



A WORLD'S BEST PRACTICE APPROACH TO ORGAN AND TISSUE DONATION FOR AUSTRALIA: OVERVIEW

Key Facts and Figures

Name of measure:	World's Best Practice Reform Package on Organ and Tissue Donation for Transplantation
Commences:	1 July 2008
Funding:	\$136.4 million over four years (ongoing)

What will the measure do?

This measure provides additional Australian Government funding of \$136.4 million over four years for a package of national reforms to organ and tissue donation for transplantation.

It will establish Australia as a world leader in best practice organ donation for transplantation and achieve a significant and lasting increase in the number of life saving and transforming transplants for Australians.

The experience of several comparable countries demonstrates clearly that a coordinated and integrated national approach followed by sustained effort will over time see real improvements in organ donation and transplantation rates.

For example in Spain, the world leader, a central agency drives and coordinates a nationally consistent approach to clinical systems and practices and to community awareness and professional education; hospitals and their staff have sufficient training and capacity to identify all potential donors; and there are no cost barriers in hospitals that prevent organ donation proceeding.

Learning from international and national experience, and based on the Australian context and local expertise, the reform package comprises the following components:

- A co-ordinated, consistent approach spearheaded by a new national organ donation and transplantation authority to be operational from 1 January 2009 and a network of nationally coordinated organ procurement organisations to facilitate the donation process;
- New funding for medical specialist positions and other clinical positions in public and private hospitals around Australia dedicated to organ and tissue donation;
- A new funding stream for Australia's public and private hospitals to cover the additional staffing and infrastructure costs associated with organ and tissue

donation;

- An enhanced national education and training program for health professionals involved with organ donation;
- An ongoing, nationally coordinated community awareness and education program to increase knowledge about organ and tissue donation and transplantation and build public confidence in Australia's donation for transplantation system;
- Appropriate support for the families of deceased donors;
- Equitable, safe and transparent national transplantation processes to manage waiting lists and the allocation of donated organs;
- A national eye and tissue donation and transplantation network; and
- Other national initiatives, including living donation programs such as 'paired kidney exchange'.

An urgent need for a new approach

Transplantation is a highly successful treatment that transforms the lives of individuals and their families. Australia is a world leader in clinical outcomes for transplant patients, and over 30,000 Australians have benefited since transplantation first became a standard treatment option. More than ninety per cent of Australians support organ donation.

Yet we have a longstanding shortage of organs for transplantation. Australia's deceased donor rate has stagnated at around 200 donors per annum over the past decade while our population has continued to grow.

Over 1,800 Australians are waiting for an organ transplant at any given time. The wait for a transplant can extend to many years and comes at a significant cost to the health system. For example, hospital based kidney dialysis costs an average of \$83,000 per person per annum. In contrast, a kidney transplant costs \$65,000 per recipient for the first year, and \$11,000 a year thereafter.

The reform package makes a significant investment in consistent, coordinated national initiatives to increase Australians' access to transplants. Increasing the number of organ transplants will save lives and significantly improve the quality of life of many of the Australians awaiting a transplant at any one time and of the families who care for them.

Funding

Total additional funding of \$136.4 million is being provided to implement the reform package over the next four years.

The Department of Health and Ageing will administer funding to state and territory governments:

- to employ specialist hospital staff dedicated to organ and tissue donation for transplantation;
- for the additional hospital costs associated with organ and tissue donation.
- to implement nationally consistent clinical protocols, 'clinical trigger' checklists, and data collection in hospitals; and
- for donor family support.

States and territories will have clear, standardised performance and reporting requirements. The funding arrangements will also include the flexibility for states to reimburse costs associated with organ donation in private hospitals.

The national authority, once established, will directly administer funds to non government organisations to provide essential associated services such as clinical data analysis and reporting, national organ matching services, and training and education for clinical staff. It will also fund community awareness activities.

More information

Factsheets providing more information on specific components of the reform package are available at www.health.gov.au

1: A NEW NATIONAL APPROACH AND SYSTEM: A NATIONAL AUTHORITY AND NETWORK OF ORGAN PROCUREMENT ORGANISATIONS

What will this measure do?

This measure will establish for the first time in Australia a nationally coordinated approach to organ procurement based on world's best practice models. A new, independent authority will be established to provide national leadership to the organ and tissue sector and to drive, implement and monitor national reform initiatives and programs.

The authority will be created under Commonwealth legislation and will report directly to the Commonwealth Minister for Health and Ageing.

