



Australian Government

Australian Government response to the
Ernst & Young report:

Review of the implementation of the national reform agenda
on organ and tissue donation and transplantation

March 2017

LIST OF ABBREVIATIONS

ACT	Australian Capital Territory
AHMAC	Australian Health Ministers' Advisory Council
AODR	Australian Organ Donor Register
AOMS	Australian Organ Matching System
CHC	Council of Australian Governments Health Council
DCD	Donation after Circulatory Death
DHS	Department of Human Services
DoH	Department of Health
EDR	Electronic Donor Record
FDC	Family Donation Conversation
ICU	Intensive Care Unit
IHPA	Independent Hospital Pricing Authority
NMW	National Minimum Wage
NSW	New South Wales
NT	Northern Territory
OTA	Organ and Tissue Authority
Qld.	Queensland
SA	South Australia
Tas.	Tasmania
THIP	Targeted Hospital Improvement Programme

Introduction

The Australian Government is committed to increasing Australia's organ and tissue donation rates, and on 26 May 2015 then Minister for Rural Health Senator the Hon Fiona Nash announced a review to examine the effectiveness of the implementation of the national reform agenda on organ and tissue donation and transplantation.

The review conducted by Ernst & Young culminated in the report entitled *Review of the implementation of the national reform agenda on organ and tissue donation and transplantation* (the Review). The Review is an important document which captures the key achievements and challenges in increasing Australia's organ and tissue donation rates as well as the views of a wide range of stakeholders to shape strategies for continued gains in this area.

This response has been prepared by the Department of Health, in consultation with the Australian Organ and Tissue Donation and Transplantation Authority (AOTDTA). It addresses all the recommendations raised in the Review and identifies areas for further activity.

Recommendations and Responses

Strategy

Recommendation 1

The DonateLife Network, led by the AOTDTA, should implement the 2015 budget measures assigned to the Network expeditiously as planned with a national focus emphasised on the Targeted Hospital Improvement Program . In addition, the DonateLife Network should continue to implement the other 2015-2016 strategic priorities.

The Australian Government agrees with this recommendation. Funding of \$10.2 million was allocated through the 2015-2016 Federal Budget for a new measure: *Accelerating Growth in Organ and Tissue Donation for Transplantation*, to improve organ and tissue donation and transplantation rates.

This two year measure (2015-16 to 2016-17) consists of four elements:

- 1) development of the Australian Organ Matching System;
- 2) delivering clinical education to hospitals which includes implementing the Targeted Hospital Improvement Programme;
- 3) facilitating on-line donor registration of consent on the Australian Organ Donor Register; and
- 4) extending the Supporting Leave for Living Organ Donors Program which continues to provide up to the National Minimum Wage, for up to nine weeks, to employers of people who have taken leave to donate an organ.

Recommendation 2

The AOTDTA, DonateLife Network and transplantation sector should continue to progress the allocation of donated organs on a national basis, following the implementation of the Australian Organ Matching System(AOMS).

The Australian Government agrees with this recommendation and is committed to the continuing implementation of the AOMS. The development of the AOMS has been funded for two years through the 2015-16 Federal Budget measure: *Accelerating Growth in Organ and Tissue Donation for Transplantation*. A scoping review to inform the next steps for the development of the AOMS has been completed by the AOTDTA. Implementation is scheduled for 2018.

Post implementation of the AOMS, the Department of Health, AOTDTA, DonateLife Network and transplant sector will consider the methodology and implications of national allocation of donated organs for transplantation.

Recommendation 3

The proportion of Intensive Care Unit specialists, staff and trainees who participate in the Family Donation Conversation (FDC) Workshops should be monitored by the DonateLife Network by hospital.

The Australian Government agrees with this recommendation. This is a new function to be implemented as part of the Targeted Hospital Improvement Program budget measure. The AOTDTA has already commenced work on implementing this recommendation via its 'Learning Management System' which will have the functionality to monitor and report on participation rates in FDC Workshops, including the upload of retrospective participation data.

