National Strategy for Organ Donation, Retrieval and Transplantation

In response to the Review of the Australian organ donation, retrieval and transplantation system and progressed in conjunction with the Organ and Tissue Authority’s Strategy 2022-2027

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# Acknowledgements

We thank all the generous donors and their families. Organ donation would not be possible without them saying yes to donation. Making the decision to donate a loved ones’ organs and tissues following their death, or to become a living donor, has a profound impact on the lives of many Australians.

All governments gratefully acknowledge the time, effort and insight provided by donor families, transplant recipients, health professionals, peak bodies and other organisations who participated in the development of the Strategy. Their participation and sharing of personal experience and expertise has been valuable.

All governments acknowledge the traditional Owners and Custodians of Country throughout Australia. We recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples and acknowledge and respect their continuing connections and relationships to country, rivers, land and sea. We acknowledge the ongoing contribution Aboriginal and Torres Strait Islander people make across the health system and wider community. We also pay our respects to Elders past and present and extend that respect to all Traditional Custodians of this land.

# Preamble

Transplantation can save lives, restore health, improve the quality of life, and offers significant cost benefits to the health system.

This document, the **National Strategy for Organ Donation, Retrieval and Transplantation** (the Strategy) seeks to build on these achievements and sets out the high-level future direction of the Australian organ donation, retrieval and transplantation system, as agreed by all governments. The Strategy will underpin policy and program delivery to provide enhanced access to transplantation for all Australians who need it.

The Australian Government, with the support of all state and territory governments, established a national program to increase organ and tissue donation in 2009, saving and improving the lives of more Australians through life changing transplantation.

The Organ and Tissue Authority (OTA) leads the national program working in collaboration with state and territory governments, the DonateLife Network, hospitals, clinicians, and the community to deliver a nationally consistent approach to donation. This successful collaboration has set the Australian health system on the right path to optimise organ and tissue donation for transplantation.

The Strategy works in conjunction with the OTA’s Strategy 2022-2027, which sets out the 5-year plan for the national organ and tissue donation program.

The Strategy focuses on improving the system for Australians needing an organ transplant and acknowledges work underway nationally to implement improved preventative health measures and provide optimal care for those affected by chronic conditions.[[1]](#footnote-2)

The Strategy’s vision is to **save and improve the lives of more Australians through a world’s best practice future-focused and equitable organ donation, retrieval and transplantation system**.

All governments are committed to build on the successes to date and continue to optimise systems with a focus on organ retrieval and transplantation services to meet Australia’s future needs.

# Development of the Strategy

## Background

In 2017, academic literature and media reports highlighted the disparities in access to organ transplantation.[[2]](#footnote-3) These articles raised the issue of inequitable access to transplant waiting lists for Aboriginal and Torres Strait Islander people and the added challenges experienced by patients in rural and remote areas of Australia. There was also evidence that the growth in donation activity over the preceding ten years was placing pressure on retrieval and transplant services.

Consequently, all governments agreed to a review to examine pre- and post-transplantation services and identify barriers to equity of access to transplant wait lists and transplantation services.

## The Review

In 2018, a Review of the Australian organ donation, retrieval and transplantation system (the Review) commenced. It was conducted in two phases. Phase 1 involved a desktop and literature review and an extensive stakeholder consultation process.

The [**Review of the Australian organ donation, retrieval and transplantation system Final Report**](https://www.health.gov.au/resources/publications/review-of-the-organ-donation-retrieval-and-transplantation-system-final-report) (Review Report) and an All Governments’ Statement responding to the Review Report were published on the Commonwealth Department of Health and Aged Care website. In the statement, Commonwealth and state and territory governments acknowledged the issues identified and agreed to thoroughly consider and assess the 57 recommendations to develop a future national approach for the system.

The Review Report found that rapid growth within the donation sector has placed downstream pressure on the retrieval and transplantation system, limiting the ability of the system to maintain growth and meet future demand. The Review Report found variability in retrieval and transplantation practice and performance across Australia and recommended a nationally coordinated effort to improve access to transplantation. It also recommended that to reduce inequities, a focus on detailed strategies to improve access to transplantation for Aboriginal and

Torres Strait Islander Australians and Australians living in rural and remote locations was needed. The Review Report identified three key priorities for action:

1. An organised, nationally driven strategy to meet the increase in organ transplantation demand
2. Governance to optimise future growth and sustainability of the donation, retrieval and transplantation system
3. A nationally driven approach to improve organ donation and transplantation rates among Aboriginal and Torres Strait Islander Australians and Australians who live in rural and remote locations.

