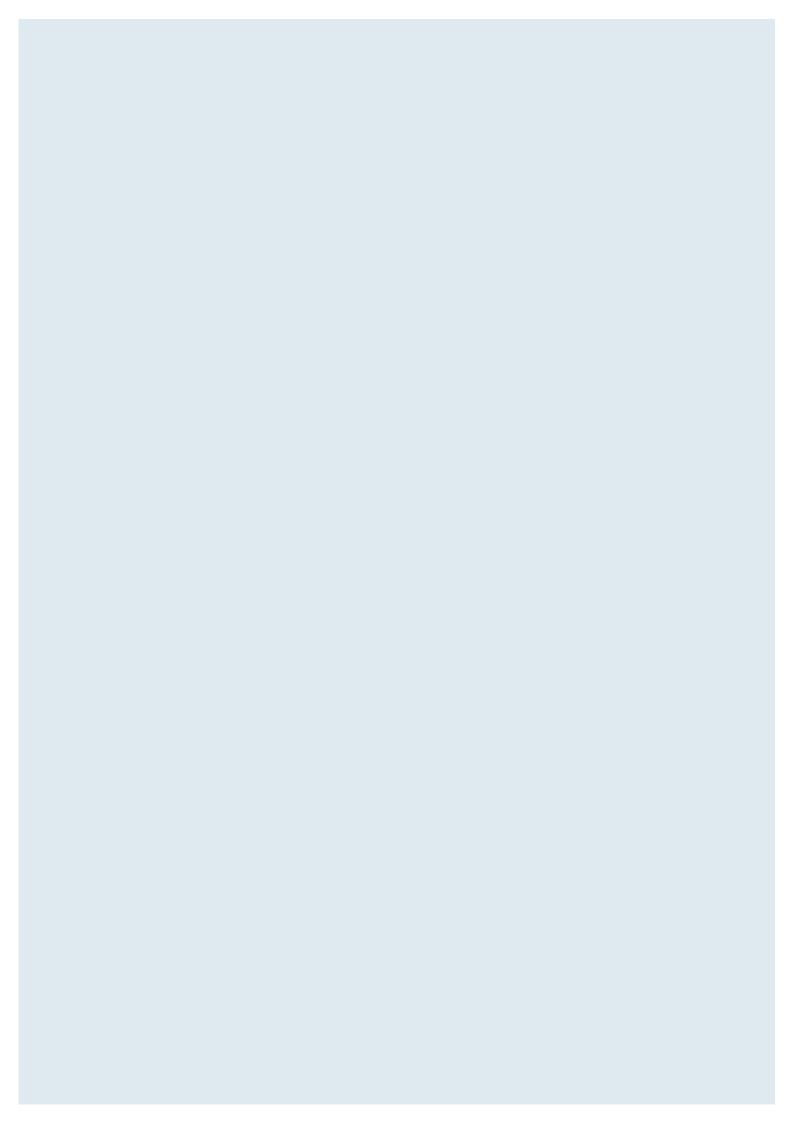




## Progressing Australian organ and tissue donation and transplantation to 2021

The 2017-18 to 2020-21 strategy



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The Organ and Tissue Authority (OTA) manages the implementation of the Australian Government's 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 is developed in consultation with the DonateLife Network leadership team and representatives of all Australian governments.

## **Foreword**

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 other treatment options.

Transplantation relies on the donation of organs and tissues. Most organs and tissues arise from donation occurring after death, with a small and select proportion of transplantations occurring from living organ donors. Conversely most tissue donations occur from living donors. 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 progress is recognised by the Australian Government which is committed to the continued delivery of the reform program. New governance arrangements for the Organ and Tissue Authority (OTA) commenced on 1 July 2017 with the establishment of the Australian Organ and Tissue Donation and Transplantation Board (the Board). The Board is responsible for the key policy and strategic functions of the OTA aiming to consolidate and build upon achievements to date.

This strategic plan outlines our vision and priorities for the four years 2017–18 to 2020–21 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 targets beyond 2018 that are yet to be agreed. In addition ten key areas of strategic focus for 2017–18 are identified.

Increasing organ and tissue donation for transplantation in Australia is a collective responsibility. Society as a whole must recognise that without donation there can be no transplantation. Unless individuals and their families agree to donation, and clinicians act to facilitate donation and transplantation at every possible opportunity, health outcomes through transplantation will not 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 that donation is a routine consideration during 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.

