19 It may be beneficial for education in faith-specific schools to be conducted in collaboration with faith leaders based within these schools. This could assist in addressing any misconceptions about the permissibility of organ donation.

14.20 A Spanish study evaluated the level of knowledge and attitudes of a group of Spanish adolescents aged 14-16 years about organ donation, transplantation and brain death. The

422 Email from Dr Heidi Waldron, Director of Medical Program, Curtin Medical School, 4 Sep 23.

423 Australian Medical Students' Association, Policy document: Organ and Tissue Donation, 2022, accessed 21 Oct 23, p 3.

424 R Nieto-Galván, 'Nurse Intervention: Attitudes and knowledge about organ donation and transplantation in adolescents,' *Transplant Proceedings*, 2022, 54(7):1697-1700.

425 Organ and Tissue Authority, *Education resources*, DonateLife, n.d., accessed 21 Oct 23.

426 Organ and Tissue Authority, *Education resources*.

study examined levels of knowledge before and after health education conducted by trained nurses. The study found that:

- Whilst attitudes were generally positive, the basic level of knowledge was insufficient and, on numerous occasions, erroneous.
- Providing training by health professionals resolved doubts and enhanced satisfaction and learning.
- Students' knowledge was improved after educational intervention, maintaining and even improving positive attitudes on the subject.[427]

FINDING 32

It would be beneficial to explore opportunities to incorporate organ and tissue donation education into the curriculum for school students.

Cultural competency education for healthcare workers

14.21 Care and support should be provided in a culturally competent manner. All healthcare professionals working in organ donation and transplantation should be provided with training on key issues relating to faith and death rituals.

14.22 There is a need to ensure that all care and support is provided in a culturally competent manner, that considers the individual patient and family needs, in terms of their socio-economic status, education, cultural background, language needs and religion.

Training provided through the Organ and Tissue Authority

14.23 As part of the national program, OTA is required to coordinate ongoing, nationally consistent and targeted professional development and training for clinicians and care workers involved in organ and tissue donation.[428]

14.24 The OTA offers specialised professional training for healthcare workers involved in donation and transplantation.

14.25 The Core Family Donation Conversation workshop provides training to various health professionals working in organ and tissue donation. The workshop must be completed by:

- DonateLife WA donation specialists; and
- intensive care medical trainees, as a requirement of the College of Intensive Care Medicine of Australia and New Zealand mandatory training requirements.[429]

14.26 The workshop is led by specialist trainers, including experienced DonateLife specialists, intensive care specialists and grief counsellors.

14.27 The workshop is regularly reviewed based on feedback from participants and professional bodies:

> The workshop is regularly reviewed in consultation with the Australian and New Zealand Intensive Care Society, the College of Intensive Care Medicine of Australia

427 R Nieto-Galván, 'Nurse Intervention: Attitudes and knowledge about organ donation and transplantation in adolescents', *Transplant Proceedings*, 2022, 54(7):1697-1700.

428 Australian National Audit Office (ANAO), *Organ and Tissue Donation: Community Awareness, Professional Education and Family Support*, Australian Government, 29 Apr 15, accessed 19 Oct 23.

429 Organ and Tissue Authority, *Core Family Donation Conversation workshop*, 2023, accessed 19 Oct 23.

and New Zealand and the Australian College of Critical Care Nurses to make sure the material is current and continues to meet training needs.[430]

14.28 The OTA also offers other professional training courses, such as training for preoperative nurses involved in organ and tissue transplantation and various advanced courses.

Community education and the role of the media

Spanish approach to communication with the media

14.29 The National Transplant Organisation (Organización Nacional de Trasplantes) (ONT) has a collaborative relationship with journalists to maintain community confidence about organ and tissue donation.

14.30 The success of the Spanish donation and transplantation program can most likely be attributed to policies that focus on trust and transparency. This trust and transparency is enhanced by direct communication with the media and round-the-clock availability for consultation.

14.31 Each year, Spain conducts a training seminar on organ donation aimed at journalists to provide first-hand information about organ donation and transplantation processes. These seminars ensure journalists possess the knowledge required to report on organ donation stories accurately and prevent the spread of misinformation. Regular meetings ensure the ONT and the media understand each other's needs.

