Progressing Australian organ and tissue donation and transplantation to 2020

THE 2016–2020 STRATEGY
The Miracle of Transplantation

Transplantation really is an extraordinary miracle.
You have patients, who are so sick and fragile while they are waiting for a new liver, then they have a transplant and a few months later they are at home cutting the lawn or playing sport.

They’re back doing the normal things they were doing before they got sick.

For every 10 patients who come to our hospital waiting for a transplant, three to four of them receive one.
The others will either get better under medical care or they die waiting for a transplant.

It is very frustrating for us to see people dying, but it is absolutely devastating for their families.

I find it extraordinary that, in their grief, families decide to donate at all.

I am always amazed by the process. There is something so fundamental about the gift of life.

By making that decision, you will be saving someone’s or several people’s lives.

The question should not be: ‘Do you want to be an organ donor?’ The question should be: ‘Do you want to make transplantation available to more Australians’

The body is made up of exquisite organs.

It is a great shame to waste them.

Professor Bob Jones
Liver Transplant Unit Director
Austin Hospital, Victoria
The Organ and Tissue Authority (OTA) manages the implementation of the Australian Governments' national reform program for increasing organ and tissue donation for transplantation in partnership with the DonateLife Network, state and territory governments, the donation and transplantation clinical sectors, eye and tissue banks and the community.

This strategic plan has been developed in consultation with the OTA Advisory Council, the DonateLife Network leadership team and representatives of state and territory governments.
Transplantation is an effective and well-established treatment that can significantly benefit Australians facing illness, disability or premature death. Transplantation can save lives, restore health, improve quality of life, and offers significant cost benefits to the health system when compared with alternate treatment options.

Transplantation relies on the donation of organs and tissues. Most organs and tissues arise from donation occurring after death, although a small and select proportion of transplantations occur from organs and tissues donated from living individuals. However, there is a persistent disparity between the supply of and need for transplantable organs and some tissues in Australia, as there is in the rest of the world. For this reason, we are committed to optimising every donation opportunity.

There has been significant growth in transplantation and donation outcomes since the Australian Government’s national reform program commenced in 2009; however, there is still more that can be done.

This strategic plan outlines our vision and priorities for 2016 to 2020 to ensure a shared understanding of our purpose and strategies to achieve our national goal of 25 organ donors per million population (dpmp) by 2018 and the new targets beyond 2018 that are yet to be agreed.

Increasing organ and tissue donation for transplantation in Australia is a collective responsibility. Society as a whole, healthcare workers and particularly clinicians involved in end-of-life care, must recognise that without donation there can be no transplantation. Unless individuals and their families agree to donation, and clinicians act to facilitate donation at every possible opportunity, transplant rates cannot improve.

We must all work together to normalise clinical and community acceptance of organ and tissue donation to ensure that potential donors and their families are provided with every opportunity to donate.

We thank and acknowledge the generous Australians and their families who have saved and transformed the lives of transplant recipients through organ and tissue donation. We also acknowledge the commitment and increasing focus of clinicians to ensuring consideration of donation as part of routine end-of-life care. These changes in clinical practice and the generosity of donors and donor families who consent to donation have, and will continue to have, a profound impact on those Australians who receive a transplant, as well as on their families and communities.

We look forward to working collaboratively with our partners and key stakeholders to implement this strategic plan to increase the availability of donor organs and tissues to ensure more Australians are able to benefit from transplantation.
**THE ISSUE**

Australia has seen an increasing number of patients who might benefit from organ or tissue transplantation due to a rising prevalence of chronic organ failure and enhanced effectiveness of transplantation as a treatment due to advancements in medical technology. It is expected that this need for transplants will continue to increase as it is around the world.

In 2015, a record outcome of 435 deceased organ donors provided 1,239 Australians with the opportunity for a life-saving or life-transforming organ transplant.

Despite the growth in donation outcomes under the national reform program, the need for organs and tissues for transplantation continues to outweigh their availability in Australia and the demand is growing.

In recent years, there have been around 1,500 Australians on the organ transplant waiting list at any one time, with the majority being patients with chronic kidney failure. A further 12,000 patients are on dialysis. This comes at a significant cost to those needing a transplant, their family and community, and the health care system.