The OTA looks forward to working collaboratively with our partners and key stakeholders to implement the strategic plan to increase the availability of organs and tissues to ensure more Australians are able to benefit from transplantation.

The strategic direction and leadership provided by the OTA Board from 1 July 2017 will inform the evolution of the strategic plan.

## The issue

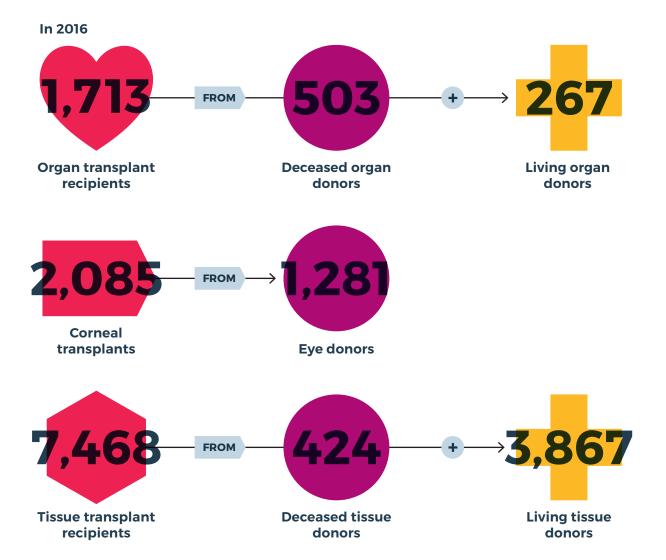
Australia has seen an increasing number of patients who could benefit from organ or tissue transplantation due to a rising prevalence of chronic organ failure and enhanced effectiveness of transplantation as a treatment due to advancements in medical technology. It is expected that this need for transplants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

In 2016, a record 503 deceased organ donors provided 1,447 Australians with the opportunity for a life-saving or life-transforming organ transplant. In addition, there were 267 living organ donors.

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

In recent years, there have been around 1,400 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.



## **Our purpose**

Our purpose is to save and improve the lives of more Australians through optimising every potential organ and tissue donation for transplantation.

On 2 July 2008 the Australian Government announced a national reform program to implement a world's best practice approach to organ and tissue donation for transplantation, which was endorsed by the Council of Australian Governments on 3 July 2008.

The Australian Government aims to improve access to life-transforming transplants for Australians through a sustained increase in the donation of organs and tissues by implementing a nationally coordinated approach to organ and tissue donation.

The national reform program aims:

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

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

# Organ donation is a rare and precious opportunity

Not everyone can be a deceased organ donor. Only 1 to 2% of deaths in hospital occur in a way that organ donation for transplantation is medically possible. In these cases 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 donation practices in hospital and a very high level of family and community awareness and support for donation.

Many more people can become eye and tissue donors as tissues can be donated following death in broader circumstances, including outside of hospital.



of deaths in hospital occur in a way that organ donation for transplantation is medically possible

# Organ and tissue donation is a shared responsibility

Increasing the number of people who donate their organs and tissues is a challenge for all Australians.

The role of the community is pivotal to increasing organ and tissue donation in Australia because consent is dependent on individuals and their families agreeing to donation.

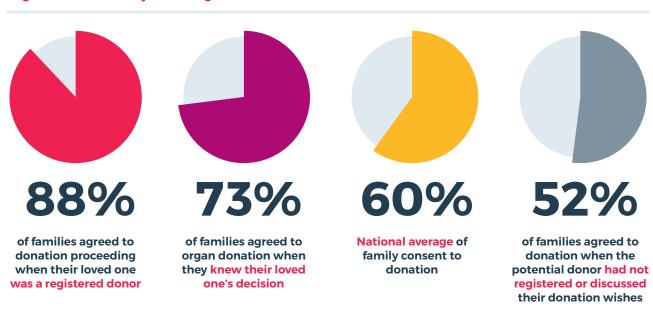
While the majority of Australians express a willingness to become organ and tissue donors, consent to donation in around 60% of cases. This means that around 40% of donations do not proceed through lack of consent. Lifting the consent rate from 60% to 75% in 2016 would have resulted in up to 126 additional organ donors and 362 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 what is usually the sudden death of their relative.

Data from 2016 shows that donation proceeded in 88% of cases when the potential donor had registered their decision to donate and 73% of cases when the potential donor's family knew of their donation decision, compared to the national average of 60%.