14.32 The Committee visited the ONT headquarters in Madrid, which coordinates the efforts of the Spanish healthcare system in organ donation. During this visit, Doctor Beatriz Domínguez-Gil, the Director General of ONT, advised the Committee that instead of making significant investments in direct promotional campaigns, which were considered to have limited cost-effectiveness, with instead dedicating time and resources to developing relationships with journalists, which is more cost-effective.

14.33 The ONT also advised the Committee that they have seen positive results from news stories focusing on the experience of the donor families.

14.34 The ONT is committed to maintaining relationships with journalists, which increases public trust and reduces promotional costs.

14.35 The ONT holds educational programs for journalists, has yearly meetings and provides a 24-hour phone line administered by staff trained in consultation.

FINDING 33

The Spanish National Transplant Organisation (Organización Nacional de Trasplantes) maintains collaborative relationships with journalists, which has proved to be effective in:

- increasing media coverage around organ and tissue donation and reducing promotional costs;
- maintaining community confidence and increasing family consent rates; and
- normalising organ donation conversations and incorporating these conversations into end-of-life care.

[430] Organ and Tissue Authority, *Core Family Donation Conversation workshop*.

RECOMMENDATION 25

The Department of Health and DonateLife WA review their existing media communication policies to ensure there is an emphasis on:

- open and effective communication with journalists;
- maintaining community confidence; and
- normalising organ and tissue donation conversations.

Mass media campaigns and appeals

14.36 The NHS Blood and Transplant regularly produces mass media campaigns and appeals in the United Kingdom. After an intense period of televised mass media campaigns, observing and logically attributing large numbers of additional registrations to these campaigns is possible. One analysis of organ donation appeals found that, across 23 campaigns, there was an average 5% increase in registry sign-ups compared to control groups.

14.37 A 2018 United Kingdom trial studied the most effective messaging techniques to encourage registry sign-ups. The trial explored the effect of adding persuasive messages to a prompt to join the Organ Donation Register after completing 'Department for Transport' (UK) payments. A total of 1,085,322 website users were presented with various messaging to determine which was the most persuasive.[431]

Table 22. *Intervention messages presented*

Intervention arm	Persuasive message
Control	No message
Social norms	Everyday thousands of people who see this page decide to register.
Social norms plus logo	Everyday thousands of people who see this page decide to register. (Plus logo)
Social norms plus image	Everyday thousands of people who see this page decide to register. (Plus image)
Loss frame	Three people die every day because there are not enough organs.
Gain frame	You could save or transform up to 9 lives as an organ donor.
Reciprocity	If you needed an organ transplant, would you have one? If so, please help others.
Cognitive dissonance	If you support organ donation, please turn your support into action.

[Source: A Sallis, H Harper and M Sanders.[432]]

14.38 The trial found the largest number of registrations by people who received the reciprocity messaging. Individuals were 1.38 times more likely to register than if they had seen the control message. Those who viewed the reciprocity message and clicked to join were also more likely to complete the registration.

[431] A Sallis, H Harper and M Sanders, 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers', *Trials*, 2018, 19(1):513.