## Jurisdictional Organ Donation, Retrieval and Transplantation Steering Committees

In October 2019, all Australian governments agreed to the establishment of a steering committee to oversee Phase 2 of the Review; the development of a national strategy for the Australian organ donation, retrieval and transplantation system. The Jurisdictional Organ Donation, Retrieval

and Transplantation Steering Committee (JODRT) comprised representation from all states and territories and the OTA and was chaired by the Commonwealth Department of Health and Aged Care.

In February 2022, the Jurisdictional Organ and Tissue Steering Committee (JOTSC) was established. The JOTSC is the consolidation of the former JODRT and the Jurisdictional Eye and Tissue Steering Committee and was formed to progress implementation of the Strategy and the National Eye and Tissue Sector Framework.

## The Eye and Tissue Sector

In 2016, the PricewaterhouseCoopers Analysis of the Australian tissue sector[[3]](#footnote-4) was finalised. In response, the Jurisdictional Eye and Tissue Steering Committee developed the National Eye and Tissue Sector Framework (Framework). The Framework was published in August 2022 following agreement by all governments.

The Framework sets national objectives that support greater consistency and oversight for the eye and tissue sector. As a key component of Australia’s organ and tissue arrangements, the

Framework supports key improvements in areas of the eye and tissue sector that are also reflected in this Strategy.

Implementation planning for the Framework began in early 2023 and will be developed by the JOTSC, in consultation with stakeholders from the eye and tissue sector. Implementation planning for the Framework and the Strategy will consider aligning common goals where appropriate.

## COVID-19

The COVID-19 pandemic had a significant impact on the national program with a 25% decrease in donation and transplantation rates across 2020-2021[[4]](#footnote-5). Whilst there was a slight recovery in 2022-2023, the number of donors and people who have received a transplant remained 6% below the peak levels of 2018-2019.

There have been significant challenges and pressure on hospitals due to the pandemic; pressures on intensive care units (ICU), hospital visitor restrictions affecting family experience at end-of-life, transplant teams having to assess risk versus benefit of transplantation for people on the waiting list, and the care of immunosuppressed transplant recipients who are more vulnerable to COVID-19.

Development of the Strategy included consideration of COVID-19 impacts in order to return donation and transplantation activity to pre-pandemic levels and drive further improvements throughout implementation of the Strategy.

## The Strategy

The development of this Strategy is Phase 2 of the Review and is the response of all Australian governments to address the three key priorities for action from the Review report. Its development follows consultation with all governments, the OTA, and clinical and community stakeholders.

Governments have identified four Priority Areas, which will provide the future direction for the Australian organ donation, retrieval and transplantation sector:

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

Underpinning the Priority Areas are ten Goals that provide a clear statement of the outcomes all governments are aiming to achieve through this Strategy. Actions, to be agreed by all governments, will be detailed in a forthcoming Implementation Plan to enable delivery of these goals.

## Transition Action Plan

The Transition Action Plan was published in August 2022 and supports delivery and development of the Strategy and forthcoming Implementation Plan. The Transition Action Plan outlines actions agreed by all governments that address both recommendations from the Review Report and agreed areas of implementation from the Framework.

The Transition Action Plan aims to consolidate and progress 13 actions identified within the four Priority Areas that would benefit from background work or could inform other actions that would be built into the Implementation Plan.

The link to the Transition Action Plan can be found at Appendix A.

# Defining the strategy

## Vision

To save and improve the lives of more Australians through a world’s best practice future-focused and equitable organ donation, retrieval and transplantation system.

### Priority areas and goals

1. **A national approach to optimise organ, donation, retrieval and transplantation**

**Goals**

* National governance and funding arrangements effectively support Australia’s organ donation, retrieval and transplantation system
* More Australians consent to deceased organ donation
* Increase opportunities for living organ donation
1. **Equitable access for Australians who would benefit from organ transplantation with a focus on Aboriginal and Torres Strait Islander people and those living in rural, regional and remote areas**

**Goals**

* Policy and programs break down barriers improving access to transplantation
* Nationally consistent, equitable and transparent wait list, organ allocation, offer and acceptance processes
1. **Enhanced organ retrieval and transplantation capability and capacity to optimise transplant outcomes**

**Goals**

* Capability and capacity within the health system deliver optimal organ retrieval and transplantation services
* Australian transplant recipients have access to high quality post- transplantation programs and services
1. **Enhanced systems and data collection and reporting to drive clinical best practice**

**Goals**

* OrganMatch functionality drives clinical practice improvement
* Data is accessible and reported to drive best practice
* Optimal use and functionality of transplantation outcome registries to inform policy and program design

# Priority area 1: A national approach to optimise organ donation, retrieval and transplantation

## Goal: Effectively support Australia’s organ donation, retrieval and transplantation system

Strategic planning and leadership at a national level is required to sustainably enhance the capability and capacity within organ donation, retrieval and transplantation services and provide consistency across the system.