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.

## Organ donation consent rates Registration and family knowledge of donation decision



Source: DonateLife Audit 2016

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.

A key clinical barrier to donation is the lack of routine consideration of donation as part of end-of-life care.

The OTA and DonateLife Network staff continue to develop and implement strategies to support clinicians in improving organ and tissue donation practice in all end-of-life care situations. This strategic plan describes key initiatives, such as the Clinical Practice Improvement Program, the Best practice guideline for offering organ and tissue donation in Australia and the Professional Education Package, that are being implemented for this purpose.

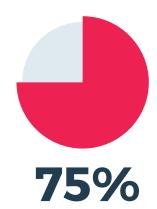
The Professional Education Package recognises that the quality of the donation conversation and the information provided to families impacts family decision making. Evidence indicates that donation proceeds more frequently when a Family Donation Conversation (FDC) trained specialist actively participates 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 a FDC trained specialist who was in addition to the treating clinical team, as compared to 55% when the family donation conversation was led by a FDC trained clinician who was also the treating specialist and 45% when the family donation conversation was led by the treating clinical specialist who was not FDC trained.

Those clinicians who deliver transplantation services also play a pivotal role in maximising transplantation opportunities. Across Australia, there is variation both within and between transplant centres about donor 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.

## Organ donation consent rates Participation of a Family Donation Conversation (FDC) trained specialist



of families agreed to organ donation when the donation conversation was led by a FDC trained specialist who was in addition to the treating clinical team



55%

of families agreed to organ donation when the donation conversation was led by a 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

1 FDC trained specialist is a clinician who has completed the core Family Donation Conversation workshop. They may be donation specialist staff (donation specialist medical, donation specialist nursing or donation specialist coordinator) employed by the hospital or DonateLife Agency, or may be other senior hospital staff such as intensive care specialists who have undergone the appropriate training.

## The plan

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

For 2017–18 the key areas of strategic focus are identified.

The strategic plan guides all other plans developed within the OTA. 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.

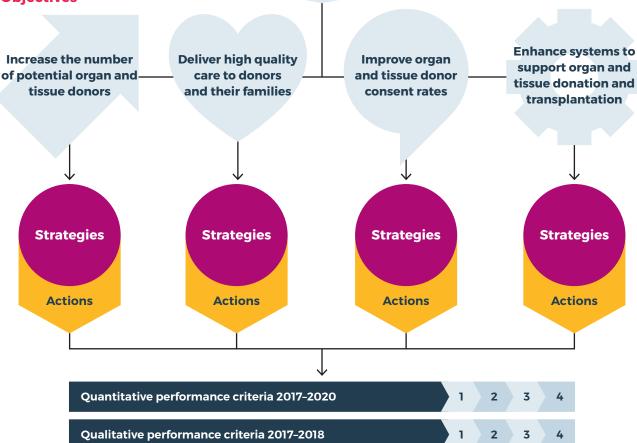
Key performance measures monitor our progress; and our performance is regularly reported to the Australian community.

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

## **Our Purpose**

is to save and improve the lives of more Australians through optimising every potential organ and tissue donation for transplantation.

## **Objectives**



## Objectives, strategies and actions 2017-2020

Strategies Actions Responsibility

## 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

To ensure that every donation opportunity is realised, consultation with donation specialist staff should occur for all intensive care unit (ICU) / emergency department (ED) patients receiving end-of-life care.

Policies and procedures should exist in hospitals to ensure consultation with the local DonateLife Agency/ hospital donation specialist teams occur in all cases.

### 1.1.1

Implement processes for routine referral to DonateLife Agency/hospital donation specialist team of all ICU/ED patients with planned end-of-life care to assess for potential suitability for donation

### 1.1.2

Develop systems for monitoring and reporting of routine referral for all patients undergoing end-of-life care

### 1.1.3

Continue to deliver and develop professional education and training to ensure all patients receiving end-of-life care are referred to the local DonateLife Agency/hospital donation specialist team

OTA, DonateLife Network, Professional Associations, Eye and Tissue Banks and the wider clinical community

## 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 an increase in DCD since its reinstatement as a donation pathway in Australia in 2006. The uptake of DCD varies across Australia and further work is required to ensure that every possible DCD donor is identified and referred for potential donation.