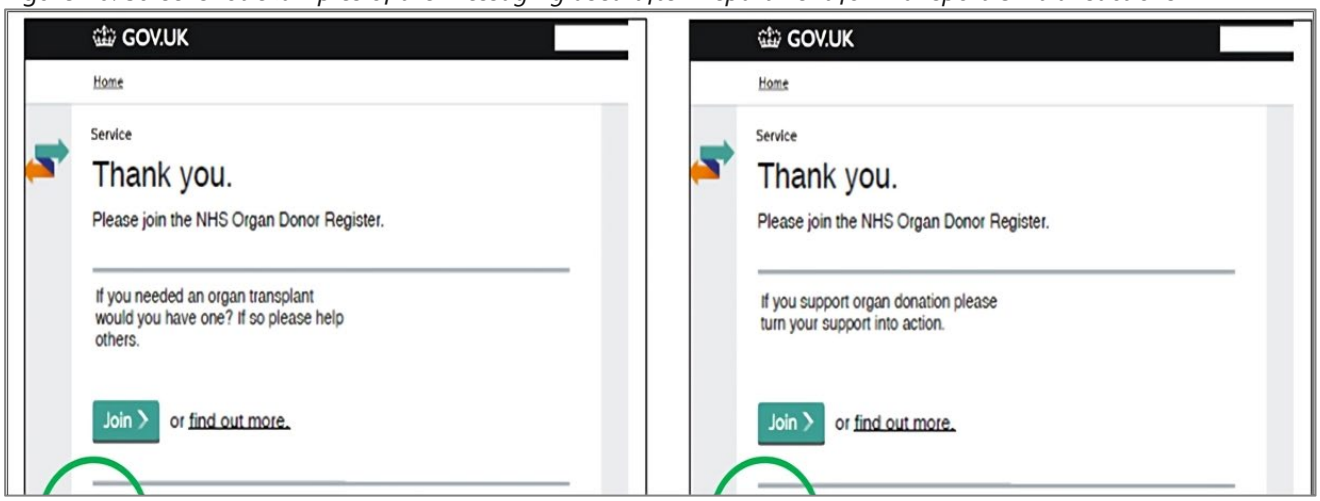
[432] A Sallis et al., 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers'.

14.39 In this context, the most effective messages in encouraging Organ Donor Register sign-ups are to offer people the chance to reciprocate and to make salient the loss of life entailed by too few organs being available for transplant.

14.40 The reciprocity message was, therefore, favoured by The NHS Blood and Transplant and implemented immediately after the trial on the GOV.UK website after completing 'Department for Transport' (UK) payments. Twenty-five government end-of-transaction web pages on GOV.UK now use this messaging, resulting in 529,000 new registrations from 2013 to 2017.[433]

14.41 In Scotland, a similar reciprocity message increased intention[434] to join the Organ Donation Register compared to controls, providing further support for using the reciprocity message for online government platforms. However, this message will at some point become reduced in novelty and need to be updated.[435]

Figure 20. *Screenshot examples of the messaging used after Department for Transport UK transactions*



[Source: A Sallis, H Harper and M Sanders.[436]]

DonateLife campaign events

14.42 DonateLife publicly promotes organ and tissue donation through 2 main annual events: DonateLife Week and Thank You Day. DonateLife Week is held annually in July and aims to encourage Australians to register on the Australian Organ Donor Register. In 2023, DonateLife Week encompassed various activities, such as, distribution of QR code stickers on café coffee cups, branded merchandise, partnerships with community groups and public events. Public buildings, including Parliament House, Luna Park, and the Perth Bell Tower, were illuminated purple in support of organ and tissue donation.

433 A Sallis et al., 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers'.

434 Participants who were not currently registered organ donors took part either face-to-face or online and were randomly allocated to a reciprocity prime or control condition. Following the manipulation, they were asked to indicate their intention to join the organ donor register on either a paper or online questionnaire. Participants shown the reciprocity message had a mean result of 5.64 compared to the control group, which had a mean of 4.96.

435 A Sallis, H Harper and M Sanders, 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers', *Trials*, 2018, 19(1):513.

436 A Sallis et al., 'Effect of persuasive messages on National Health Service Organ Donor Registrations: a pragmatic quasi-randomised controlled trial with one million UK road taxpayers'.

14.43 DonateLife launched the 'Great Registration Race' during DonateLife Week in 2021. The OTA, in their annual report, stated:

> The 3 months of the campaign period between June and August 2021 resulted in the most successful single registration drive since the program started in 2009, with 108,952 new registrations recorded on the AODR.[437]

14.44 Thank You Day is celebrated annually on the third Sunday in November. This day serves as an opportunity to remember and express gratitude to donors. DonateLife encourages individuals to share thank-you messages on social media using the #thankyouday hashtag. People are also invited to share their personal stories with DonateLife, who may then promote them on their social media platforms. To facilitate corporate involvement, an electronic resources pack and social media tiles are provided to businesses for internal promotion.

