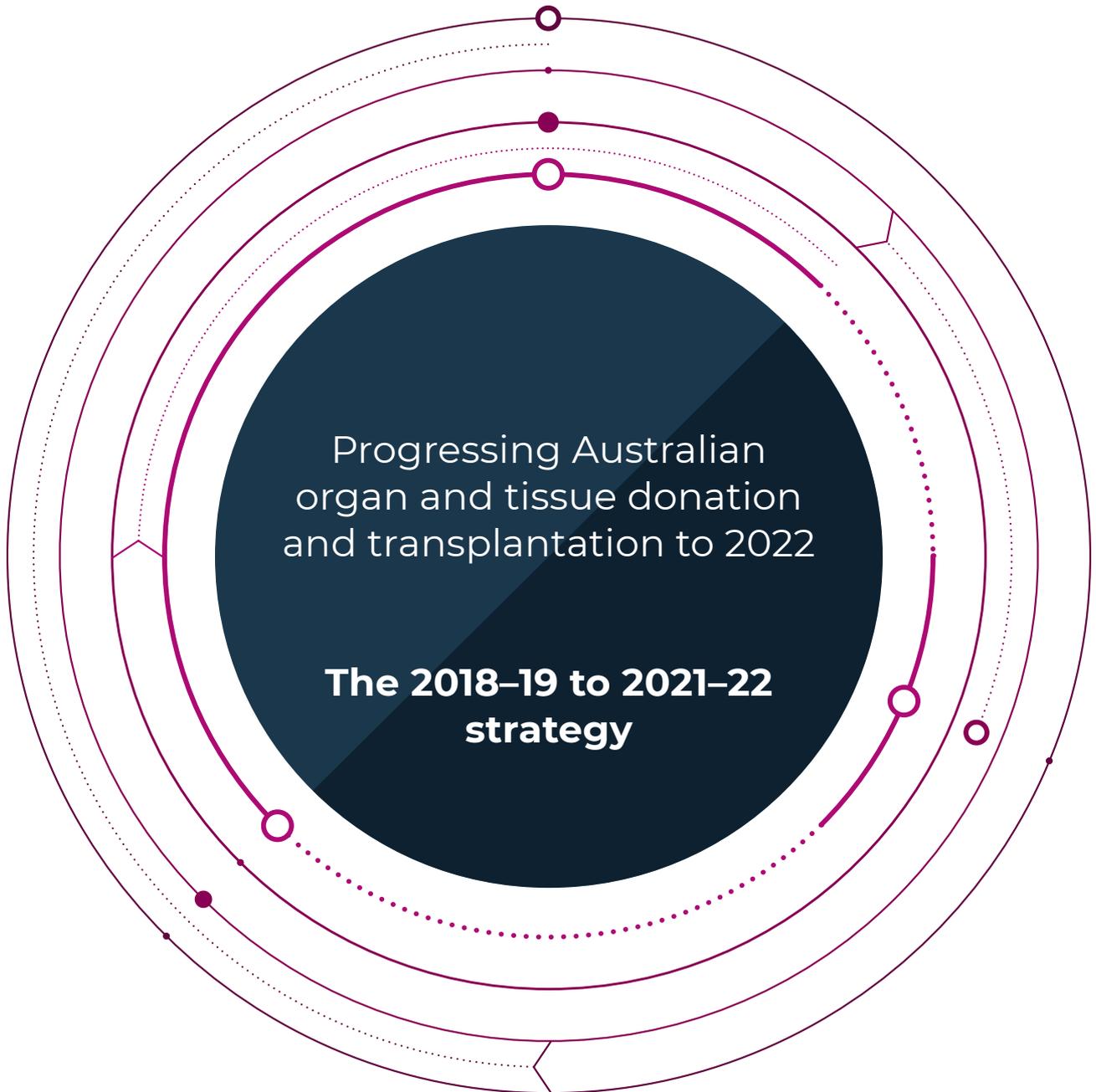




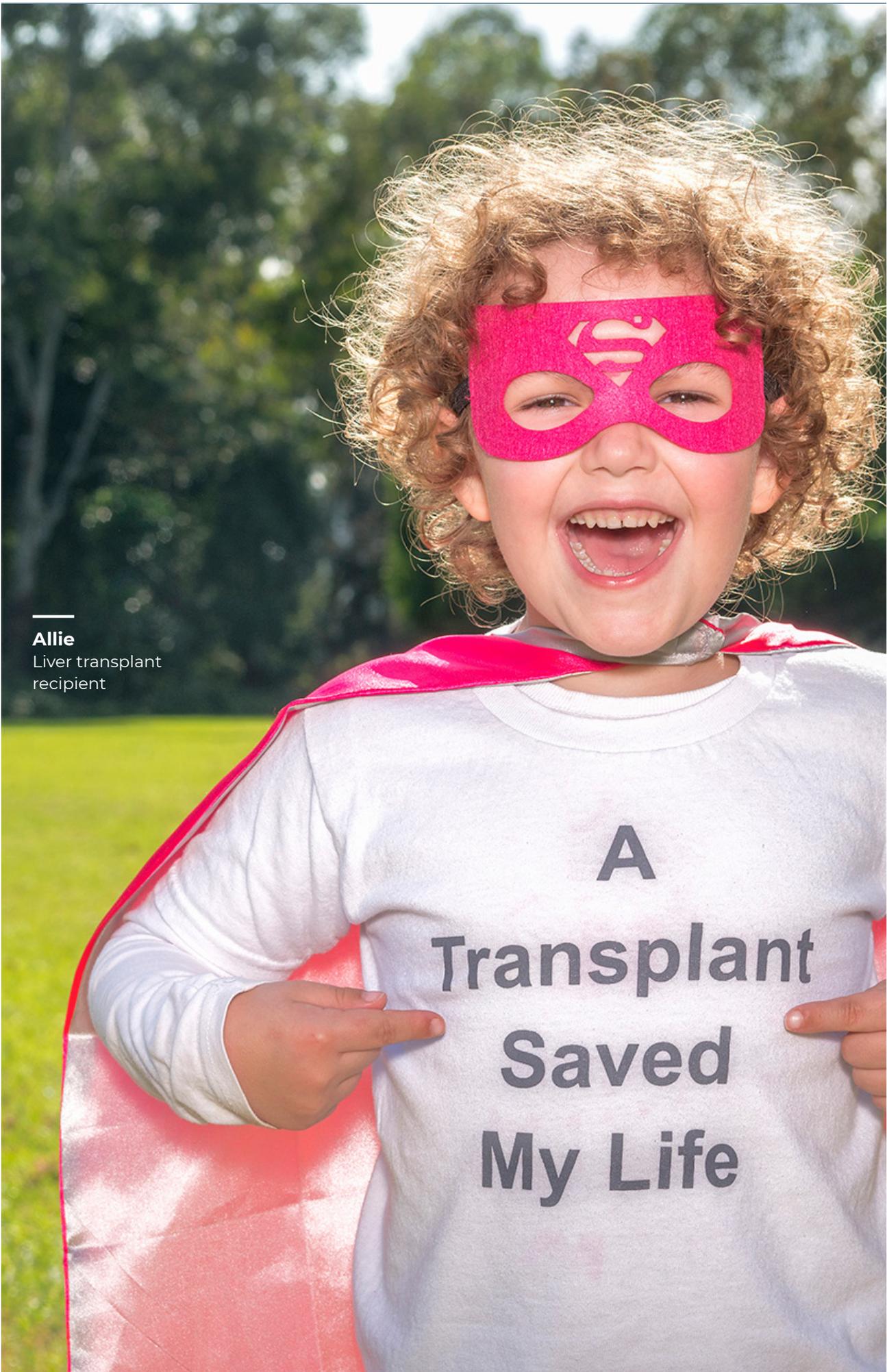
Australian Government
Organ and Tissue Authority



The Organ and Tissue Authority (OTA) manages the implementation of the Australian Government's national 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 DonateLife Network leadership team and representatives of Commonwealth, state and territory health departments.

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Allie
Liver transplant
recipient

FOREWARD

Transplantation is an effective and well-established treatment that saves lives, restores health and improves 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. 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 program commenced in 2009; however, there is still more that can be done.

The Australian Government is committed to the continued delivery of the national program. From July 2017, new governance arrangements for the Organ and Tissue Authority (OTA) commenced 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 2018–19 to 2021–22 to ensure a shared understanding of our purpose and strategies to sustain the increase in organ and tissue donation and deliver improved access to transplantation for the Australian community.

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 work together to normalise donation in Australia. This means normalising community and clinical acceptance of organ and tissue donation to ensure that potential donors and their families are provided with every opportunity to donate. At the same time, we must work with the transplant sector to ensure that all transplant opportunities presented by increased donation rates are realised.

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 ensure that donation is a routine consideration during end-of-life care in hospital intensive care units (ICUs) and emergency departments (EDs). The generosity of donors and their families who consent to donation and improvements in clinical practice 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 Board, Chief Executive Officer and staff look forward to continuing to work collaboratively with our partners and key stakeholders to implement this strategic plan to increase the availability of organs and tissues and ensure more Australians benefit from transplantation.