### 1.2.

Support and monitor the uptake of DCD, including the development and review of associated guidelines and education programs

## 1.2.2

Continue to monitor and report DCD activity

OTA, DonateLife Network, Governments, Professional Associations and the wider clinical community

## 1.3 / Increase Donation after Brain Death (DBD)

Generally, DBD is the most common and the preferred pathway to organ donation in terms of transplantation outcomes. DBD rates vary throughout Australia depending on the frequency of devastating brain injury, timing and manner of end-of-life care and associated clinical practices. Ensuring that the opportunity for DBD is identified and preserved is an important goal in optimising organ donation and transplantation outcomes.

## 1.3.

Review end of life care practices to ensure that all opportunities for DBD are identified and that processes support DBD as the preferred donation pathway

## 1.3.2

Continue to monitor and report DBD potential and outcomes

OTA, DonateLife Network, Governments, Professional Associations and the wider clinical community Strategies Actions Responsibility

## 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 considerations will increase the number of recipients who can benefit from transplantation. This will be supported by the development of 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.

## 1.4.1

Develop guidelines and implement processes to optimally utilise expanded criteria donor organs for transplantation

### 1.4.2

Monitor and report on donation and transplantation activity and outcomes from the expanded donor pool to inform better practice

OTA, DonateLife Network, Governments, Professional Associations and the wider clinical community

## 1.5 / Increase living organ donation

Living donation accounts for approximately one quarter of kidney transplants performed in Australia and is associated with excellent transplant outcomes.

The Australian paired kidney exchange (AKX) program enables living kidney transplantation through identifying suitable matches for patients whose living donor is an incompatible blood type or tissue type.

## 1.5.1

Raise awareness of living kidney donation and the Supporting Living Organ Donor Program within the community and clinical sectors

## 1.5.2

Support and promote the AKX program

## 1.5.3

Continue to report on living organ donation and transplantation outcomes

OTA, DonateLife Network, Governments, Professional Associations and the wider clinical community, Community

## Objective 2: Deliver high quality care to donors and their families

# 2.1/ Engage with the community to inform continuous improvement of donation practice and the donation experience

Working with the community promotes a culture of shared responsibility for increasing organ and tissue donation and is integral to the successful implementation of the national reform program.

Donor families and the broader community are encouraged to contribute to the ongoing development of donation services to meet their needs.

### 2.1.1

Continue to develop family donation conversation training for health professionals to better support families make an informed and enduring donation decision

## 2.1.2

Seek input from donor families through the donor family survey. Report on donor family experience and satisfaction to inform future practice

### 2.1.3

Provide opportunities for community consultation to inform continuous improvement of the donation and transplantation practice and experience

OTA, DonateLife Network, Community, Professional Associations, Eye and Tissue Banks and the wider clinical community

## 2.2 / Provide support for the families of potential organ and tissue donors

Donation conversations with families of potential donors invariably occur at times of intense emotion and grief. Families of potential and actual donors require care and support as they consider donation, in the hospital setting and after they go home.

### 2.2.1

Ensure that the families of all potential donors receive optimal support and communication from staff who are specifically trained and competent in the role in accordance with the Best practice guideline for offering organ and tissue donation in Australia

## 2.2.2

Continue to deliver the DonateLife Family Support Service to provide families of potential and actual donors with the support and care that best meet their needs OTA, DonateLife Network, Professional Associations, Eye and Tissue Banks and the wider clinical community

## 2.3 / Acknowledge the generosity and gift of donation

Organ and tissue donation is only possible through the generosity of living and deceased organ and tissue donors and their families.

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

## 2.3.1

Promote the recognition of the contribution of organ and tissue donors and their families at local, state and national levels

OTA, DonateLife Network, Governments, Community, Eye and Tissue Banks and the wider clinical community

Actions Responsibility **Strategies** 

## Objective 3: Improve organ and tissue donor consent rates

## 3.1 / Increase community acceptance of organ and tissue donation

Access to the life-saving and enhancing benefits of organ and tissue transplantation is contingent upon community willingness to donate and public confidence in the donation process. Donation must be seen as shared responsibility across the community.