Australia is not alone in facing a shortfall in transplantable organs and tissues. Across the developed world the gap between the available supply of and demand for organs and tissues for transplantation has led to the introduction of a variety of initiatives to improve donation rates.

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**Donation outcomes vs. organ availability**

- Deceased donors
- Transplant recipients
- Patients on waiting list

![Graph showing donation outcomes vs. organ availability](image)

**Source:** Australia New Zealand Organ Donation (ANZOD) Registry 2015

**Note:** Waiting list data is collected by National Organ Matching System (NOMS) and reported by the ANZOD. This data refers only to people on the “active” waiting list who would be transplanted immediately if an organ was available on the date reported. It does not reflect the transitions on and off the waiting list over the period since data was last reported to the ANZOD.
Our purpose is to save and improve the lives of more Australians through optimising every potential organ and tissue donation for transplantation.

Receiving the amazing gift of a donated liver has changed my life in so many ways. Being able to be a mum to my two children for longer will be something I will be eternally grateful for.
Our mission is to deliver a nationally consistent world’s best practice approach to organ and tissue donation for transplantation in Australia, in collaboration with the states and territories, clinicians and the community.

The twin objectives of this national reform program are:

1. To increase the capability and capacity within the health system to maximise donation and transplantation rates, and

2. To raise community awareness and stakeholder engagement with the goal of encouraging all Australians to make a decision to support organ and tissue donation.

The Australian reform program is consistent with international best practice adapted to the Australian clinical environment.

The key reform elements adopted in Australia are:

- An appropriate legal and ethical framework
- A national coordinating body
- Hospital-based clinical donation specialists
- Specialist training for clinical staff in management of the donation process and family donation conversations
- Implementation of a national clinical governance framework that supports quality assurance and audit of hospital clinical practice and governance of the donation process
- Financial support to donor hospitals to ensure that costs related to donor management are not a barrier to donation
- Media engagement and national community awareness and education
- International cooperation to share best practice.

A liver transplant means that I can now see my daughter Iva grow up
ORGAN DONATION IS A RARE AND PRECIOUS OPPORTUNITY

Fewer than 1,000 people die in Australia each year in circumstances that allow for organ donation.

The major limiting factor is where and how death occurs, with only 1 to 2% of deaths in hospital occurring in a way that organ donation for transplantation is medically possible. The deaths that can proceed to organ donation for transplantation usually result from a sudden and unexpected clinical event e.g. stroke; motor vehicle accident where end-of-life care is provided to the patient in an intensive care unit or sometimes emergency department.

Maximising donation outcomes from this small donor pool, means having optimal practices applied to every step of a potential donor’s end-of-life care in hospital and a very high level of family and community awareness and support for donation.

A far greater number of people have the opportunity to donate tissues\(^1\) and benefit from receiving tissue transplants. Tissue donation does not require a donor’s death to have occurred within such limited clinical circumstances as organ donation; and, unlike organs, tissues can be stored for varying periods of time for up to five years.

### Australia’s potential organ donor population

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian population(^1)</td>
<td>~23,781,169</td>
</tr>
<tr>
<td>Australian deaths(^2)</td>
<td>~153,580</td>
</tr>
<tr>
<td>Deaths in hospitals(^3)</td>
<td>~76,577</td>
</tr>
<tr>
<td>Potential donors(^4)</td>
<td>~934</td>
</tr>
<tr>
<td>Donation requests(^4)</td>
<td>~905</td>
</tr>
<tr>
<td>Consented donors(^4)</td>
<td>~564</td>
</tr>
<tr>
<td>Actual donors(^5)</td>
<td>435</td>
</tr>
<tr>
<td>Transplant recipients(^6)</td>
<td>1,239</td>
</tr>
<tr>
<td>Organ transplant procedures(^6)</td>
<td>1,301</td>
</tr>
<tr>
<td>Organs transplanted(^6)</td>
<td>1,481</td>
</tr>
</tbody>
</table>

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1 Throughout this plan, unless otherwise specified, ‘tissue’ refers to all tissue types, including eye tissue.