The authority's specific responsibilities will include:

- overseeing and supporting a national network of clinical specialists in hospitals who are dedicated to organ donation (see factsheet 2);
- overseeing a national network of organ procurement organisations which will manage the organ procurement process according to national protocols and systems;
- managing and monitoring an ongoing national professional education and training program (see factsheet 4);
- managing and monitoring an ongoing national community awareness and education program (see factsheet 5);
- introducing and managing a world class national data and reporting system;
- administering funds to non government organisations to provide essential associated services such as clinical data analysis and reporting, national organ matching services, and professional training and education for clinical staff; and
- working closely with national clinical organisations in the development of nationally consistent clinical practice protocols covering the organ donation process, organ allocation and waiting list management.

Senior representatives of the Commonwealth, state and territory governments, and national professional and community organisations will form an advisory board to the CEO. The authority will have strict performance indicators and an appropriate reporting and audit regime.

A nationally coordinated network of organ procurement organisations (OPO) will be established to manage the organ donation process at the state and territory level according to national protocols and systems as determined by the national authority. OPO staff will work closely with the new dedicated medical specialist and other clinical positions in hospitals.

Why do we need this initiative?

Approximately 1,800 Australians are on transplant waiting lists at any given time due to Australia's longstanding shortage of organs for transplantation. World's best practice and our best national expertise points to the need for a new nationally coordinated approach to organ donation if we are to turn this situation around and improve access to transplants.

Who will benefit?

Australians on transplant waiting lists will benefit from improved access to transplantation. Families of deceased organ donors will receive support services such as bereavement counselling and assistance with costs. Medical and nursing staff working in hospitals will receive enhanced professional education and training. The community will receive ongoing information about organ and tissue donation through ongoing, nationally coordinated awareness and education campaigns. A new national minimum dataset, data system and report will provide regular, reliable information about organ and tissue donation in Australia.

How much will it cost?

\$46.0 million over the four year period 2008-09 to 2011-12. This amount includes funds held by the national authority for its administered programs. This will be partly offset by \$14.7 million redirected from funding for existing organ and tissue programs within the Department of Health and Ageing.

When will it commence?

Subject to legislative processes, the national authority will be established by 1 January 2009. The national authority will work with state and territory governments and existing state based organ donation agencies to transition existing operations into the national OPO network. The OPO network is expected to come into operation in 2009-10.

**2: SPECIALIST HOSPITAL STAFF AND SYSTEMS
DEDICATED TO ORGAN DONATION**

What will this measure do?

Funding will be provided for selected public and private hospitals to employ trained, medical specialists dedicated to organ donation. In accordance with world's best practice, the medical specialists will work closely with hospital teams in emergency departments (EDs) and intensive care units (ICUs). They will facilitate and

coordinate organ and tissue donation activity and outcomes, and support and educate hospital teams in line with the national programs.

‘Clinical trigger’ checklists will be introduced in all public and private hospital EDs and ICUs to provide a nationally consistent protocol and strict criteria to identify potential organ and tissue donors by all clinical staff. Appropriate referral protocols will also be established between EDs, ICUs and operating theatres for the ongoing care of identified potential donors.

Funding will also be provided for the appointment of other clinical staff to assist with educating staff and ensure that national programs are implemented effectively at the local level.

Larger hospitals will establish outreach arrangements to smaller hospitals, including private hospitals.

Why do we need this initiative?

International and national experience has demonstrated that a dedicated focus on organ donation by medical and nursing staff within hospitals, coupled with national coordination of organ donation processes, is the key to improving donor rates and thereby improving access to transplants.

The initiative will ensure that all potential donors are properly identified and that individuals and families have the opportunity to agree to organ donation if they so wish. It will also ensure that the processes leading to organ donation, including support for the donor’s family and medical testing, are coordinated by a dedicated specialist.

Who will benefit?

Depending on the capacity of the hospital to manage organ and tissue donation, selected public and private hospitals will receive funding to employ clinical staff to dedicated, funded organ donation positions.

How much will it cost?

\$67.0 million over the four year period 2008-09 to 2011-12.

When will it commence?

Recruitment to the new medical specialist and other clinical positions will commence in 2008-09.

3: NEW FUNDING FOR HOSPITALS

What will this component do?

A new funding stream for public and private hospitals will be introduced to address the additional staffing, bed and other infrastructure costs associated with organ and tissue donation.

These additional costs vary from hospital to hospital and may include pathology and imaging, staffing time in the emergency department (ED), intensive care unit (ICU) and the operating suite and the cost of an ICU bed.

These costs are *additional* to the costs incurred in the care of critically ill patients which are covered by existing funding streams.