Continue to develop and undertake national initiatives to promote awareness of and support for organ and tissue donation, such as DonateLife Week

OTA, DonateLife Network, Governments, Eye and Tissue Banks, Community

Strengthen stakeholder engagement with existing and new partnerships across sectors and communities to normalise organ and tissue donation as part of end-of-life decision-making

## 3.1.3

312

Increase culturally and linguistically diverse and Aboriginal and Torres Strait Islander community, awareness of and support for organ and tissue donation

## 3.2 / Increase registration on the Australian 3.2.1

Although the majority of Australians report a willingness to donate, the consent rate in Australia is only 60%. Data shows that actions such as letting family members know about donation decisions and joining the AODR are associated with higher rates of consent.

**Organ Donor Register (AODR)** 

Continue to develop and undertake national initiatives to encourage family discussion and registration on the AODR

## 3.2.3

Identify opportunities to improve the ease and efficiency of AODR registration

OTA, DonateLife Network, Governments, Eye and Tissue Banks, Community

## 3.3 / Increase family consent to donation

The opportunity for organ and tissue donation most often arises in the context of a sudden and unexpected illness or injury leading to death. Families are more likely to agree to donation proceeding when the deceased is a registered donor and the family has prior knowledge of the deceased's wishes.

There is also evidence that the way in which healthcare staff support and guide the family through the donation decision making process affects their experience and the rate of consent. Families must receive the best possible support and information from staff who are skilled communicators, compassionate and highly trained.

## 3.3.1

Embed the elements of the Best practice guideline for offering organ and tissue donation in Australia into clinical practice

## 3.3.2

Continue to deliver and develop education and training for health professionals involved in family donation conversations

## 3.3.3

Continue to report, monitor and analyse rates of consent and declines, including factors that influence family consent and reasons for declining donation

OTA, DonateLife Network, Professional Associations, Eve and Tissue Banks, Community and the wider clinical community

## Objective 4: Enhance systems to support organ and tissue donation and transplantation

## 4.1 / Optimise accurate and timely donor assessment

There are few absolute contraindications to organ and tissue donation and suitability criteria have become more permissive over time. To optimise deceased organ and tissue donation, medical suitability decisions require consultation with donation specialist staff who will seek suitability advice from medical advisers if required.

### 4.1.1

Support the implementation of mechanisms to ensure timely expert advice is sought and available to determine donor suitability

OTA, DonateLife Network, Professional Associations, Eye and Tissue Banks and the wider clinical community

## 4.2 / Improve organ and tissue donation systems and processes in hospitals

Growth in donation and transplantation outcomes has been achieved through the work of the DonateLife Network clinical specialists employed in hospitals who, along with their local DonateLife Agency and hospital colleagues, embed clinical practices in hospitals that optimise the opportunity for donation. Sustained increase in outcomes requires collaboration and a focus on continuous clinical practice improvement.

### 4.2.1

Facilitate senior hospital executive engagement and leadership to ensure a positive donation culture within hospitals

## 4.2.2

Identify and engage with clinical champions in hospitals to drive a positive donation culture and remove barriers to donation

### 4.2.2

Embed the elements of the Best practice guideline for offering organ and tissue donation in Australia into clinical practice

## 4.2.3

Utilise audit, measurement and reporting systems to inform and drive clinical practice improvement

OTA, DonateLife Network, Governments, Professional Associations, Eye and Tissue Banks and the wider clinical community

# 4.3 / Care for the potential donor to optimise the function and condition of organs for transplantation

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

## 4.3.1

Continue to implement, develop and disseminate standards and guidelines to optimise the physiological management of potential organ donors

OTA, DonateLife Network, Governments, Professional Associations, Eye and Tissue Banks and the wider clinical community

## 4.4 / Improve utilisation of retrieved organs and tissues

There have been medical advances that improve organ function following retrieval, such as preservation fluids and machine technologies. Australia continues to develop improved allocation and matching systems and processes, as well as clinical guidance and standards to maximise the utility and function of all donated organs.

## 4.4.

Support the evaluation and implementation of new techniques and technologies for the preservation of retrieved organs and utilisation of tissues

## 4.4.2

Develop and implement the Australian organ matching system – OrganMatch (previously known as AOMS) – to improve organ allocation and matching processes

## 4.4.3

Provide ongoing guidance on organ donor and recipient eligibility and organ allocation to the community and the clinical sectors through the use of ethical and clinical guidelines

OTA, DonateLife Network, Governments, Professional Associations, Eye and Tissue Banks and the wider clinical community Strategies Actions Responsibility

## 4.5 / 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 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.

## 4.5.1

Implement a national vigilance and surveillance system for deceased organ and tissue donation and transplantation

OTA, DonateLife Network, Governments, Professional Associations and the wider clinical community

## 4.6 / 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 system needs to continually adapt and change to ensure the best possible donation and transplantation outcomes. As donation rates increase, there will be a flow-on effect that will increase the demand for downstream services which will have workforce and resourcing implications for state and territory governments. Constraints on downstream services could compromise access to transplantation and improved health outcomes.