2 ABS 3302.0 Deaths, Australia, 2014 (released 12 November 2015)
4 Estimated using DBD request and consent rates and extrapolated to include the DCD pool, DonateLife Audit, September 2015. Future modeling may inform revision of these numbers.
5 Deceased Organ Donation in Australia, ANZOD, December 2015.
ORGAN AND TISSUE DONATION IS A SHARED RESPONSIBILITY

Increasing the number of people who donate their organs and tissues is a challenge for the whole of society – all of the Australian community, including clinicians who provide end-of-life care and transplantation services.

The role of the community is pivotal to increasing organ and tissue donation in Australia because consent is dependent on individual and family willingness and agreement to donation.

While the majority of Australians express a willingness to become organ and tissue donors, families consent to donation in around 60% of cases. This means that around 40% of donations do not proceed through lack of consent. Lifting the consent rate from 62% to 75% in 2015 would have resulted in up to 89 additional organ donors and 252 additional transplant recipients.

From a community point of view, the main barrier to donation is a lack of family knowledge of a person’s donation decision. The family is always asked to confirm the donation decision of a potential donor before donation can proceed. Registration and family knowledge of donation decisions makes a major difference when families are faced with the usually sudden death of their relative.

Data from 2015 shows that donation proceeded in 91% of cases when the potential donor had registered their decision to donate and 75% of cases when the potential donor’s family knew of their donation decision, compared to the national average of 62%.

Further, when the potential donor had neither registered their donation decision nor discussed their wishes with family members, donation only proceeded in 52% of cases.

Equally, donation for transplantation cannot be maximised without the pivotal input of those clinicians involved in end-of-life care and the provision of transplantation services.

The main clinical barrier to donation is the lack of routine consideration of donation as part of end-of-life care, compounded by the inconsistent application of the proven donation management system in all Australian hospitals with the potential for donation.

### Organ donation consent rates

<table>
<thead>
<tr>
<th>Registration and family knowledge of donation decision</th>
<th>Of families agreed to donation proceeding when their loved one was a registered donor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>91%</td>
</tr>
<tr>
<td></td>
<td>Of families agreed to organ donation when they knew their loved one’s decision</td>
</tr>
<tr>
<td></td>
<td>75%</td>
</tr>
<tr>
<td>National average</td>
<td>Of families agreed to donation when the potential donor had not registered or discussed their donation wishes</td>
</tr>
<tr>
<td></td>
<td>62%</td>
</tr>
<tr>
<td></td>
<td>52%</td>
</tr>
</tbody>
</table>

Source: DonateLife Audit 2015
The quality of the donation conversation and the information provided to families impacts family decision making. Evidence indicates that donation proceeds more frequently when an Family Donation Conversation (FDC) trained requester actively participates in family conversations about donation when donation is first raised with the family.

Data from 2015 shows that donation proceeded in 75% of cases when the family donation conversation was led by an FDC trained requester who was not part of the treating clinical team, as compared to 55% when the family donation conversation was led by an FDC-trained treating clinical specialist and 45% when the family donation conversation was led by the treating clinical specialist who was not FDC trained.

Those clinicians that deliver transplantation services also play a pivotal role in maximising transplantation opportunities. Across Australia, there is variation both within and between transplant centres about the donor organ characteristics that may preclude transplantation. While maintaining appropriate quality and safety approaches to maximise transplantation outcomes, transplant clinicians must have support systems in place to assist them and the potential recipient to balance the benefit of transplantation against potential risks to optimise health outcomes.

My husband Michael donated a kidney to me in 2014. We are looking forward to sharing many more years and growing old together, and seeing our son develop into a man with his own family.