Dr Mal Washer
Chair, OTA Board
1 July 2018

THE ISSUE

Australia has seen an increasing number of people who could benefit from organ or tissue transplantation due to a rising prevalence of chronic disease 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.

There has been significant growth in donation and transplantation outcomes since the Australian Government's national program commenced in 2009. Between 2009 and 2017 the number of deceased organ donors more than doubled (106%) and the number of transplant recipients increased by 75%.

Despite the improvements in donation and transplantation outcomes under the national program, the number of people waiting for a transplant remains high. There are around 1,400 Australians on organ transplant waiting lists 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.

It is therefore vital that we continue to build on our current success by optimising every donation and transplantation opportunity.

Organ donation is a rare and precious opportunity

Not everyone can be a deceased organ donor. To be an organ donor, people must die in hospital. Of those who die in hospital, fewer than 2 per cent die in circumstances where it is feasible for them to donate organs.

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 these can be donated following death in broader circumstances, including outside of hospital.

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 program 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 OTA works to implement the national program in partnership with the DonatLife Network, states and territories, the donation and transplantation clinical sectors, eye and tissue banks, and the community.

The national 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.

INCREASING ORGAN AND TISSUE DONATION IS A SHARED RESPONSIBILITY

Lifting our national consent rate is fundamental to saving more lives through transplantation. This can be achieved by increasing the number of people on the Australian Organ Donor Register, and by ensuring the issue of donation is always discussed with families by trained donation specialists in our hospitals.

Working with the community

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, 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 60% to 70% would place Australia in the world's top ten performing countries.

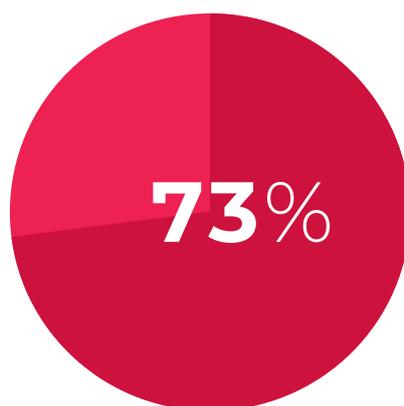
Registration and family knowledge of donation decisions makes a major difference when families are faced with this situation.

Data from 2017 shows that donation proceeded in 9 out of 10 cases when the potential donor had registered their decision to donate and in 7 out of 10 cases when the potential donor's family knew of their donation decision. Further, when the family was unaware of their loved one's donation decision, consent proceeded in only 4 out of 10 cases.

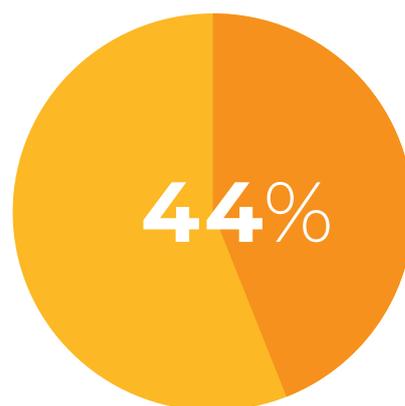
Registration and family knowledge of donation decision makes a difference



of donations proceeded when the potential donor had registered their decision to donate



of donations proceeded when the potential donor's family knew of their donation decision



of donations proceeded when the family was unaware of their loved one's donation decision