Point of care information will be collected in EDs and ICUs for transmission to the national authority, once it is established. This will enable donor data to be collected for reporting, audit and benchmarking of activity levels and the resources used by individual hospitals to provide organ procurement activity.

Why do we need this initiative?

The care of a donor in the ED and ICU, from the time they are identified as a potential donor to the time the surgical transplantation team comes in, requires additional resources such as staffing, infrastructure, pathology and diagnostic imaging.

This new funding will reimburse hospitals for these extra costs to ensure cost is not a barrier to organ and tissue donation for transplantation occurring. This approach has been successful in world leading countries such as Spain.

Who will benefit?

Hospital staff can focus on donor care knowing that the hospital has a separate budget to cover the resources necessary to facilitate organ and tissue donation.

By ensuring cost is not a factor in determining whether organ and tissue donation proceeds, it is expected that the number of organs available for life saving transplants will increase.

How much will it cost?

\$17.1 million over the three year period 2009-10 to 2011-12.

When will it commence?

The Department of Health and Ageing will begin negotiations with state and territory governments to establish this new funding mechanism and the data collection and reporting requirements that go with it.

Once the national authority is established, by 1 January 2009, it will establish a national data and reporting system that will assist in monitoring and the administration of the funding arrangements.

4: NATIONAL PROFESSIONAL AWARENESS AND EDUCATION

What will this component do?

The national authority will coordinate an ongoing, nationally consistent and targeted program of recognised professional development and training.

The program will be developed in consultation with the relevant professional craft groups and clinical colleges and will build on existing programs.

Hospitals, professional societies and specialist medical training providers will provide nationally consistent and targeted education programs to staff involved in organ and

tissue donation as determined by the national authority. Medical and nursing school curricula will also be enhanced to better encompass organ and tissue donation.

The new, dedicated medical directors and other clinical staff (see factsheet 2) will manage awareness-raising, training and education programs for medical and nursing staff and students across participating public and private hospitals in their region.

Education and training programs will target:

- medical directors of organ donation;
- bereavement counsellors and donor family support staff;
- intensive care and emergency department specialists and trainees who care for potential organ donors;
- other clinical hospital staff, particularly in neurosurgery, cardiology and neurology to raise awareness and knowledge of donation and transplantation;
- nursing and allied health staff to raise awareness and knowledge of donation and transplantation;
- medical and nursing students; and
- General Practitioners

Why do we need this initiative?

This component is essential to continually enhance the skills, qualifications and professional standing of the medical, nursing and allied health specialists who work to improve Australia's organ and tissue donation and transplantation rates.

The Australasian Donor Awareness Programme (ADAPT) is currently funded by the Australian Government and provides modular-based training and education to a range of clinical staff working in the sector. The current program will be extended to a nationally consistent, recognised training and continuing education program

Who will benefit?

The clinical and professional staff who will drive cultural and organisational change in public and private hospitals and will implement the front-end clinical work of increasing donation and transplantation rates.

How much will it cost?

\$720,000. Taking into account awareness and education allocations in other components of the reform package, an additional \$3.2 million over the four year period 2008-09 to 2011-12 will be provided to support and deliver an enhanced national education, training and awareness program. This includes staff in the national authority to develop and implement the new national program, funding to deliver specific training programs and support for the new hospital based clinical staff.

When will it commence?

The national authority will employ staff to develop the national professional awareness and education program, building on existing resources and modules, for progressive national implementation from 2009.

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5: COORDINATED, ONGOING COMMUNITY AWARENESS AND EDUCATION

What will this component do?

An ongoing, coordinated and evidence based national community education and awareness program will increase knowledge about organ and tissue donation and transplantation and build public confidence in Australia's new donation system.

The national program will give Australians regular, clear, factual and relevant information about organ and tissue donation, and how they can make a difference.

National, state and local community awareness activities will contribute to increase public understanding of the benefits of transplantation.

Greater knowledge will lead to increased consent rates by donor families and therefore more transplants and lives saved and improved.

Key elements of a new national approach will include:

- **An ongoing, national community awareness and education program.** The national authority, once established, will set the directions, key messages and strategies of a national program, including an annual awareness week and donor recognition – based on social marketing research and market testing – that will be rolled out at a national, state and local level.
- **A national community awareness framework.** A national communications framework for organ and tissue donation for transplantation will provide stakeholders with a nationally consistent, coordinated and evidence-based approach and resources to assist their community awareness activities. The framework will encourage stakeholders to collaborate and build on each other's efforts and avoid unnecessary duplication of work, research and resources.
- **A national community awareness charter.** The charter will allow stakeholders (government and non government) to sign up to the principles of the national framework and will express their commitment to conduct community awareness activities in line with nationally consistent messages. The national authority, once established, will administer community grants and funding arrangements for non-government organisations.