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**Organ donation consent rates**

Participation of a Family Donation Conversation (FDC) trained requester

- **75%** of families agreed to organ donation when the donation conversation was led by an **FDC-trained requester who was in addition to the treating clinical team**
- **55%** of families agreed to organ donation when the donation conversation was led by an **FDC-trained treating clinical specialist**
- **45%** of families agreed to organ donation when the donation conversation was led by the **treating clinical specialist who was not FDC trained**

*Source: Towards a national model for organ donation requests in Australia: evaluation of a pilot model, Critical Care and Resuscitation, Vol 17 Number 4, December 2015*

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2 An FDC trained requester is a clinician who has completed the core FDC workshop. They may be donation specialist staff employed by the hospital or DonateLife Agency, or may be other senior hospital staff such as intensive care specialists who have completed the core FDC workshop. The core FDC workshop provides the knowledge and skills to communicate with families about death and donation, and to support families to make an informed donation decision.
THE PLAN

Key objectives

1. OBJECTIVE 1
   Increase the number of potential organ and tissue donors
   P. 16

2. OBJECTIVE 2
   Improve organ and tissue donor conversion rates
   P. 18

3. OBJECTIVE 3
   Enhance systems to support organ and tissue donation and transplantation
   P. 20

This four year strategic plan has been developed to ensure that organ and tissue donation and transplantation services are delivered consistently across Australia. The current target aims to increase Australia’s organ donation outcomes to 25 donors per million population (dpmp) by 2018.

The plan identifies the objectives, strategies and actions resulting from consultation with OTA stakeholders, as well as agreed performance measures.

The key objectives specify the outcomes needed to achieve and guide our strategies and actions for the next four years.

The strategic plan guides all other plans developed within the OTA and it is the responsibility of executive management to ensure that any work plans for each business unit and individual performance agreements align with the strategic plan.

Key performance measures will monitor our progress; and our performance will be regularly reported to the community and the Australian Government.

A double-lung transplant has given me a chance at a better life and a promising future with precious family and friends. Whether it’s walking the dog, keeping fit or working hard to achieve my career goals—things I was unable to do prior to my transplant—my donor is always close to my heart.
The Australian Government’s ongoing support for organ and tissue donation

The Australian Government remains committed to increasing organ and tissue donation rates to improve access to life-transforming transplants for all Australians.

In the 2015–16 Budget, the Australian Government announced a two-year measure, Accelerating growth in organ and tissue donation for transplantation, to enhance the national reform program through an efficient investment in systems and processes; and additional education to continue to remove clinical barriers to expanding the donor pool and increasing consent to donation.

Significant progress was made towards delivery of this budget measure in 2015–16 and work will continue in 2016–17.

The 2016–17 Budget included a one-year measure, Organ and Tissue Donation Review – implementation of review recommendations, to progress the implementation of several recommendations of the Ernst and Young Review Report on the implementation of the national reform program released in February 2016; and to promote the Supporting Leave for Living Organ Donors (SLLOD) program.

Actions to deliver these budget measures have been incorporated into this strategic plan.

Annual review

The strategic plan is reviewed and updated annually. The annual review will provide the opportunity to assess the effectiveness of the strategies and actions in terms of progress towards achievement of the objectives; to identify any changed circumstances, needs or priorities; and to update the plan to ensure it remains relevant and practicable.

The annual review in 2017–18 will include a systematic analysis of the effectiveness of the current programs and policies in order to prepare advice on 2018 and beyond for Health Ministers.
Strategic priorities

Consistent with our three key objectives and government budget measures, the OTA, in partnership with the DonateLife Network and the community sector, has identified ten strategic priorities for 2016–17:

1. Implement the Clinical Practice Improvement Program Phase 2 and the DonateLife Collaborative strengthening organ and tissue donation practice in DonateLife Network hospitals
2. Partner with state and territory governments and the transplant sector to optimise organ utilisation for transplantation through using organ perfusion technology, understanding blood borne virus transmission, and exploring further opportunities to expand the donor pool
3. Collaborate with the Blood Service, the DonateLife Network and the transplant sector to deliver the Australian Organ Matching System scheduled for implementation in 2018, to maximise access and enhance clinical outcomes for organ donation and transplantation e.g. specific age matching of donors to recipients
4. Contribute to increasing awareness and access to living organ donation
5. Deliver the national donor online registration campaign calling on Australians to register donation decisions on the Australian Organ Donor Register and to discuss their decision with family and loved ones
6. Implement and monitor the Australian best practice model for offering organ and tissue donation in Australia providing optimal information and support for families and clinicians when organ donation is possible
7. Implement the Electronic Donor Record Eye Module supporting a nationally consistent approach to eye donation from the point of donor identification to the dispatch of processed eye tissue to clinicians for surgical use
8. Contribute to the implementation of the recommendations of the Economic Analysis of the Australian Tissue Sector Report pending an agreed implementation plan

9. Contribute to the implementation of the recommendations of the Ernst and Young Review Report, Review of the implementation of the national reform agenda on organ and tissue donation and transplantation
10. Model projected organ donation growth and identify indicative organ donation targets for agreement by Health Ministers. The agreed targets will inform workforce and resource planning to ensure that all possible donation and transplantation opportunities are realised.