Recommendation 4

The number of living kidney donations should be reported and reviewed by the DonateLife Network and reported on the AOTDTA website.

The Australian Government agrees in principle with this recommendation. The implementation of this recommendation is dependent on the cooperation of several agencies who currently collect and disseminate data.

Currently, the AOTDTA provides data on living kidney donations from its own Australian Paired Kidney Exchange Program. The AOTDTA's level of reporting will be expanded to include all live donors, including those who are eligible for the Supporting Leave for Living Organ Donors Program, as well as those who are not.

Governance of the OTA (Recommendations 5-9)

Recommendation 5

The Australian Government should consider amendments to the Australian Organ and Tissue Donation and Transplantation Authority Act 2008 to establish a Board of governance of seven to nine people to govern the AOTDTA.

Recommendation 6

The Chair of the Board of governance should be an experienced leader of public hospital organisations, but need not be a clinician.

Recommendation 7

The skill base of the Board should include community leadership, health promotion expertise, DonateLife Network clinical expertise, transplantation clinical expertise, consumer experience and communication skills.

Recommendation 8

The Chair should be nominated by the Australian Government, the deputy chair nominated by the states and territories, with the balance of members nominated collectively by the CHC members.

Recommendation 9

The members should be appointed for a term of four years by the Australian Government Minister, with staggered appointments at the commencement of Board of governance operations.

The Australian Government agrees with recommendations 5 to 9.

The *Australian Organ and Tissue Donation and Transplantation Authority Amendment (New Governance Arrangements) Act 2016* (the Amendment Act) received Royal Assent on 30 November 2016.

The Amendment Act, once enacted on 1 July 2017, establishes the Australian Organ and Tissue Donation and Transplantation Board to govern the AOTDTA and transfers the key policy and strategic functions currently vested in the CEO to the Board. The Board will comprise:

- a Chair;
- a Deputy Chair;
- five members; and
- the CEO.

The Board will report directly to the responsible Commonwealth Minister, and will be the accountable authority under the *Public Governance, Performance and Accountability Act 2013*.

The Department of Health is responsible for implementation of these recommendations, and is undertaking the processes, as stipulated in the legislation, through which Board members will be appointed to ensure the Board is established and functional on 1 July 2017.

Performance

Recommendation 10

The AOTDTA should prominently publish the following data on the performance of the DonateLife Network:

- *Donation rates by jurisdiction – quarterly for NSW, Qld., Vic., SA and WA and annually for Tas., ACT and NT.*
- *Numbers of people on the transplant waiting list for each organ type annually.*
- *Deaths on the waiting list for each organ type annually.*

In addition, the AOTDTA should further consider the publication of donation performance (appropriately risk adjusted) by hospital.

The Australian Government agrees in-principle with this recommendation, and will seek the support of states and territories in implementing it, with due regard to issues of patient privacy and confidentiality.

Recommendation 11

States and territories should clearly define who is responsible for organ donation rates within their jurisdiction and monitor the implementation of the DonateLife Network positions within their constituent Local Hospital Networks.

The Australian Government agrees in principle with this recommendation noting that organ and tissue donation and transplantation is a state and territory responsibility.

Audit of donation practices

Recommendation 12

The DonateLife Network, led by the AOTDTA, should define minimum standards for auditing of organ donation practices and seek the endorsement of the CHC for these standards.

The Australian Government agrees with this recommendation. This is a key component of the Targeted Hospital Improvement Program funded by the 2015-2016 Federal Budget measure: *Accelerating Growth in Organ and Tissue Donation for Transplantation* and the embedding of the Clinical Practice Improvement Program – Phase 2, a strategic priority for the AOTDTA and the DonateLife Network.

Recommendation 13

The audit of potential donors should be expanded as planned to include DCD donors, so that both donation pathways are reflected in the DonateLife Audit.

The Australian Government agrees with this recommendation. Work in this area has been agreed and identified in the AOTDTA's 2015-19 Strategic Plan, and has already commenced with expanded reporting parameters expected to be available in 2016.