Why do we need this initiative?

Surveys show that over 90 per cent of Australians support the idea of organ donation yet Australia has a long standing shortage of organs for transplantation.

Nearly six million Australians are registered on the Australian Organ Donor Register (about 37 per cent of the eligible population). However, an additional one million registrations since 2002 has not resulted in more donors, more transplants and more lives saved and improved.

The challenge is to turn this high level of community support into more life saving and life transforming transplants.

Social marketing research concluded in October 2007 confirms this strong public support for organ donation but also some misunderstandings that influenced people's behaviour and attitudes. Few respondents could recall any recent promotional activity and the vast majority indicated a preference for an information campaign that dispels the myths surrounding organ donation, motivates action and encourages people to tell family of their wishes.

Who will benefit?

A nationally coordinated approach to community awareness and education will bring together and harness the efforts of the sector, and avoid duplication and the confusion caused by mixed messages.

How much will it cost?

\$13.4 million over the four year period 2008-09 to 2011-12.

When will it commence?

The Department of Health and Ageing will develop and implement the first major campaign in the lead up to the national authority being established. Once established the national authority will set nationally-consistent directions, key messages and strategies for an ongoing communications program, to be implemented at national, state and local levels.

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6: SUPPORT FOR DONOR FAMILIES

What will this component do?

Through a nationally coordinated approach deceased donor families will be provided with respectful support which is responsive to the needs of each family.

All families whose next of kin are identified as possible donors will be offered end-of-life support including bereavement counselling at the time, whether or not the potential donor proceeds to donation.

All families who consent to the donation of their loved one's organs and/or tissue donation will be offered information and ongoing contact and support.

Why do we need this initiative?

Currently donor families are provided with a high level of support from the various state based agencies.

However, programs and resources to support and acknowledge families vary greatly from state to state. New funding and a nationally consistent approach to support families will be developed and implemented by the national authority.

Funding will be provided for program staffing and best practice bereavement and family support resources. The program will be delivered by a new national network of organ procurement organisations with staffing outreach to donor hospitals.

Who will benefit?

The families of deceased donors will receive the support they need at the time of organ donation and afterwards.

The professional staff who provide bereavement and other support services will be supported to do so by the national authority and will be given resources to assist them in doing their jobs.

How much will it cost?

\$1.9 million for the period from 2009-10 to 2011-12.

When will it commence?

Once it is established, the national authority will develop a national donor family support program and resources. A new Commonwealth funding stream will enable organ procurement organisations to provide nationally consistent support to donor families.

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7: SAFE, EQUITABLE AND TRANSPARENT NATIONAL TRANSPLANTATION PROCESSES

What will this initiative do?

The new national authority, in collaboration with the relevant professional societies, will be responsible for maintaining and auditing the implementation of approved national transplantation protocols and standards. This will ensure that the management of transplant waiting lists and the allocation of organs and tissues is effective, equitable and transparent, regardless of where the donor and recipient reside.

The Transplantation Society of Australia and New Zealand (TSANZ) will be funded to manage an enhanced role for its clinical standing committees. Organ specific standing committees will meet more regularly to develop and maintain these national transplantation protocols. There is a need to integrate the different organ and tissue allocation processes into one agreed protocol that is then implemented and reviewed each year. An annual forum will be held to include community representation.

Funding will be provided to enhance and secure the operation of the National Organ Matching Scheme (NOMS).

Why do we need this initiative?

The allocation of organs is a complex process that depends on a range of factors including medical need, urgency, capacity to benefit and donor/recipient matching criteria which vary according to the type of organ to be transplanted. Allocation is guided by state-specific guidelines, local hospital protocols and procedures, and protocols developed by TSANZ and Australian Transplant Coordinators' Association (ATCA). TSANZ Standing Committees oversee and review the donor organ allocation protocols and ATCA conducts audits of donor allocation. Efforts are needed to ensure a national approach to the allocation of organs and tissues.

Who will benefit?

Patients who are in need of a transplant will benefit through an equitable and transparent process for the management of transplant waiting lists and the allocation of donated organs once available across Australia.

How much will it cost?

\$1.0 million over the four year period 2008-09 to 2011-12.

When will it commence?

The development of nationally consistent, safe, equitable and transparent transplantation processes will continue through close consultation between professional societies, the Department of Health and Ageing, and state and territory departments of health.

The national authority, in collaboration with the professional societies, will be responsible for maintaining and auditing the implementation of approved national transplantation protocols and standards from 1 January 2009, pending legislative processes.