Performance framework

A key element of the Public Governance, Performance and Accountability Act (PGPA) is the implementation of an enhanced whole-of-government performance framework.

The performance framework is based on Section 38 of the PGPA Act, which requires all Commonwealth entities to measure and assess their performance and is underpinned by the principle that confidence in the efficient, effective and proper use of public resources is supported by a strong performance framework.

Indicative national and jurisdictional organ donation key performance indicators for projected donation and transplant trajectories have been in place since 2012. Our aim is for Australia to achieve an organ donation rate of 25 dpmp by 2018 with targets to 2020 to be identified in 2016–17.
### Performance framework

#### OUR PURPOSE

#### OUR MISSION

#### Objectives

1. Increase the number of potential organ and tissue donors
2. Improve organ and tissue donor conversion rates
3. Enhance systems to support organ and tissue donation and transplantation

#### Strategic priorities

<table>
<thead>
<tr>
<th>Performance measures</th>
<th>Target</th>
<th>Current level (2015)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Organ transplant recipients (from deceased donors) per million population (trpmp)</td>
<td>70 trpmp by 2018</td>
<td>52.1 trpmp</td>
</tr>
<tr>
<td>2 Deceased organ donors per million population (dpmp)</td>
<td>25 dpmp by 2018</td>
<td>18.3 dpmp</td>
</tr>
<tr>
<td>3 Request rate</td>
<td>100%</td>
<td>97%</td>
</tr>
<tr>
<td>4 Consent rate</td>
<td>75%</td>
<td>62%</td>
</tr>
<tr>
<td>5 Conversion rate</td>
<td>70%</td>
<td>52%</td>
</tr>
<tr>
<td>6 Develop and implement performance measures for living donation by the end of 2017</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Develop and implement performance measures for the tissue sector by the end of 2018</td>
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</tbody>
</table>

#### Note

Performance measures are reported by calendar year to align with Australian and international donation and performance reporting practice. Progress against these performance measures will be reported in the OTA Annual Report and progress reports on transplantation and donation activity.

Performance Measures 1 and 2 are specific to deceased organ donors, public reporting will include transplant recipients from deceased donors per million population as well as transplant recipients from combined deceased and living donors per million population.

Performance Measures 1 and 2 are time limited targets and progress is measured using national organ transplantation and donation data reported by ANZOD. These targets are reviewed annually.
Receiving the gift of a kidney transplant has really improved my life. It has freed me from years of dialysis and being away from my country. I can spend more quality time with my wife and family. Now that I am well I want to spend time sharing health information with others.
Objective 1: Increase the number of potential organ and tissue donors

1.1 Embed organ and tissue donation as a routine part of end of life care

Every person in Australia should expect organ and tissue donation to be considered as a routine part of their end-of-life care. As donation continues to become normalised in the Australian community, clinicians must be ready to identify and respond to all donation opportunities. Resources must be invested in strengthening donation systems and continued education provided to support clinicians in embedding donation as part of routine end-of-life care.

1.2 Increase the uptake of Donation after Circulatory Death (DCD)

While donation after brain death is the major pathway to donation in Australia, there has been a consistent increase in the uptake of DCD since its reinstatement as a donation pathway in Australia in 2006. However, the uptake of DCD varies across Australia and further work is required to ensure that every potential DCD donor is identified and referred for donation.