Source: DonatLife Audit 2017

Increasing organ and tissue donation is a shared responsibility *continued*

Working with our DonateLife Network and clinical stakeholders

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

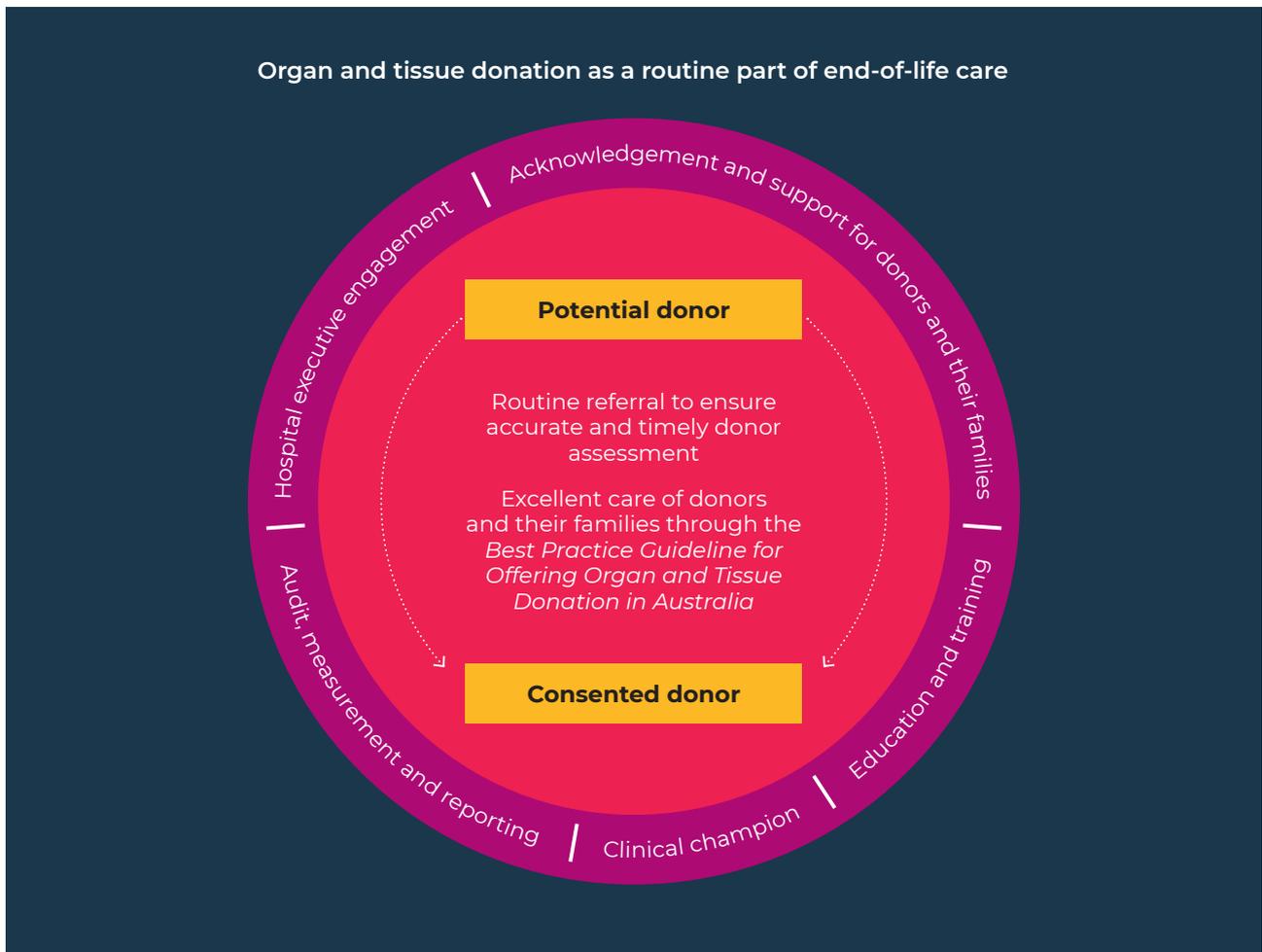
Organ and tissue donation is now firmly embedded in our national health system with a network of DonateLife Agencies and dedicated hospital-based medical and nursing staff working across 95 hospitals in Australia.

The 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 in hospital. This strategic plan describes key initiatives including the *Best practice guideline for offering organ and tissue donation in Australia* (the Best Practice Guideline), the national education strategy, and the Clinical Practice Improvement Program that are being implemented for this purpose.

The diagram below shows the elements of the Clinical Practice Improvement Program which are focused on timely routine referral of all ICU and ED patients with planned end-of-life care to DonateLife Network staff and providing excellent care to donors and their families.

Clinical Practice Improvement Program



Consideration of organ and tissue donation comes at an intensely emotional time for families and can be challenging for all involved. Specific knowledge and skills are required to care for and support families and their decision-making at this time.

We know that more families agree to donation when they are well-informed and supported by a trained donation doctor or nurse specialist¹.

In 2017 families consented to donation in 7 out of 10 cases when they were supported by a trained donation specialist. Families consented to donation in only 4 out of 10 cases when there was no trained donation specialist involved.