This Strategy facilitates national governance arrangements and a collaborative, crossdisciplinary approach by all Australian governments, clinicians, advisory bodies and the community. While responsibility for the clinical delivery of organ retrieval and transplantation services will remain with the states and territories, all governments and the OTA will work together to support a nationally consistent approach to retrieval and transplantation. This will follow agreement of the OTA’s role through delivery of the Transition Action Plan and is expected to build on the OTA’s current activities in organ and tissue donation.

Future arrangements will leverage and enhance existing committees to facilitate expert advice from across state and territory governments, the clinical sector including donation, retrieval and transplantation clinicians, and the community sector.

National approaches will continue to recognise jurisdictional and regional requirements, and the need for local systems.

Funding to support Australia’s organ donation, retrieval and transplantation system will include the outcome of the Independent Health and Aged Care Pricing Authority’s (IHACPA) review of organ donation, retrieval and transplantation activity classification and costing.

The Transition Action Plan sets out actions to settle future governance, any expanded role of the OTA, and review funding arrangements. Detailed implementation planning will further clarify roles and responsibilities to support a nationally consistent approach. This may include consideration of elements such as:

* enhanced stakeholder engagement and collaboration
* national data collection, analysis and enhanced reporting
* professional education and resources
* enhanced national community awareness and messaging
* collaboration with stakeholders to develop and monitor nationally consistent clinical practice protocols
* improved efficiency of donation, retrieval and transplantation processes with consideration of current and emerging best practice
* a national approach for transport and other services that support donation, retrieval and transplantation

## Goal: More Australians consent to deceased organ donation

Donor families have a pivotal role in the organ donation consent process. Without their consent, the lives of Australians wait listed for transplant could not be saved or transformed. Families are much more likely to consent to organ donation when their family member was registered on the Australian Organ Donor Register (AODR), compared to when their family member was not a registered donor and had not discussed donation with their family.[[5]](#footnote-6)

The AODR is the national register for Australians to record their organ and tissue donation decision. The Review Report called for consideration of broader strategies to support increased registration rates, including consideration of new and previous arrangements such as using driver licence- based systems.

Around 36% of the population aged 16 and over have registered their intent to donate on the AODR. Australians can currently register on the AODR through:

* the online form on the [**donatelife.gov.au**](https://www.donatelife.gov.au/) website
* their MyGov account
* their Express Plus Medicare app
* the printed registration form
* driver’s licences in South Australia.

The aim of increasing the number of registered donors on the AODR is to increase consent rates in the small number of cases in which it is clinically possible for organ donation to proceed after a person’s death.

Very few people are able to become organ donors at the end of their life. In Australia around 2% of people who die in hospital (~1,500 people in 2023), die in a way that allows organ donation to be considered. All governments have agreed, through the Transition Action Plan, to consider options to support increased consent for donation through leveraging other processes, such as driver licence applications and renewals, to increase donor registration without compromising the integrity of AODR data.

All governments agree that every Australian should be encouraged to consider whether they want to be a donor at the end of their life and to discuss their decision with family. Strategies to encourage conversations with family and friends about organ and tissue donation will be considered during implementation of the Strategy.

Additionally, all governments agree that implementation of the Strategy should include actions to improve organ donation registration and consent rates in culturally and linguistically diverse communities and with Aboriginal and Torres Strait Islander peoples. Culturally appropriate education and engagement programs and dedicated resources and strategies, developed in partnership with Aboriginal and Torres Strait Islander people and local communities, will be necessary to achieve this.

## Goal: Increase opportunities for living organ donation

Given the number of people who die in hospitals in circumstances where donation is possible is limited, more Australians could receive organ transplants through the generosity of living donors. Living donation offers an alternative for patients, mostly for those who need a kidney transplant, or in very specific circumstances, a liver transplant. Generally, a living donor is a relative or friend of the transplant recipient. However, altruistic donors can also donate a kidney anonymously to a person on the transplant waiting list.

Living donation rates have slowly decreased since 2017 and COVID-19 contributed to a significant downward spike in 2020. Since then, living organ donation rates have recovered to almost pre COVID-19 levels.