1.3 Increase Donation after Brain Death (DBD)

While DBD is the most common pathway to organ and tissue donation worldwide, Australia has a relatively low rate of DBD compared with some other countries. This is believed to be the result of clinical decisions to limit or withdraw treatment for patients with non-survivable brain injuries before brain death has evolved or can be diagnosed. In Australia end-of-life care practices should always consider support of the potential for DBD, particularly in circumstances where individuals have stated their wish to donate organs and tissues after death. A review of end-of-life care practices to support the identification and early referral of all severely brain-injured patients likely to develop brain death will support an increase in DBD.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibility</th>
</tr>
</thead>
</table>
| 1.1.1 Implement a routine referral system for all potential organ and tissue donors | • OTA  
• DonateLife Network |
| 1.1.2 Continue to implement and develop the Clinical Practice Improvement Program, including the DonateLife Collaborative | • OTA  
• DonateLife Network |
| 1.1.3 Deliver professional education and training to sustain and increase clinicians understanding and expertise in organ and tissue donation | • OTA  
• DonateLife Network |
| 1.1.4 Provide funding to hospitals as a contribution toward the costs associated with organ donation activity | • OTA |
| 1.2.1 Continue to develop and implement the national DCD program, including protocols and training | • OTA  
• DonateLife Network  
• Professional Associations |
| 1.2.2 Review end-of-life care practices to ensure that all opportunities for DCD are identified | • OTA  
• DonateLife Network  
• Professional Associations |
| 1.2.3 Expand public reporting to include DCD activity at the national, state and hospital level | • OTA  
• DonateLife Network  
• Governments |
| 1.3.1 Review end-of-life care practices to ensure that all opportunities for DBD are realised | • OTA  
• DonateLife Network  
• Professional Associations |
| 1.3.2 Improve public reporting of DBD activity at the national, state and hospital level | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations and the wider clinical community |
1.4 Increase the transplantation of organs from an expanded donor pool

As has been the case internationally, expanding the donor pool while balancing benefit and potential risk, increases the number of recipients who benefit from transplantation. This must be supported by appropriate systems, policies and protocols to provide the community and clinicians with the confidence to proceed, while being assured of the ongoing safety and ethical approach to donation and transplantation in Australia.

1.5 Increase living organ and tissue donation

International data frequently indicates that living donor rates decrease as deceased donor rates increase. This has occurred in Australia with 2015 data showing that transplant recipients from living donors decreased by 26% from 329 transplant recipients in 2009 to 245 in 2015. A 2013 national report identified multiple opportunities for increasing living organ donation in Australia, including raising awareness of living donation with clinicians and the community, and to implement systems and programs to promote living donation as an option for transplantation. Increased reporting and analysis of living donation data can inform an increase in living donation in Australia.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibility</th>
</tr>
</thead>
</table>
| 1.4.1 Provide ongoing guidance on levels of acceptable risk to the community and the clinical sectors through the use of ethical and clinical guidelines relevant to the individual recipient’s needs and wishes | • OTA  
• DonateLife Network  
• Professional Associations  
• Community Organisations |
| 1.4.2 Continue to implement and develop a national program for transplantation of organs from an expanded donor pool | • OTA  
• DonateLife Network  
• Professional Associations and the wider clinical community |
| 1.4.3 Develop public reporting to include donation and transplantation activity from an expanded donor pool | • OTA  
• DonateLife Network  
• Governments |

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibility</th>
</tr>
</thead>
</table>
| 1.5.1 Raise awareness of living organ and tissue donation within the community and clinical sectors | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations, Community Organisations |
| 1.5.2 Continue to deliver and develop the AKX program | • OTA  
• Governments  
• Professional Associations and the wider clinical community |
| 1.5.3 Expand public reporting to include living organ and tissue donation and transplantation activity | • OTA  
• Governments |
**Objective 2: Improve organ and tissue donor conversion rates**