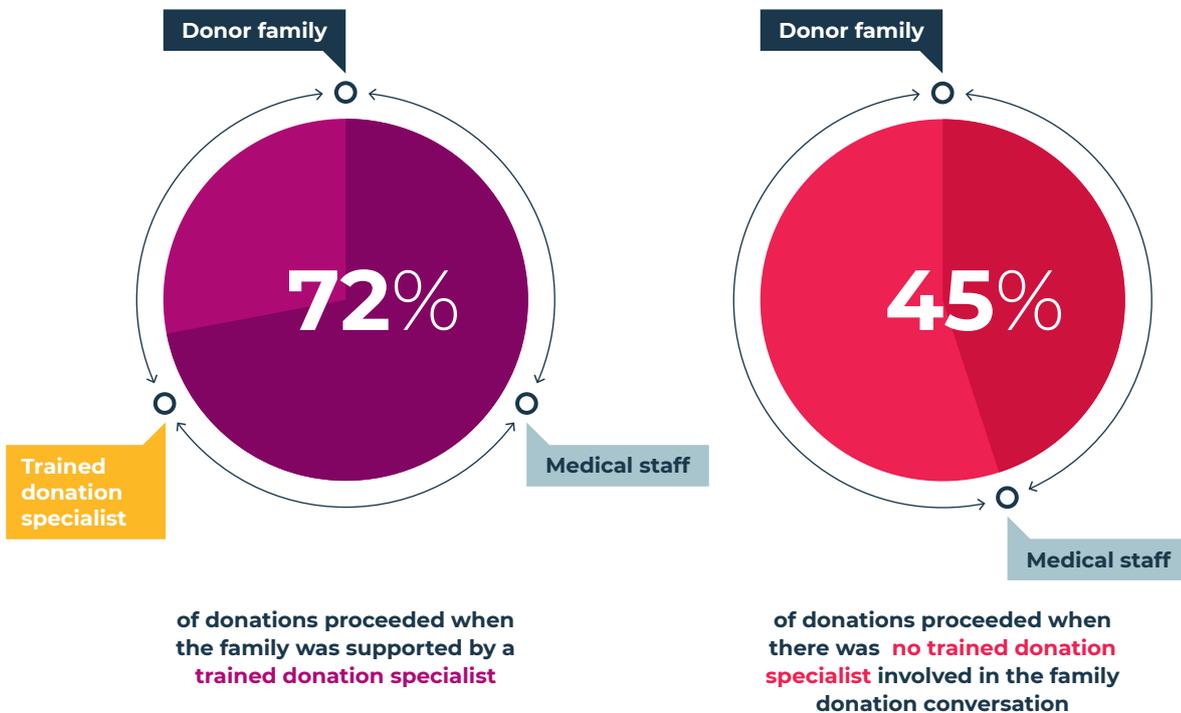
Working with the transplant sector

The clinicians who deliver retrieval and transplantation services also play a pivotal role in maximising donation and transplantation opportunities.

In April 2018 Australian Health Ministers agreed to the Commonwealth undertaking a review of pre- and post-transplantation services to identify areas within our health system which could compromise future growth and sustainability of donation and transplantation outcomes. This includes addressing the pressure points being experienced in our retrieval and transplant services as a direct result of increased donation rates.

The review will inform the development of a long-term strategy for organ retrieval and transplantation which will build on the Government's national program for increasing organ and tissue donation for transplantation.

Involvement of trained donation specialists makes a difference



Source:
DonateLife Audit 2017

¹ A trained donation 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.