14.45 In 2022 the OTA ran the first Eye and Tissue Awareness Week, which used social media content to raise awareness and share stories about eye and tissue donation. The OTA, in their annual report, stated:

> Eye and Tissue Awareness Week was a great success, with high levels of engagement including 394,000 social media impressions and 15,000 total engagements.[438]

FINDING 34

DonateLife Week, Eye and Tissue Awareness Week and Thank You Day offer opportunities to increase public awareness about organ and tissue donation.

RECOMMENDATION 26

The Western Australian government and DonateLife WA advocate for the Organ and Tissue Authority to increase the effectiveness of the DonateLife Week campaign.

Hon Pierre Yang MLC
Chair

[437] Organ and Tissue Authority, *Annual Report 2021-22*, DonateLife, 2022, accessed 22 Jan 24.

[438] Organ and Tissue Authority, *Annual Report 2021-22*, DonateLife, 2022, accessed 22 Jan 24.

APPENDIX 1

SUBMISSIONS, PUBLIC HEARINGS, EXTERNAL MEETINGS & SITE VISITS

Submissions

Number	From
1.	Zaidee's Rainbow Foundation
2.	Transplant Advocacy
3.	Jane Ratten
4.	Private Citizen
5.	Private Citizen
6.	Private Citizen
7.	Augusta Pinch
8.	WA Country Health Service
9.	Dr Bruce Powell
10.	Nicholas Fardell
11.	Donor Mate
12.	Health Consumers' Council WA
13.	Nicholas Fardell
14.	Donor Families Australia Inc
15.	Mark Folkard MLA
16.	National Health and Medical Research Council
17.	Western Australia Kidney Transplant Service
18.	Victoria Castledine
19.	Private submission
20.	Lions Eye Institute
21.	Transplant Australia
22.	Plus Life WA
23.	Organ and Tissue Authority
24.	Leukaemia Foundation
25.	Department of Heath

Number	From
26.	DonateLife WA and North Metro Health Service

Public hearings

Date	Participants
10 May 2023	WA Health (DonateLife WA) Dr Simon Towler, Chief Medical Officer, WA Department of Health, and State Medical Director, DonateLife WA Dr Karen McKenna, Senior Medical Advisor, Department of Health Mrs Julie Crouch, Jurisdictional Advisory Group Representative, DonateLife WA Dr Sharon Nowrojee, Medical Advisor, Department of Health Ms Melissa Smith, Clinical Nurse Manager, DonateLife WA Dr Helen Van Gessel, Executive Director Clinical Excellence, WA Country Health Service Ms Jo Fagan, Director Public Health, North Metropolitan Health Service
10 May 2023	Zaidee's Rainbow Foundation Mr Allan Turner, Managing Director/Co-Founder
17 May 2023	Organ and Tissue Authority Ms Lucinda Barry, Chief Executive Officer Dr Helen Opdam, National Medical Director Mr Mark McDonald, National Manager, Analytics and Technology
17 May 2023	Dr Bruce Powell
14 June 2023	Health Consumers' Council WA Ms Carolyn Boyd, private citizen Ms Clare Mullen, Executive Director Mrs Nadeen Laljee-Curran, Cultural Diversity Engagement Lead Ms Tania Harris, Aboriginal and Disability Engagement Lead
14 June 2023	Transplant Australia Mr Chris Thomas, Chief Executive Officer Mr Troy Scudds, Chair Mrs Rowena Alexander, private citizen

External meetings & site visits

Date	Participants
4 May 2023	Plus Life WA
4 May 2023	Cell and Tissue Therapies WA
15 May 2023	Lions Eye Institute
3 July 2023	Organización Nacional de Trasplantes, Spain
5 July 2023	Transplant Coordinator of Cantabria and Hospital Coordinator of Marqués de Valdecilla University Hospital, Dr Eduardo Miñambres, Spain
6 July 2023	Donation and Transplantation Institute, Spain
6 July 2023	Organización Catalana de Transplantes, Spain
10 July 2023	NHS Blood and Transplant, United Kingdom
11 July 2023	Human Tissue Authority, United Kingdom
12 July 2023	Team Margot Foundation, United Kingdom
12 July 2023	The Rt Hon Lord Hunt of Kings Heath, United Kingdom
13 July 2023	British Transplant Society, Dr Krishna Menon, United Kingdom