Funding policy

Recommendation 14

The AOTDTA should publish the breakdown of state and territory DonateLife Network funding clearly on the AOTDTA website. This should include a table demonstrating the share of the state and territory funding allocated to each jurisdiction for each year including 2015-16.

The Australian Government agrees with this recommendation. The additional funding information has been published by the AOTDTA.

Recommendation 15

All Australian governments should advocate the inclusion of tissue typing and the surgical procedures for organ retrieval, transportation and transplantation activity in the 2015/16 Independent Hospital Pricing Authority (IHPA) Pricing Framework as an in-scope public hospital service, noting that this is a proposal which is already being considered.

The Australian Government agrees in-principle with this recommendation.

Surgical procedures for organ retrieval and transplantation activity have been included in the IHPA Pricing Framework. The inclusion of tissue typing and transportation for the purposes of donation and transplantation is currently under consideration.

Awareness strategies, communication and donor family support

Recommendation 16

The Australian Government should consider the implementation of a further national awareness campaign that is timed to coincide with the implementation of enhancements to the AODR and has the objective of improving the prevalence of AODR registration among the community, noting that this forms part of the current budget measure.

The Australian Government agrees with this recommendation. Funding for an on-line advertising campaign, to coincide with the implementation of on-line donor registration consent on the AODR, has already been allocated through the 2015-2016 Federal Budget measure: *Accelerating Growth in Organ and Tissue Donation for Transplantation*.

Recommendation 20

Once the enhancement to the AODR is fully operational, a further campaign to increase enrolment should be undertaken as planned.

The Australian Government agrees with this recommendation in principle. Beyond 2017, advice on the direction of the campaign will be sought through the Board, to be established in line with recommendations 5-9.

Recommendation 17

The proposed Board of governance should consider the DonateLife Community Awareness and Education Programme annually, including the Stakeholder Engagement Framework, to ensure a nationally consistent, evidence-based approach to communications about organ and tissue donation for transplantation.

Recommendation 18

The AOTDTA should consider the DonateLife logo in light of the concerns expressed by donor families and the AOTDTA should consult donor families on appropriate donor memorials throughout Australia.

Recommendation 19

The proposed Board should consider the key criteria for selection of grant recipients prior to the commencement of the grant recipient selection process.

The Australian Government agrees with recommendations 17, 18 and 19, and will refer these recommendations to the new Board, once established, for consideration.

Electronic Donor Record (EDR)

Recommendation 21

The EDR should be enhanced as planned to record all referrals to the DonateLife Network (not only those that proceed to donation) and the reasons for any decision not to proceed to donation.

The Australian Government agrees in-principle with this recommendation, and will engage constructively with states and territories to implement it. Scoping work will be required in regard to enhancements of the EDR to assess establishment and maintenance costs. This recommendation also relates to recommendation 16 agreed and identified in the AOTDTA's 2015-19 strategic plan.

Recommendation 22

States and territories through the CHC should align their privacy and health records legislation to facilitate the full electronic implementation of the EDR and allow access to the EDR for research purposes.

Aligning different jurisdictions' privacy and health record legislation is a complex objective. The Australian Government supports this recommendation, noting that states and territories have responsibility for their legislation.

New organ perfusion technologies

Recommendation 23

The effectiveness of organ and perfusion technologies should be evaluated by AHMAC and the CHC and consideration given to their ongoing utilisation in the future, with costs reflected in the retrieval services IHPA price recommended at Recommendation 15.

The Australian Government agrees with this recommendation, and will engage constructively with states and territories to implement it.

Eye and tissue donation and transplantation

Recommendation 24

Following the completion of the Economic Analysis of the Eye and Tissue Sector, through the CHC, states and territories should agree the implementation of any recommendations that allow for a national and standardised approach to the supply of eyes and tissues for transplantation, including amending jurisdictional human tissue legislation.

The Australian Government agrees in-principle with this recommendation, and will work closely with states and territories on implementation.