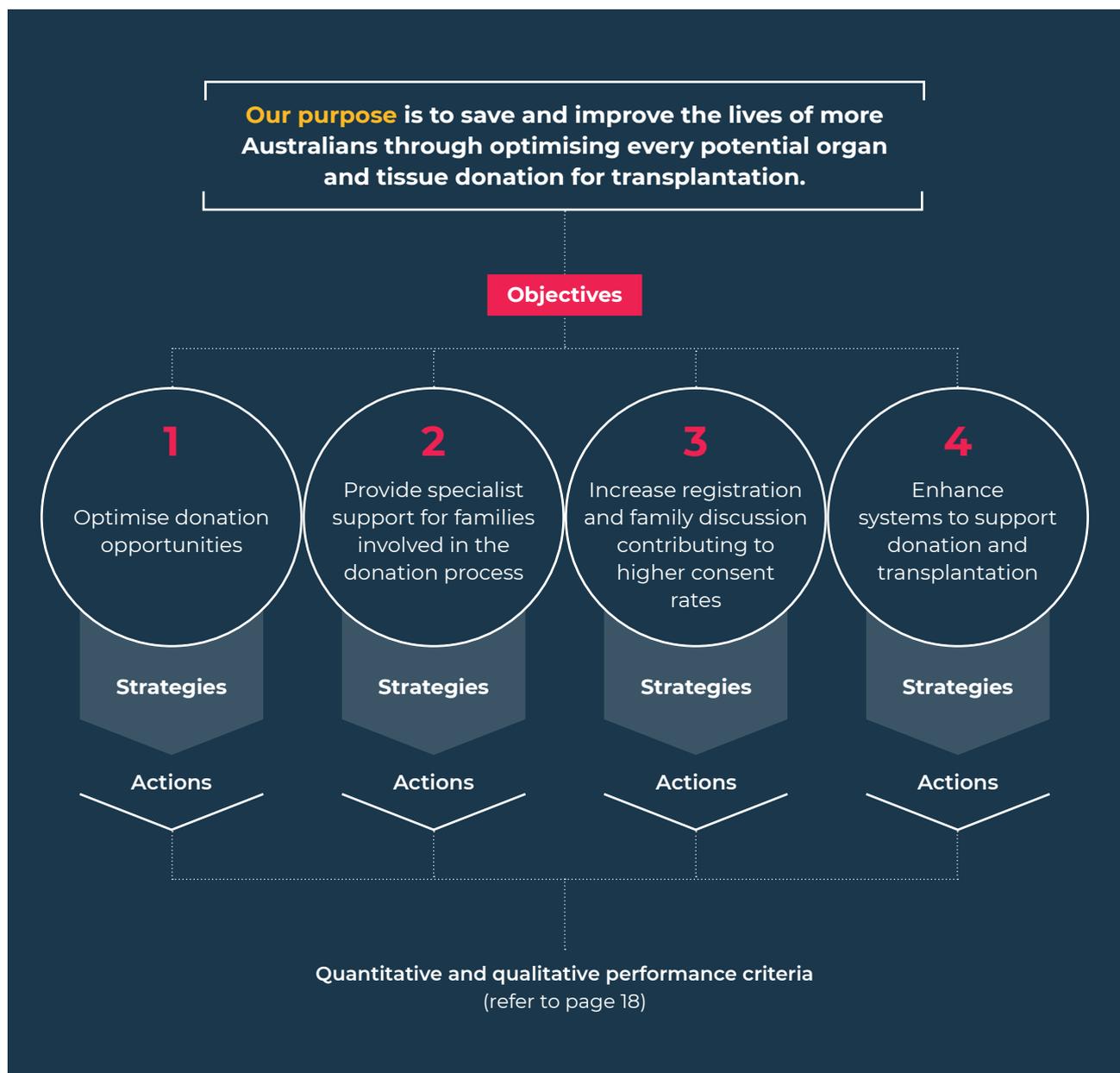
THE PLAN

This four year strategic plan has been developed to ensure that organ and tissue donation and transplantation services are delivered consistently across Australia.

The plan identifies the objectives, strategies and actions for the four years 2018–19 to 2021–22 and the key performance measures against which our progress will be reported.

The key areas of strategic focus for 2018–19 are also identified.

The strategic plan is an evolving and dynamic document that is edited and updated over time. As part of this process, 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.



OBJECTIVES, STRATEGIES AND ACTIONS

Objective 1: Optimise donation opportunities

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

The potential for organ and tissue donation should be considered in all patients at the end of their life. Organ donation is usually only possible when patients on life support die in the intensive care unit (ICU) or emergency department (ED). Tissue donation is feasible in a broader range of circumstances.

Appropriate and timely advice on donor potential and suitability should be sought from clinicians with donation expertise who may consult with transplantation and other experts.

1.1.1 Partner with ICU/ED clinicians to support routine referral of all patients with planned end-of-life care to donation specialist staff² to assess for potential suitability for organ and tissue donation

1.1.2 Implement systems for monitoring and reporting of routine referral for all patients undergoing end-of-life care in ICU and ED

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

1.1.4 Continue to develop and deliver professional education and training to ensure optimal donation practices with respect to donor identification and referral

1.2 Ensure that donation processes occur according to best practice

All patients should receive excellent end-of-life care that meets their physical, psychosocial and spiritual needs. This care, delivered with a focus on patient dignity and comfort, should be provided to all potential organ and tissue donors, while their care is simultaneously managed to optimise donation and transplantation outcomes.

Collaboration between treating staff providing end-of-life care to the patient and donation specialist staff managing the donor assessment and donation coordination process is necessary to obtain the best outcome for the patient who is a potential donor, their family and possible recipients.

1.2.1 Continue to develop education programs and resources for donation specialist and hospital staff to optimise all aspects of potential organ and tissue donor care via the donation after brain death (BD) and donation after circulatory death (DCD) pathways

1.2.2 Contribute to guidelines relevant to the ethical and clinical practice of donation that are developed by professional groups, including intensive care, emergency medicine, donation and transplantation

1.2.3 Where tissue donation is possible, support processes to ensure the opportunity for donation is optimised

1.2.4 Support engagement of jurisdictional representatives and DonateLife Network staff with senior hospital executive and leadership to ensure a positive donation culture within hospitals

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

² 'Donation specialist staff' is inclusive of the DonateLife Agency and hospital donation specialist staff

Objective 1: Optimise donation opportunities

1.3 Increase the transplantation of organs from an expanded donor pool

As has been the case internationally, expanding the donor pool (e.g. age) while balancing benefit and potential risk considerations increases the number of recipients who can benefit from transplantation. This is supported by the development and implementation of appropriate systems, policies and protocols to provide clinicians and the community with the confidence to proceed while being assured of the ongoing safety and ethical approach to donation and transplantation in Australia.