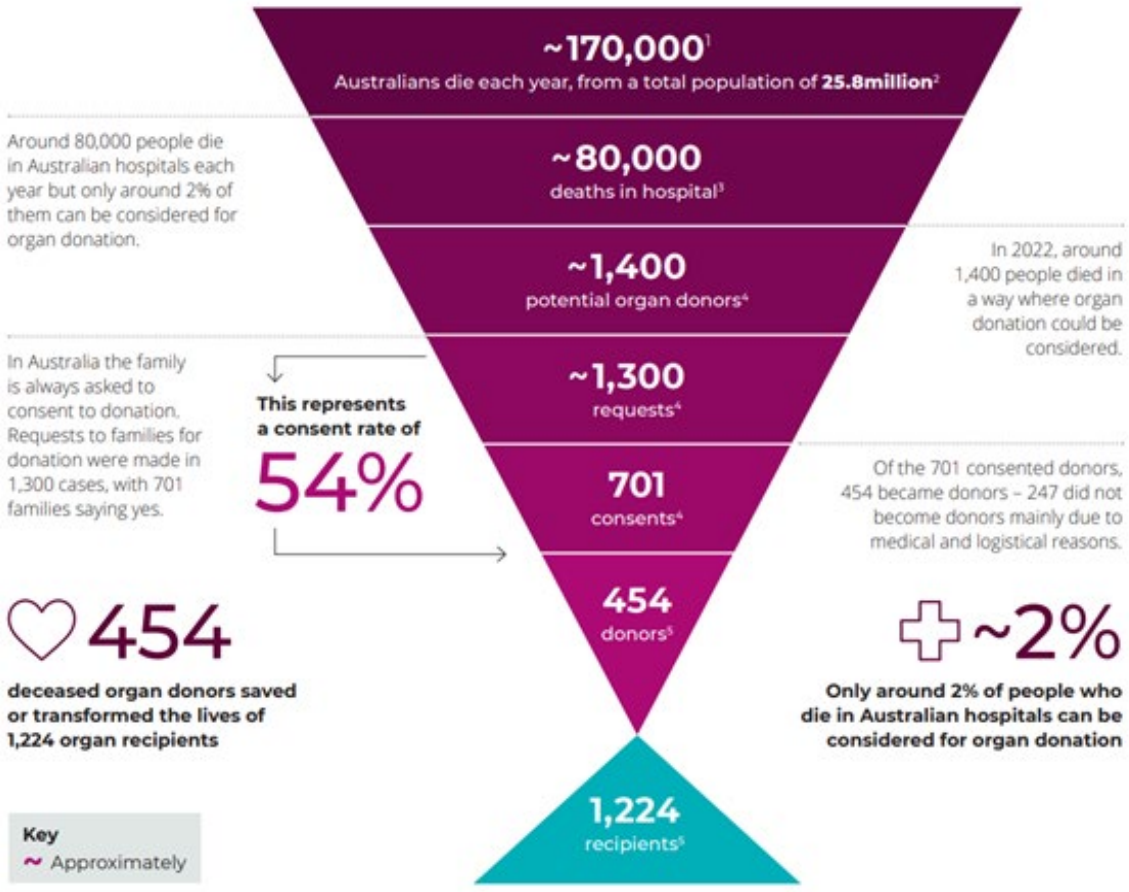
APPENDIX 2

ORGAN AND TISSUE DONATION LEGISLATION IN AUSTRALIAN JURISDICTIONS

Jurisdiction	Legislation
Australian Capital Territory	*Transplantation and Anatomy Act 1978*
Northern Territory	*Transplantation and Anatomy Act 1979*
New South Wales	*Human Tissue Act 1983*
Queensland	*Transplantation and Anatomy Act 1979*
South Australia	*Transplantation and Anatomy Act 1983*
Tasmania	*Human Tissue Act 1985*
Victoria	*Human Tissue Act 1982*
Western Australia	*Human Tissue and Transplant Act 1982*

APPENDIX 3

AUSTRALIA'S POTENTIAL DECEASED ORGAN DONOR POPULATION & TRANSPLANTATION OUTCOMES



[Source: Organ and Tissue Authority.[439]]

[439] Organ and Tissue Authority, Australian Donation and Transplantation Activity Report 2022, accessed 23 Oct 23, p 12.