**Figure 1. Number of living organ donors in Australia 2016-2023**



The Paired Kidney exchange program commenced in 2010, developing into the Australian and New Zealand Paired Kidney Exchange (ANZKX) program in 2019. The program has increased the number of living kidney donations by matching incompatible donor and recipient pairs with other incompatible pairs across Australia and New Zealand. During 2023, 55 of 253 kidney transplant recipients who received an organ from a living donor, were matched through the program[[6]](#footnote-7).

The Australian Government administers the Supporting Living Organ Donors Program (the Program) to reduce the financial stress associated with being a living organ donor. The Program provides a financial contribution to employers who have paid an employee for leave to attend medical appointments and/or undergo and recover from living donor surgery. In 2023 the Program supported 90 applicants who donated a kidney or partial liver in Australia.

The Program will be reviewed to ensure living donors are best supported to undergo donor assessment, retrieval surgery, recovery and post-donation care.

# Priority area 2: Equitable access for Australians who would benefit from organ transplantation with a focus on Aboriginal and Torres Strait Islander people and those living in rural, regional and remote areas

## Goal: Policy and programs break down barriers and improve access to transplantation

The Review Report describes the challenges faced by Aboriginal and Torres Strait Islander people and Australians living in rural and remote locations in their access to transplantation. The 2019 Transplantation Society of Australia and New Zealand (TSANZ) Performance Report: Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia (TSANZ Performance Report[[7]](#footnote-8)), described the barriers that make access to kidney transplantation difficult for Aboriginal and Torres Strait Islander people. The two reports provide the direction for change over the coming decade, including the importance of policies and programs being developed in partnership with Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander people, and Australians living in rural and remote areas, experience significant challenges. The Review Report found that many rural and remote areas do not have the infrastructure or availability of appropriately trained health professionals to support transplantation and post-transplantation assessment and care. This can mean that long distance travel or relocation to urban areas are the only options for a patient to progress to the next stage in the treatment pathway. Those that follow this path then face the social and financial implications of travelling or moving far from home. Lack of education, language barriers, and difficulties in negotiating cultural and social sensitivities contribute to this inequality in access to transplantation and post-transplantation care.[[8]](#footnote-9)

The National Indigenous Kidney Transplantation Taskforce (NIKTT) was established in response to the TSANZ Performance Report. The objectives of the NIKTT were to:

* enhance data collection and reporting,
* pilot initiatives to improve patient equity and access, and
* evaluate cultural bias interventions.

The NIKTT commissioned the Australia and New Zealand Dialysis and Transplantation Registry (ANZDATA) to develop new data forms for renal services to identify reasons for Aboriginal and Torres Strait Islander peoples not being wait listed. Data collected in 2020 shows that there were significant differences in treatment methods for Aboriginal and Torres Strait Islanders with end- stage kidney disease. Only 15% of Indigenous Australians accessed transplantation as a treatment option, compared to 51% of non-Indigenous Australians[[9]](#footnote-10).

* The NIKTT initiated equity and access pilot projects across Australia including; patient navigators, education sessions, workforce strengthening, outreach clinics and Indigenous Reference Groups. Findings showed the positive impact each program had on the number of Aboriginal and Torres Strait patients waitlisted and transplanted.
* Additionally, the NIKTT published the Cultural Bias Report in March 2022[[10]](#footnote-11).

The work of the NIKTT will inform implementation against the Strategy’s priority area of equitable access to transplantation and post-transplantation care. It is essential that geographical, cultural, educational and language barriers are considered, including close to home care options for rural patients, where safe to do so. The Transition Action Plan recognises the need to leverage the work of the NIKTT, including findings from relevant initiatives, to inform actions to implement the Strategy.

There is also recognition from all governments that culturally appropriate education programs and resources for Aboriginal and Torres Strait Islander people are required, so all potential transplant recipients, including Aboriginal and Torres Strait Islander people, receive information that is appropriate. Multiple interventions and active engagement with local communities will be necessary to achieve this goal.

More broadly, implementation planning will consider other actions that could support health services and potential transplant recipients from all backgrounds to enable early assessment for transplant eligibility and wait listing. This may require action by primary care services, dialysis units, kidney transplant programs, clinicians and continuing medical education providers.

## Goal: Nationally consistent, equitable and transparent wait list, organ allocation, offer and acceptance processes

The Review Report outlines inconsistencies in assessment practices and wait list management nationally. It recognises that states and territories, and their Local Hospital Networks, are primarily responsible for the delivery of organ retrieval and transplantation services. However, it also identifies a range of issues impacting organ retrieval and transplantation that could benefit from a nationally coordinated approach.