1.3.1 Continue to collaborate and engage with the transplant sector to optimise donation and transplantation processes and outcomes, including the optimal use of organs from the expanded donor pool

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

1.4 Increase opportunities for living kidney donation through the Australian paired Kidney Exchange (AKX) Program

The AKX Program increases living donor kidney transplants by identifying matches 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 or tissue type.

1.4.1 Continue to support the AKX program to optimise living kidney donation outcomes

1.4.2 Continue to explore opportunities for expanding the AKX Program, including collaboration with New Zealand

Objective 2: Provide specialist support for families involved in the donation process

2.1 Provide high quality care for families throughout the donation experience

The opportunity for donation most often arises in the context of a sudden and unexpected illness or injury leading to death.

Donation conversations with families of potential donors invariably occur at times of intense emotion and grief.

Families must receive the best possible support and information from staff who are skilled communicators, compassionate, highly trained and knowledgeable about the donation process.

Families require care and support as they consider donation, in the hospital setting and after they go home.

Feedback about the experience of donor family members can inform and improve donation practices.

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

2.1.2 Embed the elements of the *Best practice guideline for offering organ and tissue donation in Australia* into clinical practice through education and training

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

2.1.4 Monitor and report implementation of elements of the *Best practice guideline for offering organ and tissue donation in Australia* including routinely accessing the Australian Organ Donor Register prior to raising donation with families and the involvement of trained staff in family donation conversations

2.1.5 Continue to deliver the DonatLife Family Support Service to provide families of potential and actual donors with the support and care that best meet their needs

2.1.6 Seek input from donor families through the Donor Family Study and report on donor family experience to inform best practice

2.1.7 Provide opportunities for donor families and the broader community to inform continuous improvement of donation practice and experience

2.2 Acknowledge the generosity and gift of donation

Donation is only possible through the generosity of donors and their families. Acknowledgement of the generosity and gift of donation is an important way to recognise the contribution made by the donors and their families.

2.2.1 Continue to recognise the contribution of donors and their families at local, state and national levels

**Objective 3:
Increase registration and family discussion contributing to higher consent rates**

3.1 Increase community acceptance of donation

Access to the life-saving and enhancing benefits of transplantation depends on community willingness to donate and public confidence in the donation process.

Working with the community promotes a culture of shared responsibility.

3.1.1 Continue to develop and undertake national initiatives to promote community education and awareness of donation

3.1.2 Engage and collaborate with stakeholders to normalise community acceptance of donation as part of end-of-life decision-making

3.1.3 Continue to engage with culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities to increase awareness of and support for donation

3.2 Increase registration on the Australian Organ Donor Register (AODR)

Although the majority of Australians report a willingness to donate, only 1 in 3 Australians has registered a donation decision.

Data shows that actions such as letting family members know about donation decisions and joining the AODR are associated with higher rates of consent.

3.2.1 Continue to develop and undertake national and jurisdictional initiatives to encourage registration on the AODR

3.2.2 Identify opportunities to increase access to online AODR registration through third party platforms and partnerships

3.2.3 Continue to explore opportunities and/or mechanisms for increasing AODR registrations

3.3 Increase family discussion and knowledge of donation decisions

Families generally wish to honour the donation wishes of their family members.

Family knowledge of a person's donation choice is associated with higher consent rates.

3.3.1 Continue to develop and undertake national and jurisdictional initiatives to encourage family discussion about donation and donation decisions

Objective 4: Enhance systems to support donation and transplantation

4.1 Use data to inform clinical best practice for donation and transplantation

An essential part of improving the safety and quality of the donation and transplantation processes is the collection, analysis and application of data on the donation and transplantation process from both the clinical and the community points of view.

4.1.1 Work with states and territories to develop and implement an overarching data governance framework to ensure nationally consistent data collection and utilisation

4.1.2 Expand and enhance the existing performance measurement and reporting framework to inform evidence-based practice in the clinical and community aspects of donation and transplantation

4.1.3 Collaborate with the donation and transplantation sector to develop a national de-identified data set to inform continual improvement in donation and transplantation systems

4.1.4 Work with the states and territories to model projected growth in donation and transplantation beyond 2018 to inform the development of forward work plans and the resourcing required

4.2 Improve utilisation of retrieved organs

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.

There have been medical advances that improve organ function following retrieval, such as preservation fluids and machine technologies.