APPENDIX 4

NHS BLOOD AND TRANSPLANT FORM TO APPOINT A REPRESENTATIVE TO MAKE ORGAN AND TISSIE DONATION DECISIONS

NHS
Blood and Transplant

APPOINTING A REPRESENTATIVE

to make organ donation decisions on your behalf

This form allows you to appoint a Representative to make organ donation decisions on your behalf should you die in circumstances in which you could become an organ donor.

You can record up to two Appointed Representatives on the NHS Organ Donor Register.

If you choose to record two Representatives their views will have equal status.

This means the order in which you record them below does not matter, both of their views will be equally valid.

However, unless the appointment provides that they are appointed to act only jointly, the default position is that the Appointed Representatives can make the decision jointly or separately. This means that they do not have to agree, so one can give consent regardless of what the other representative decides.

Organ Donation decisions need to be taken quickly.

This means it is important to give us phone numbers, especially mobile numbers, and that these details are kept up to date.

Your details and the details of your Representative will only be recorded on the Register once this form is received and verified by NHSBT.

Please note that legally NHSBT need authorisation from the Representative to store their details on the Register, and for this appointment to be binding it needs to be witnessed by an independent person.

This means for this form to be correctly filled in you will need the signatures of:

the Appointer

any Representatives

and a Witness.

If any of these signatures are not present on the form when returned, NHSBT will not be able to record your Appointed Representatives.

To act as an Appointed Representative you must be over the age of 18.

Please return the completed form to:

ODR Team
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
BS34 8RR

If you need any help or advice when filling in this form you can contact us by emailing **odr@uktransplant.nhs.uk** or calling 0117 975 7553.

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NHS
Blood and Transplant

YOUR DETAILS - APPOINTER Section 1

SURNAME: _____ FORENAME/S: _____

TITLE: _____

ADDRESS: _____

_____

_____ DATE OF BIRTH: ☐☐ ☐☐ ☐☐☐☐

POSTCODE: _____

TELEPHONE: _____ E-MAIL: _____

MOBILE: _____

I would like to appoint the Person/People named below to act as my Appointed Representative in relation to organ donation. I understand that they will make any decisions relating to organ donation on my behalf. I understand that in the event I could become an organ donor details of my medical history may need to be shared with them to help them make a decision. I also understand that Appointed Representatives are not recognised in Scottish law so if I were to die in Scotland my family would be asked to consent instead of my Representative.

I would like my Appointed Representatives to act only jointly when making the decision about organ donation (this means that they must come to an agreed decision) ☐

Please tick to confirm

Signed: Date:

REPRESENTATIVE/S DETAILS Section 2

REPRESENTATIVE A

SURNAME: _____ FORENAME: _____

TITLE: _____

ADDRESS: _____

_____

_____ DATE OF BIRTH: ☐☐ ☐☐ ☐☐☐☐

POSTCODE: _____

TELEPHONE: _____ E-MAIL: _____

MOBILE: _____

By signing below I confirm I am happy to act as an Appointed Representative with regards to deceased organ donation for the person named under Section 1 on this form. I confirm that I am over 18. I agree to my information being held by NHS Blood and Transplant on the NHS Organ Donor Register for this purpose. I understand that this appointment is not valid under Scottish law.

Signature of Representative A: Date:

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NHS
Blood and Transplant

REPRESENTATIVE/S DETAILS Section 2

REPRESENTATIVE B

SURNAME: _____ FORENAME: _____

TITLE: _____

ADDRESS: _____

_____

_____

DATE OF BIRTH: ☐☐ ☐☐ ☐☐☐☐

POSTCODE: _____

TELEPHONE: _____ E-MAIL: _____

MOBILE: _____

By signing below I confirm I am happy to act as an Appointed Representative with regards to deceased organ donation for the person named under Section 1 on this form. I confirm that I am over 18. I agree to my information being held by NHS Blood and Transplant on the NHS Organ Donor Register for this purpose. I understand that this appointment is not valid under Scottish law.