The Review Report outlines the variation in waiting list numbers, reflecting nonuniform practices in wait listing potential recipients and the management of waiting lists. It reports evidence of late referrals of potential recipients to transplantation programs for assessment. In particular, it notes that there is widespread variability in waiting list practices for people receiving dialysis across Australia and a widening gap in this variability. Further, there is variation across jurisdictions in allocation, reasons for offer declines and acceptance practices.

All governments recognise that a nationally consistent approach is needed, acknowledging that there may continue to be some variation in jurisdictional clinical service delivery. Additionally, all governments will support the sector to facilitate patient pathways towards transplantation and enable equity of access and optimal patient outcomes.

As a starting point, the Transition Action Plan supports the work being undertaken by the current TSANZ Working Groups. There will be continued support and collaboration with the transplant sector in considering the recommendations from the review of renal and non-renal allocation, including implementation of agreed recommendations for implementation in OrganMatch.

It is also important to acknowledge that other treatment pathways and prevention activity may decrease the need for some transplants in future. These issues are beyond the scope of this Strategy but could also benefit from a consistent national approach.

# Priority area 3: Enhanced organ retrieval and transplantation capability and capacity to optimise transplant outcomes

## Goal: Capability and capacity within the health system delivers optimal organ retrieval and transplantation services

The Review Report highlighted the need to develop strategies that would address inefficiencies across the organ donation, retrieval and transplantation system.

Demand for Australia’s donation, retrieval and transplantation services is growing. There were around 1,380 people on the organ transplant wait list in 2017, compared to around 1,800 people on the organ transplant wait list in 2023[[11]](#footnote-12).

Additionally, there are approximately 14,000 people receiving dialysis, many of whom might also benefit from access to kidney transplantation.

The Review Report identified the need to address capacity and capability issues, with a particular emphasis on workforce planning and coordination of retrieval and transplantation services.

The effects of COVID-19 on Australia’s health system interrupted a 10-year period of growth in donation and transplantation rates. All governments and the OTA remain committed to working with the donation, retrieval and transplantation sector to increase rates as the system recovers.

All governments agree to consider elements including national coordination for retrieval and transplantation, and review of efficiencies across the system and workforce planning to build capability and capacity.

## Goal: Australian transplant recipients have access to high quality post-transplantation programs and services

Post-transplantation care is complex, and patients require extensive monitoring following surgery. In most cases, monitoring is required for the rest of the recipient’s life. High quality post- transplantation care is essential to maintain and increase survival rates.

The Review Report found that although kidney transplantation programs generally support patients to return to their homes following transplantation; heart, lung and liver programs do not have similar post-transplantation care networks available. Due to the smaller number of patients who receive heart, lung or liver transplants and the treatment complexity, primary care is driven by the primary treating transplant unit. There are resourcing and logistical complexities that can place stress and additional financial burdens on transplant recipients and their families. It is important to consider all options for delivery of effective post transplantation care.

All governments are committed to building on the high-quality care already provided, to support post-transplantation care close to home where safe to do so, with the aim that transplant recipients have quality of life post-transplantation. This may include consideration of shared care, distributed arrangements, provision of rehabilitation, and transition from paediatric to adult services. All states and territories commit to reviewing their models of post-transplantation care to ensure appropriate support and equitable access for transplant recipients and their families.

Transplant units and DonateLife agencies follow the national guidelines that support anonymous written communication between transplant recipients and donor families. For some donor families and transplant recipients, this is an important part of their experience.

# Priority area 4: Enhanced systems and data collection and reporting to drive clinical best practice

## Goal: OrganMatch functionality drives clinical practice improvement

The national OrganMatch system went live in April 2019, replacing the outdated National Organ Matching System (NOMS). The OrganMatch system supports patient wait listing, optimal immunological matching and organ allocation.

The Review Report recognised the opportunities delivered through OrganMatch including delivering transparency and process efficiencies across wait listing and the organ allocation and offer processes. It found that this system facilitates more streamlined, timely and efficient information sharing, and has the capacity to maintain clinical best practice for organ matching.

The Australian Government has committed ongoing funding to allow continued improvements and efficiencies to be made to OrganMatch, with the aim to improve patient outcomes.

The Strategy aims to further support OrganMatch as the system to drive optimal clinical best practice, ensuring Australia has a system with the capability to work with future capacity requirements and technological advancements.

All governments have agreed through the Transition Action Plan that OrganMatch be used as the national wait list and organ allocation system and the platform to drive clinical best practice. In addition, governments have agreed that the functionality of OrganMatch be expanded in line with clinical feedback to improve the efficiency of the organ allocation and offer process subject to available resourcing.