4.2.1 Deliver, in partnership with the Australian Red Cross Blood Service, the Australian organ matching system – OrganMatch – to maximise equity of access and clinical outcomes for organ transplant recipients

4.2.2 Provide, in partnership with the community, and the donation and transplantation sectors, best-practice guidance on organ donor and recipient eligibility and organ allocation e.g. review of ethical and clinical guidelines

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

4.3 Enhance the safety of organ donation and transplantation

Strict measures are required to safeguard public health in organ and tissue donation and transplantation. High quality, safe and efficacious procedures are essential for donors and recipients alike.

Review and analysis of data will identify risks and trends that will inform clinical practice improvements with the aim of improving safety and quality of process.

A national system to collect, review, analyse and report on serious adverse events and reactions is essential to these processes.

4.3.1 Continue to evolve the national vigilance and surveillance system, supporting the collection, review and analysis of data relating to serious adverse events and reactions for deceased organ donation.

4.3.2 Support the review of the clinical and ethical guidelines for deceased and living organ and tissue donors ensuring guidelines are current in relation donor and recipient care and safety.

Objective 4: Enhance systems to support donation and transplantation

4.4 Improve the efficiency of donation and transplantation

As donation activity increases, the donation and transplantation systems need to continually adapt and change to ensure the best possible outcomes.

As donation rates increase, there is a flow-on effect that increases the demand for downstream services which have workforce and resourcing implications for state and territory governments. Constraints on downstream services compromise patient access to transplantation and improved health outcomes.

4.4.1 Collaborate with states and territories to ensure the health system has the capacity and capability to support future growth and sustainability of donation and transplantation outcomes

4.4.2 Facilitate forums to support collaboration between the donation and transplant sector including the 2019 Donation and Transplantation Conference

4.4.3 Work with the clinical and community sectors to develop processes, systems and services to support best practice in organ and tissue donation

4.4.4 Explore opportunities for assessing clinical practice at the hospital level to ensure a nationally consistent best practice approach to the delivery of donation services

4.4.5 Work with state and territory governments to agree the model and resourcing for the delivery of donation services beyond 2020–21

4.4.6 Support the work of the Jurisdictional Eye and Tissue Steering Committee in implementing the recommendations of the PricewaterhouseCoopers *Analysis of the Australian Tissue Sector Report*

4.4.7 Continue to collaborate with the eye and tissue sector to optimise the efficiency of tissue donation for transplantation

KEY AREAS OF STRATEGIC FOCUS 2018–19

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

1

Continue to evolve the clinical practice improvement program to ensure best donation practice. This includes enhancing the national education strategy to advance the capacity and capability of donation specialists and other clinical staff

2

Enhance the performance reporting framework for the donation and transplantation sector to inform best practice

3

Collaborate with States and Territories to enhance the capacity and capability of the health system to support future growth and sustainability of donation and transplantation outcomes

4

Implement OrganMatch in partnership with the Australian Red Cross Blood Service

5

Increase community awareness and support for donation and provide more opportunities for online registration on the Australian Organ Donor Register through third party platforms and partnerships

Note: These key areas of strategic focus align with the qualitative performance criteria identified on page 18.

PERFORMANCE CRITERIA

Quantitative performance criteria

	2017 result	2018 target	2019 target	2020 target	2021 target
1	Organ transplant recipients (from deceased donors) per million population (trpmp)				
	57 trpmp	≥70 trpmp	Not available	Not available	Not available
2	Deceased donors per million population (dpmp)				
	20.7 dpmp	≥25 dpmp	Not available	Not available	Not available
3	Rate of consent to deceased organ donation				
	59%	≥70%	Not available	Not available	Not available
4	The increase in the number of registrations on the Australian Organ Donor Register (AODR)				
	159,365 new registrations on the AODR	10% increase on the number of new annual registrations from 2017	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).

The Department of Human Services (DHS) manages the AODR under contract with the Commonwealth Department of Health. Performance criteria 4 is calculated using registration data provided by DHS.

Qualitative performance criteria

- 1 Implement Phase 3 of the Clinical Practice Improvement Program in all DonateLife Network hospitals. The program identifies elements of clinical strategic focus with associated key performance indicators that are integral to achieving best practice organ and tissue donation in ICUs and EDs
- 2 Expand and enhance the performance measurement and reporting framework for the donation and transplantation sectors to inform nationally consistent evidence-based best practice
- 3 Collaborate with states and territories to ensure the health system has the capacity and capability to support future growth and sustainability of donation and transplantation outcomes
- 4 Deliver, in partnership with the Australian Red Cross Blood Service, the Australian organ matching system – OrganMatch – by 30 June 2019 to maximise equity of access and clinical outcomes for transplant recipients in Australia
- 5 Continue to educate the Australian community about the importance of registering on the Australia Organ Donor Register and sharing this decision with their family. This includes working with our national partners to promote and normalise organ and tissue donation through their engagement with the community