## 4.6.1

Continue to collaborate and engage with the transplant sector to optimise donation and transplantation processes and outcomes

### 4.6.2

Continue to analyse and report data to inform continuous improvement of organ and tissue donation and transplantation

### 4.6.3

Work with state and territory governments to to agree the funding and model for the delivery of organ and tissue donation services

## 4.6.4

Support the ongoing development of the eye and tissue sector in collaboration with governments and professional bodies

## 4.6.5

Work with state and territory governments to identify and address retrieval, tissue typing and transplantation capacity and resourcing requirements

## 4.6.6

Provide funding to support donation activity at the hospital level

## 4.6.7

Review and improve support for research in line with strategic objectives

OTA, DonateLife Network, Governments, Professional Associations, Eye and Tissue Banks and the wider clinical community

## **Key areas of strategic focus 2017-18**

As part of the annual review of the strategic plan, ten key areas of strategic focus are identified for the year ahead.

Community education and awareness initiatives promote donor registration and family discussion to ensure that donation wishes are known 2

Routine referral to the DonateLife Agency/ hospital donation specialist team occurs for all intensive care unit and emergency department patients with planned end-of-life care, to ensure accurate and timely donor assessment 3

Families of potential donors receive excellent care and communication, through implementation of the Best practice guideline for offering organ and tissue donation in Australia

4

Education and training of donation specialists, intensive care staff and other clinical staff to optimise donation practices

5

Donors and their families are acknowledged for their generous gift of donation and are provided with support services that best meet their needs 6

Clinical champions remove barriers and normalise organ and tissue donation within hospitals

7

Senior hospital executive engagement provides leadership to ensure a positive donation culture within hospitals 8

Use of audit, measurement and reporting informs and drives clinical practice improvement to increase donation and transplantation

9

Transplant allocation systems and technologies support access to efficient, equitable and safe transplantation

10

Adequate downstream resourcing exists for surgical retrieval, tissue typing and transplantation services

## **Performance criteria**

Quantitative performance criteria 2017-2020							
	2016 Result	2017 Target	2018 Target	2019 Target	2020 Target		
1	Organ transplant recipients (from deceased donors) per million population (trpmp)						
	60 trpmp	≥65 trpmp	≥70 trpmp	N/A	N/A		
2	Deceased organ donors per million population (dpmp)						
	21 dpmp	≥23 dpmp	≥25 dpmp	N/A	N/A		
3	Rate of consent to organ donation						
	60%	≥65%	≥70%	≥75%	≥75%		
4	The increase in the number of registrations on the Australian Organ Donor Register						
	150,000 new annual registrations on the Australian organ Donor Register	10% increase on the number of new annual registrations from 2016	10% increase on the number of new annual registrations from the prior year				

## Note

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

Progress against performance criteria 1 and 2 is measured using national organ and transplantation data reported by ANZOD. These targets are reviewed annually and are COAG endorsed to 2018 only. While these criteria are specific to deceased organ donors, public reporting includes transplant recipients from combined deceased and living donors per million population.

Performance criteria 3 is the number of consents as a percentage of all requests of potential organ donors including Donation after Circulatory Death (DCD) and Donation after Brain Death (DBD). Progress is measured using DonateLife Audit data.

## Qualitative performance criteria 2017-2018

- In collaboration with the DonateLife Network, strengthen accountability and performance of DonateLife hospitals through an updated performance measurement framework to promote the uptake of best practice consent and request models
- Implement the Australian organ matching system OrganMatch by 30 June 2018 to maximise equity of access and clinical outcomes for transplants in Australia, to be delivered in partnership with the Australian Red Cross Blood Service
- Deliver an additional simplified registration channel by 30 December 2017 to encourage more Australians to register their donation decision on the Australian Organ Donor Register
- 4 Continue to educate the Australian community about the need for family discussion, knowledge, and the normalisation of organ and tissue donation in end-of-life care



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