As set out in the Transition Action Plan, the Commonwealth funds OrganMatch. To drive a nationally consistent approach to wait listing, and organ offering and allocation, future funding arrangements and further enhancements will be negotiated and agreed with governments.

## Goal: Data is accessible and reported to drive best practice

Robust and accessible data to inform practice is essential for the sustainability of the organ donation, retrieval and transplantation system in Australia. The Review Report makes several recommendations about greater access and analysis of data and support for outcomes registries to inform clinical best practice.

Work on improving availability and use of data is underway.

All governments have agreed through the Transition Action Plan to continue to support the OTA to facilitate information sharing and access to an expanded de-identified data set. This will also

support policy makers and clinicians to deliver system planning improvements and enhancements. Through the Transition Action Plan all governments will also consider expansion of the availability of hospital donation performance data, and data relating to the profile and numbers of patients on transplantation waiting lists.

OTA will continue to enhance horizon scanning and monitoring of health sector developments potentially impacting on deceased donor organ transplantation. This will include monitoring of living donor kidney programs and the Australian and New Zealand Paired Kidney Exchange Program.

## Goal: Optimise functionality and use of transplantation outcome registries to inform policy and program design

Outcome registries play a valuable role in collecting, analysing and reporting on donation and transplantation data, and informing clinical best practice, future policies and program development. The Review Report highlights areas for improvement, including additional data capture, and streamlining of data submission processes.

All governments agree to review registries to consider how best to enhance data capture and reporting capabilities. This may include considering the value of additional data being captured by registries.

In the longer term, governments will consider the value of consolidation of all transplant outcome registries into one central registry. Any decision will take into account the Commonwealth’s Clinical Quality Registry Strategy.

# Next steps

## Delivering the Strategy

All governments are committed to the Goals and Priority Areas set out in the Strategy, and these will form the basis of future actions to support improvements in the sector.

Implementation of actions to support the Strategy is already underway through the Transition Action Plan. Progression of actions in the Transition Action Plan will deliver enhancements across the organ, eye and tissue donation, retrieval and transplantation sectors, and underpin and inform implementation of the Strategy.

Following Health Ministers’ agreement to the final Strategy, all governments will continue to collaborate on an implementation plan to deliver actions against each of the goals. This will include a staged approach to the development of the implementation plan with consideration of the feasibility, available resourcing and agreed prioritisation. A staged approach will allow for stakeholder consultation and learnings from actions to be incorporated iteratively into future planning and for priorities to be adjusted based on the most recent evidence and data. This will mean the implementation plan will be a dynamic document that is reviewed regularly.

Community and clinical stakeholder consultation is critical to the process, both in determining prioritisation of actions and throughout delivery. The approach to the development of the implementation plan will include clear mechanisms for engagement, such as expert advisory committees or other appropriate consultation structures identified by the sector. Key actions from this Strategy and those arising from the National Eye and Tissue Sector Framework will be aligned to ensure common issues and solutions are captured for both sectors.

The implementation plan will complement and build on the OTA’s Strategy 2022-2027, which outlines the five-year plan for the national organ donation program and is led by the OTA, and delivered collaboratively with the DonateLife Network, and Commonwealth, state and territory health governments. Future Strategic Plans will include all relevant activities for organ donation, retrieval and transplantation, and the eye and tissue sector. **This approach will ensure the sector is guided by one plan into the future**.

## Measurement and accountability

As Strategy implementation progresses, it will be critical to understand the impact of new activities or changes to existing arrangements. All governments are committed to measure, track and report on outcomes under the Strategy, through collaboration with key stakeholders. Implementation planning will incorporate evaluation and research to demonstrate where policies, programs and systems are working well, and highlight where improvements are required, or investments need to be refined or retargeted.

## Roles and responsibilities

A key element of Strategy implementation will be to define and put in place ongoing governance arrangements to ensure a nationally consistent approach. In the interim, the Commonwealth Department of Health and Aged Care, working closely with the OTA, will continue to lead implementation planning through jurisdictional committee arrangements. All jurisdictions and the Commonwealth will have a role to play in implementation.

Some actions will be the responsibility of the Commonwealth to lead and fund, coordinated by either the Department of Health and Aged Care or the OTA. Others will be driven and funded by states and territories through their health systems. The aim will be for a nationally consistent

approach, though different arrangements and available resourcing may mean that there is some variation in both delivery and timing.