Signature of Representative B: Date:

WITNESS DETAILS Section 3

This appointment must be witnessed by an independent party. This means the witness below cannot be one of the Appointed Representatives or the Appointer.

SURNAME: _____ FORENAME: _____

TITLE: _____

ADDRESS: _____

_____

_____

DATE OF BIRTH: ☐☐ ☐☐ ☐☐☐☐

POSTCODE: _____

Witness statement

I confirm I witnessed the signing of this document and that:

- The signature in Section 1 is that of the person appointing a Representative;
- The signature listed in the section for Representative A is that of Representative A, and
- The signature listed in the section for Representative B is that of Representative B [cross this bullet point out if there is no representative B].

Signature of witness: Date:

GLOSSARY

Term	Definition
Act	*Human Tissue and Transplant Act 1982* (WA)
ABMDR	Australian Bone Marrow Donation Registry
AHD	Advance Health Directive
ANZOD	Australian and New Zealand Organ Donation Registry: Collects data on organ and tissue donations.
AODR	Australian Organ Donor Register: The national register for Australians to record their decision about becoming an organ and tissue donor after death.
Best Practice Guideline	Best Practice Guideline for Offering Organ and Tissue Donation in Australia: A guideline developed to outline the preferred approach when speaking with families about organ donation. The guideline includes the goals of family communication, staff roles and responsibilities, timing and elements of the family donation conversation, training requirements and review of practice.
Brain death	A commonly used term for death determined by the irreversible loss of all function of the brain. It must be distinguished from severely brain damaged states such as permanent or persistent coma or unconsciousness, post-coma unresponsiveness (vegetative state) or minimally conscious state.
CALD	Culturally and linguistically diverse
Circulatory death	Circulatory death or cardiac death are terms for death determined upon irreversible cessation of circulation. Criteria for diagnosing cardiac death clearly differentiate this from other states such as irreversible cardiac disease in which circulation is failing or is maintained artificially, or where cessation of circulation is predicted but has not yet occurred.
Clinical Guidelines for Organ Transplantation from Deceased Donors	Guidelines developed by the Transplantation Society of Australia and New Zealand that inform eligibility and assessment criteria for organ transplantation, and protocols for the allocation of deceased donor organs to waitlisted patients.
COAG	Council of Australian Governments
Committee	Standing Committee on Public Administration
Consent rate	Number of consents as a proportion of the number of requests made of potential donors.
DBD	Donation after brain death
DCD	Donation after circulatory death

Term	Definition
DonateLife	The Australian Government brand for all initiatives undertaken as part of the national program to increase organ and tissue donation for transplantation.
DonateLife agencies	Agencies responsible for delivering the national program in their respective state or territory. They employ specialist staff in organ and tissue donation coordination, professional education, donor family support, communications, and data and audit roles.
Deceased donor	A person who gives organs and/or tissue after death for the purpose of transplantation into another person.
Designated officer	A medical practitioner who is officially appointed by the chief medical administrator to be responsible and accountable under State legislation for the process of organ and tissue donation in that hospital.
Donor coordinator	A person whose role is to facilitate the organ and tissue donation process by acting as the liaison between the donor hospital, donor family and transplant centre(s).
Donor Specialist nurse	Donor specialist nurses are employed by DonateLife WA. They are usually ICU nurses who receive special training to facilitate conversations about organ and tissue donation and assist families to make a fully informed decision.
dpmp	Donors per million population. This is the method to measure transplantation rates internationally. It compares rates of donation against population count.
ECMO	Extracorporeal Membrane Oxygenation
ED	Emergency Department
EDR	Electronic Donor Record
Ethical guidelines for organ transplantation from deceased donors	Guidelines that inform ethical practice and decision-making by everyone involved in assessing the eligibility of an individual for transplantation, assessing the suitability of donor organs for transplantation, and allocating organs from deceased donors.
EVLP	Ex-vivo lung perfusion technique
HCC	Health Consumers' Council WA
HLA	Human Leukocyte Antigens: Proteins found on most cells in the body. The immune system uses these markers to recognise which cells belong in your body and which do not. A close match between a donor's and a patient's HLA markers is essential for a successful transplant outcome.
HPC	Hematopoietic progenitor cells
ICU	Intensive Care Unit
Indigenous Australians	Aboriginal and Torres Strait Islander Australians