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8: NATIONAL EYE AND TISSUE DONATION AND TRANSPLANTATION NETWORK

What will this measure do?

This measure will establish a national network to manage eye and tissue donation, retrieval, processing, storage and transplantation. It will introduce systems that will deliver a coordinated, accountable, national tissue transplantation service for patients across Australia.

A new national eye and tissue network will assist the national authority to drive reforms in seven priority action areas to achieve a cohesive national program:

- community awareness and education;
- automated real time donor notification systems;
- family contact and consent to ensure a single coordinated point of contact;
- enhanced training for requesters, collectors and eye and tissue bank scientists;
- a national eye and tissue donor database;
- national eye and tissue allocation protocols; and
- national eye and tissue outcome data registries.

Specifically, the network will:

- assist the national authority with the implementation of all aspects of the priority action areas;
- prepare sector wide input to the national regulatory framework for eye and tissue banking;
- develop and endorse education and training programs and relevant competencies for staff in the eye and tissue donation and transplant sector;
- represent the eye and tissue donation and transplant sectors on collaborative national groups and programs in the organ and tissue sector; and
- develop and endorse the data collection, storage, analysis and reporting requirements for eye and tissue donation and transplantation.

Why do we need this initiative?

The eye and tissue sectors are the largest donation and transplant sectors in Australia with a significantly higher number of referrals for eye and tissue donation compared to solid organ referrals. Eye donation is the single most common and likely donation from deceased donors and demand for other tissues continues to exceed supply.

Greater consistency and closer coordination of the operational relationships between the sectors is important to ensure improved access to eye and tissue transplants for Australians. One of the key issues for the eye and tissue sector is the lack of a formal mechanism for developing national approach, driving reforms and improving coordination between the tissue and eye banking sectors.

Who will benefit?

Australians in need of an eye or tissue transplant will benefit through improved

donation and transplantation systems.

How much will it cost?

\$3.1 million over the four year period 2008-09 to 2011-12.

When will it commence?

The development of a national eye and tissue donation and transplantation network will begin immediately through close consultation between relevant professional societies, the Department of Health and Ageing, and state and territory departments of health. The national network will be established and operational by 30 June 2009.

The national authority, in collaboration with the professional societies, will be responsible for implementing and overseeing the network from 1 January 2009.

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9: OTHER NATIONAL INITIATIVES, INCLUDING LIVING DONATION PROGRAMS

What will this measure do?

This measure will establish national protocols to guide initiatives including the practice of 'paired kidney exchange' between living donors and recipients, and living donor liver transplantation.

Each of these types of donation practices, while not new, will facilitate an increase in donor numbers thereby improving Australians' access to transplants, while ensuring that these practices continue to operate in a safe, effective and ethical manner.

The new national authority will coordinate the development, endorsement by the relevant colleges and societies, and implementation of a national program to coordinate 'paired kidney exchange'.

It will also monitor the implementation of the living donor liver donation policy framework to facilitate consistent, ethical and safe practice nationally including monitoring of health outcomes and adverse events for donors and recipients.

Why do we need this initiative?

Kidney transplantation from a live donor to a recipient currently accounts for 43 per cent of all kidney transplants in Australia. Sometimes the situation arises where the kidney of a person wishing to donate is incompatible with the person whom they wish to receive their kidney. It is estimated conservatively that at least 30 percent of willing, and otherwise appropriate, kidney donor-recipient pairs are incompatible, and currently do not proceed to live donor transplantation. Paired kidney exchange is a process that matches one incompatible donor-recipient pair with another incompatible pair, providing the opportunity for an exchange of donor kidneys.

Living donor liver transplantation involves resection of one lobe of a healthy, matched donor's liver and transplanting it into a recipient with whom the donor has a genetic or close personal relationship. Advances in medical science and clinical practice over the last decade have enabled this procedure to be developed overseas, and more recently, it has been introduced in Australia as a potential treatment of last resort for end-stage liver failure.

Who will benefit?

Australians who are in need of an organ transplant, particularly a kidney or liver transplant. Families interested in undertaking a living 'paired kidney exchange' due to matching incompatibility with their own family members.

How much will it cost?

\$0.82 million over the four year period 2008-09 to 2011-12.

When will it commence?

The development of a national living 'paired kidney exchange program', a national living liver donation protocol, and a national protocol to guide the practice of 'donation after cardiac death' will continue through close consultation between relevant professional societies, the Department of Health and Ageing, and state and territory departments of health.

The national authority, in collaboration with the professional societies, will be responsible for implementing and the ongoing oversight of these initiatives from 1 January 2009, pending legislative processes.