Some actions may require cost-shared funding with contributions from both the Commonwealth and jurisdictions. These will be delivered through projects requiring agreement from all jurisdictions before implementation can progress.

To be effective, implementation planning will need to draw on the extensive expertise throughout the sector. This will involve leveraging existing expert advisory committees and may involve the establishment of further working groups or expert advisory committees, which can advise on barriers and enablers for implementation of key actions.

# Appendix A

## Associated plans, strategies and frameworks

The following references are national plans, strategies and frameworks intersecting with the organ donation, retrieval and transplantation sector. States and territories also have a range of other planned frameworks and strategies to complement the list below:

### OTA Strategy 2022-2027

This Strategy was developed by the OTA in consultation with the DonateLife Network and representatives of Commonwealth, state and territory health departments. The Strategy identifies the OTA’s goals and objectives over the next five years.

The 3 goals of the Strategy are;

1. Build support- More people say yes to donation
2. Optimise opportunities- Donation and transplantation services deliver the best outcomes
3. Enhance systems- Enable quality outcomes through information, technology and resources

### The National Eye and Tissue Sector Framework ([Framework](https://www.health.gov.au/resources/publications/eye-and-tissue-sector-framework?language=en))

The Framework provides the future directions for the Australian eye and tissue sector. The Framework sets the national objectives to achieve the vision that all Australians have safe, equitable and ethical access to life-altering and/or life-saving tissue transplantation, through a strong and effective Australian eye and tissue donation for transplantation sector.

### The Transition Action Plan ([TAP](https://www.health.gov.au/resources/publications/transition-action-plan?language=en))

The TAP consolidates under 4 priority areas, 12 actions that can be progressed prior to implementation planning for the National Organ Donation, Retrieval and Transplantation Strategy and the National Eye and Tissue Sector Framework. These actions inform the implementation approach for both policy documents.

### National Strategic Action Plan for Kidney Disease (Action Plan)

The Action Plan provides a blueprint for transforming kidney disease in Australia with over 30 actions across 3 priority areas designed to address the most pressing needs in kidney disease.

### Australian National Diabetes Strategy 2021-2030

The Australian National Diabetes Strategy 2021–2030:

* considers current approaches to diabetes services and care;
* considers the role of governments and the diabetes sector;
* ensures current efforts and investments align with identified needs;
* maximises the efficient use of health care resources and
* articulates a vision for preventing, detecting and managing diabetes.

### Closing the Gap

All Australian governments are working with Aboriginal and Torres Strait Islander people, their communities, organisations and businesses to implement the new [**National Agreement on Closing the Gap**](https://www.closingthegap.gov.au/national-agreement) at the national, state and territory, and local levels.

### Nurse Practitioner Workforce Plan

The purpose of the Plan is to describe a set of actions that can be taken to address nurse practitioner workforce issues and enhance the delivery of nursing care to the Australian community.

# Appendix B

## Abbreviations and acronyms

**ANZDATA**: Australia and New Zealand Dialysis and Transplant Registry

**ANZKX**: Australian and New Zealand Paired Kidney Exchange Program

**AODR**: Australian Organ Donor Register

**COVID-19**: Coronavirus Disease of 2019

**Framework**: National Eye and Tissue Sector Framework

**ICU**: Intensive Care Unit

**JODRT**: Jurisdictional Organ Donation, Retrieval and Transplantation Steering Committee

**JOTSC**: Jurisdictional Organ and Tissue Steering Committee

**NIKTT**: National Indigenous Kidney Transplantation Taskforce

**NOMS**: National Organ Matching System

**OTA**: Organ and Tissue Authority

**Program**: Supporting Living Organ Donors Program

**Review Report**: Review of the Australian organ donation, retrieval and transplantation system Final Report

**Strategy**: National Strategy for Organ Donation, Retrieval and Transplantation

**TSANZ**: Transplantation Society of Australia and New Zealand

## Glossary of terms

**Australian Government:** Commonwealth Government

**Australian Organ and Tissue Donation and Transplantation Authority (OTA)**: A statutory body established under the **Australian Organ and Tissue Donation and Transplantation Authority Act 2008** to deliver the national program. Also known as the Organ and Tissue Authority (OTA).

**Australian Organ Donor Register (AODR)**: The national register for Australians to record their organ and tissue donation decision.

**Australian and New Zealand Paired Kidney Exchange (ANZKX) Program**: A paired kidney donation program between Australia and New Zealand. It aims to increase living donor kidney transplants for patients who are eligible for a kidney transplant and have a living donor who is willing but unable to donate because of an incompatible blood type of tissue type. Incompatible pairs are enrolled in the program and are matched against other incompatible pairs.