### 2.1 Increase community acceptance of organ and tissue donation

Australians must understand that transplantation can only occur as a result of organ and tissue donation; however public awareness without action does not increase the number of transplants. Donation must be seen as a community responsibility. As a community we must get to a point where families perceive it to be normal to be approached for organ and tissue donation for there to be a high rate of consent such that donation proceeds.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibility</th>
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<tbody>
<tr>
<td>2.1.1</td>
<td>Support national debate to identify changing community attitudes towards organ and tissue donation and transplantation</td>
</tr>
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<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<td>• Governments</td>
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<td></td>
<td>• Community Organisations</td>
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<tr>
<td>2.1.2</td>
<td>Continue to develop and implement national programs to promote a shift in community behaviour and increase consent to organ and tissue donation</td>
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<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<td>• Governments</td>
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<td></td>
<td>• Community Organisations</td>
</tr>
<tr>
<td>2.1.3</td>
<td>Promote family discussion and AODR registration of organ and tissue donation decisions</td>
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<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<td>• Governments</td>
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<tr>
<td></td>
<td>• Community Organisations</td>
</tr>
<tr>
<td>2.1.4</td>
<td>Increase culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (Indigenous Australian) communities awareness of organ and tissue donation</td>
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<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<td></td>
<td>• Governments</td>
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<tr>
<td></td>
<td>• Community Organisations</td>
</tr>
<tr>
<td>2.1.5</td>
<td>All governments promote organ and tissue donation and transplantation to engage the community and increase the consent for donation</td>
</tr>
<tr>
<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<td>• Governments</td>
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</tbody>
</table>

### 2.2 Increase family consent to donation

In Australia, around 40% of potential donations don’t proceed due to families declining donation, sometimes against the known wishes of the potential donor. There is evidence that the way in which the option of donation is presented to a grieving family can have a critical impact on the outcome. To improve consent rates, all involved must be given the best possible support and information when faced with the offer and consideration of donation.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.2.1</td>
<td>Embed the best practice model for offering organ and tissue donation in Australia which ensures that families of all potential donors are approached by someone who is specifically trained in the role</td>
</tr>
<tr>
<td></td>
<td>• OTA</td>
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<tr>
<td></td>
<td>• DonateLife Network</td>
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<tr>
<td></td>
<td>• Professional Associations and the wider clinical community</td>
</tr>
<tr>
<td>2.2.2</td>
<td>Continue to deliver and develop education and training for professionals involved in family donation conversations</td>
</tr>
<tr>
<td></td>
<td>• OTA</td>
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<td>• Professional Associations</td>
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<td>2.2.3</td>
<td>Expand public reporting to include request, consent and conversion outcomes at the national and state levels</td>
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2.3 Provide support for the families of potential organ and tissue donors

Donation conversations invariably occur at times of intense emotion and grief. Families of potential and actual donors require care and support as they consider donation, as well as after the event.

Community acknowledgement of the generosity and gift of donation is an important way to recognise the social contribution made by the donors and their families.

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| 2.3.1 Deliver the DonateLife Family Support Service to provide families of potential and actual donors with access to bereavement care and support | • OTA  
• DonateLife Network |
| 2.3.2 Recognise the contribution of donors and their families through national, state and hospital initiatives | • OTA  
• DonateLife Network  
• Governments  
• Community Organisations |

2.4 Optimise the function and condition of donor organs and tissues prior to retrieval

People make decisions about donating their organs in order to save and transform the lives of those who receive them. It is reasonable to assume that donors would wish the best possible good to come from their donation, and it is vital therefore that as many organs as possible are retrieved, and that they are maintained in the best possible condition for transplantation.

This requires the careful management of clinical care to maintain acceptable physiological parameters for donation to proceed, while preserving the dignity and comfort of the potential donor.

To optimise the opportunity for donation, it is necessary to continue or even to escalate critical care prior to organ retrieval, so as to correct any physiological damage or disturbance to potentially retrievable organs.

This care of the potential donor must be supported and directed by appropriate and agreed standards and guidelines for care of the potential donor.

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| 2.4.1 Continue to implement, develop and disseminate standards and guidelines to optimise the physiological management of potential organ and tissue donors | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations and the wider clinical community |
### Objective 3: Enhance systems to support organ and tissue donation and transplantation

#### 3.1 Improve utilisation of retrieved organs and tissues

There remains ongoing discussion amongst both the community and healthcare professionals about the most appropriate use of the limited number of organs from deceased donors. The rationale for both selection and allocation is based on consideration of utility, benefit and need. The relative importance of these different factors will vary for different organs.