Term	Definition
NAT	Nucleic acid testing
NHMRC	National Health and Medical Research Council
NHS	National Health Service: Government-funded health care and medical services provided to the UK. It consists of NHS England, NHS Wales and NHS Scotland. The publicly funded health care services in Northern Ireland is called the Health and Social Care Services.
NHS Blood and Transplant	NHS Blood and Transplant is United Kingdom's government agency responsible for the supply of blood, organs, tissue and stem cells. It collects and supplies blood to hospitals in England and is the organ donation organisation for the United Kingdom.
NRL	National (Serology) Reference Laboratory, Victoria
NRP	Normothermic regional in-situ perfusion
Intensivist	Intensive care medical specialist staff who are involved in the assessment, resuscitation and ongoing management of critically ill patients with life-threatening single and multiple organ system failure.
ONT	Spanish National Transplant Organisation
Organ	A part of the body that performs vital function(s) to maintain life. These include the kidney, heart, lung, liver, pancreas and intestine.
ODHSF	Organ donation hospital support funding
OrganMatch	A sophisticated software system developed by the Australian Government in partnership with the Australian Red Cross Lifeblood. This system replaces the National Organ Matching System (NOMS) and facilitates optimal matching of donor organs to transplant recipients.
OTA	Australian Organ and Tissue Donation and Transplantation Authority: A statutory body established under the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* to deliver the national organ and tissue donation and transplantation program. Also known as the Organ and Tissue Authority (OTA). The OTA are based in Canberra.
SCS	Standard cold storage
S&T Grants	DonateLife Network state and territory grants
Taskforce	National Clinical Taskforce on Organ and Tissue Donation
TGA	Therapeutic Goods Administration
Tissue	A group of specialised cells (eg cornea, heart valves, bone, skin) that perform defined functions.
TPN	Total parenteral nutrition: Where a person requires all their nutrition to be given through a drip into a vein because their bowel is unable to absorb nutrients from any food they eat.

Term	Definition
TSANZ	Transplantation Society of Australia and New Zealand: Responsible for developing eligibility criteria for organ transplantation and protocols for allocating deceased donor organs to wait-listed patients.
UK	United Kingdom
UK Protocol	Protocol for Normothermic Regional Perfusion in controlled Donation after Circulatory Determination of Death
USA	United States of America
VAD	Voluntary Assisted Dying

Standing Committee on Public Administration

Date first appointed:

17 August 2005

Terms of Reference:

The following is an extract from Schedule 1 of the Legislative Council Standing Orders:

'**5. Public Administration Committee**

5.1 A *Public Administration Committee* is established.

5.2 The Committee consists of 5 Members.

5.3 The functions of the Committee are to —

(a) inquire into and report on —

(i) the structure, efficiency and effectiveness of the system of public administration;

(ii) the extent to which the principles of procedural fairness are embodied in any practice or procedure applied in decision making;

(iii) the existence, adequacy, or availability, of merit and judicial review of administrative acts or decisions; and

(iv) any Bill or other matter relating to the foregoing functions referred by the Council;

and

(b) consult regularly with the Parliamentary Commissioner for Administrative Investigations, the Public Sector Commissioner, the Information Commissioner, the Inspector of Custodial Services, and any similar officer.

5.4 The Committee is not to make inquiry with respect to —

(a) the constitution, function or operations of the Executive Council;

(b) the Governor's Establishment;

(c) the constitution and administration of Parliament;

(d) the judiciary;

(e) a decision made by a person acting judicially;

(f) a decision made by a person to exercise, or not exercise, a power of arrest or detention; or

(g) the merits of a particular case or grievance that is not received as a petition.'

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4 Harvest Terrace, West Perth WA 6005
Telephone: +61 8 9222 7300
Email: lcco@parliament.wa.gov.au
Website: http://www.parliament.wa.gov.au