**Consent rate**: The number of consents as a percentage of all requests made to potential deceased donor families in the hospital.

**Donor families**: Families who have donated their loved ones’ organs and tissues.

**DonateLife Network**: The national network of state-based DonateLife agencies including staff focused on increasing organ and tissue donation.

**Governance**: The set of relationships and responsibilities that establish how an organisation or system is controlled and operates, including the mechanisms for monitoring performance.

**Governments**: Commonwealth, state and territory governments.

**Horizon scanning**: The activity of trying to understand what is likely to happen or change in the future, especially what new technologies or risks are likely to appear.

**Living donor**: An individual who donates a kidney or part of their liver to another person.

**Local Hospital Network (LHN)**: An organization that provides public hospital services in accordance with the National Health Reform Agreement. An LHN can contain one or more hospitals, and is usually defined as a business group, geographical area or community. Every Australian public hospital is part of an LHN.

**Outcome registry**: Standardised collection of clinical and patient outcomes data used to identify outcome benchmarks, significant outcome variance and inform improvements in healthcare quality.

**OrganMatch**: Database that facilitates compatibility matching of recipients and donors for organ transplantation in Australia.

**Primary care**: The first point of contact people have with the health system and can include services delivered to individuals by general practice, allied health, social services, community health and community pharmacy and broader population level/public health functions.

**Shared care**: Joint responsibility for planned care that is agreed between healthcare providers, the patient and any carers.

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All information in this publication is correct as at September 2024

1. A guide to associated plans, strategies and frameworks is at Appendix A [↑](#footnote-ref-2)
2. For example, Lawton P et al, 2017, ‘Organ Transplantation in Australia: Inequities in Access and Outcome for Indigenous Australians’ The Official Journal of the Transplantation Society and the International Liver Transplantation Society, Vol: 101 Issue: 11, pp. 345-346; Organ transplant system tipped towards non-Indigenous patients, 2017, radio program, ABC Radio, Sydney 14 December 2017. [↑](#footnote-ref-3)
3. PricewaterhouseCoopers Report: Analysis of the Australian tissue sector:

<https://www.donatelife.gov.au/about-us/corporate-information/government-reports> [↑](#footnote-ref-4)
4. [2023 Australian Donation and Transplantation Activity Report](https://www.donatelife.gov.au/sites/default/files/2024-02/2023%20Donation%20and%20Transplantation%20Activity%20Report.pdf) [↑](#footnote-ref-5)
5. [2023 Australian Donation and Transplantation Activity Report](https://www.donatelife.gov.au/sites/default/files/2024-02/2023%20Donation%20and%20Transplantation%20Activity%20Report.pdf) [↑](#footnote-ref-6)
6. [2023 Australian Donation and Transplantation Activity Report](https://www.donatelife.gov.au/sites/default/files/2024-02/2023%20Donation%20and%20Transplantation%20Activity%20Report.pdf) [↑](#footnote-ref-7)
7. [TSANZ Performance Report - Improving Access to and Outcomes of Kidney Transplantation for Aboriginal and Torres Strait Islander People in Australia](https://www.anzdata.org.au/wp-content/uploads/2019/07/TSANZ-Performance-Report-Improving-Indigenous-Transplant-Outcomes-Final-edited-1.pdf) [↑](#footnote-ref-8)
8. K. Dole, A. Casilli, N. Tinsley, J. Collett, S.W. Majoni, Improving access to renal transplantation among Indigenous patients with end-stage renal disease: A review from the Top End of Northern Australia where graft and patient outcomes have generally been poor, Transplant Journal of Australasia, 27:1, 2018, pp. 14-22. [↑](#footnote-ref-9)
9. [ANZDATA AR 2021 - Chapter 10 - End Stage Kidney in Aboriginal and Torres Strait Islander Australians](https://www.anzdata.org.au/wp-content/uploads/2021/09/c10_indigenous_2020_ar_2021_v1.0_20220224_Final.pdf) [↑](#footnote-ref-10)
10. [Cultural Bias Indigenous Kidney Care and Kidney Transplantation Report (2022), NIKTT](https://www.niktt.com.au/_files/ugd/1f23c8_e5fa9c7b929a40e2a02570febd4be94a.pdf) [↑](#footnote-ref-11)
11. [2023 Australian Donation and Transplantation Activity Report](https://www.donatelife.gov.au/sites/default/files/2024-02/2023%20Donation%20and%20Transplantation%20Activity%20Report.pdf) [↑](#footnote-ref-12)