In the past decade, there have been advances in the preservation of organs following retrieval that improve organ function e.g. improvements in preservation fluids and machine technologies. These approaches are now being considered in Australia with a view to improving the utilisation of all donated organs for transplantation.

Australia continues to develop improved allocation and matching systems and processes, as well as improving clinical guidance and standards to maximise the utility and function of all donated organs.

There is variation both between and within centres with respect to the application of donor organ acceptance criteria. Clinicians use their judgement based on current evidence to decide non-acceptance of some organ offers. While accepting that there are many potential reasons for the variation in acceptance rates, governments and the OTA must support clinicians in adapting their practice to balance the benefits of transplantation against the potential risks.

#### 3.2 Enhance the safety of organ and tissue donation and transplantation

Strict measures are required to safeguard public health by reducing the risk of adverse outcomes such as transmission of diseases through the transplantation of donor organs. A national system to review and communicate Serious Adverse Events and Reactions (SAERs) is essential. Review and analysis of data will assist in guiding informed and evidence-based clinical decision-making.

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<tr>
<td>3.1.1 Evaluate and implement new techniques and technologies for the preservation of retrieved organs and utilisation of tissues for transplantation</td>
<td>• OTA&lt;br&gt;• DonateLife Network&lt;br&gt;• Governments&lt;br&gt;• Professional Associations</td>
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<td>3.1.2 Develop and implement the Australian Organ Matching System (AOMS) and other initiatives to improve organ allocation and matching processes</td>
<td>• OTA&lt;br&gt;• Professional Associations</td>
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<td>3.1.3 Provide ongoing guidance on organ and tissue donor and recipient eligibility and allocation to the community and the clinical sectors through the use of ethical and clinical guidelines</td>
<td>• OTA&lt;br&gt;• DonateLife Network&lt;br&gt;• Governments&lt;br&gt;• Professional Associations&lt;br&gt;• Community Organisations</td>
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<td>3.1.4 Develop and implement an education program to facilitate informed consent for potential recipients to optimise their chance of receiving a timely appropriate transplant</td>
<td>• Professional Associations</td>
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<td>3.2.1 Develop and implement a national vigilance and surveillance system for deceased organ and tissue donation and transplantation</td>
<td>• OTA&lt;br&gt;• DonateLife Network&lt;br&gt;• Governments&lt;br&gt;• Professional Associations</td>
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3.3 Improve the efficiency of organ and tissue donation and transplantation

The DonateLife Network provides organ and tissue donation services across Australia. As donation activity increases, the model needs to continually adapt and change to support the increasing workload; the provision of a service to the potential donor and their family; and the donation management process. The use of technology, information and data; and the application of relevant research, will support the continuous improvement of donation practices across Australia.

As donation activity increases, there will be a flow-on effect which will increase the demand for downstream retrieval and transplantation services that will have workforce and resourcing implications for state and territory governments.

### Actions

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| 3.3.1 Continue to develop and implement data systems and outputs to inform continuous improvement of organ and tissue donation and transplantation | • OTA  
• DonateLife Network  
• Governments |
| 3.3.2 Subject to state and territory government policy, governments agree formal contracts for organ and tissue donation service delivery within all funded hospitals | • OTA  
• DonateLife Network  
• Governments |
| 3.3.3 Review and develop the workforce strategy for delivery of organ and tissue donation services | • OTA  
• DonateLife Network  
• Governments |
| 3.3.4 Continue to implement and develop the Clinical Practice Improvement Program, including the DonateLife Collaborative | • OTA  
• DonateLife Network  
• Governments |
| 3.3.5 Support the ongoing development of the eye and tissue sector in collaboration with governments and professional bodies | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations |
| 3.3.6 Address retrieval and transplantation capacity and resourcing requirements | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations |
| 3.3.7 Review and improve support for research in line with strategic objectives | • OTA  
• DonateLife Network  
• Governments  
• Professional Associations |

Since my corneal transplants I have moved into and decorated a new house, had two daughters marry in the same year, been presented with three granddaughters, started netball coaching again and can consider future travel. I’m the ‘on call’ Gran for minding Maya, Laura and Ava.