

Increasing Organ Donation in NSW

Government Plan 2012



Health

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Foreword



It seems to me that nothing is more truly a reflection of our shared humanity than when we take steps to save another person's life – even more so when that person may well be a total stranger.

Donating tissues and organs saves lives; it's as simple as that.

The real human impact of organ donation is brought home when you read the uplifting stories of Jessica Sparks, Chandana Guha and her daughter Ishita or Sumith Abkari, Brian Myerson, Michelle Bradley and her mother Enid. These are real stories about real people and I wish we were able to read more of them.

I invite you to learn from family members who have supported a loved one's desire to be a donor and how they found that difficult decision easier in the knowledge they were respecting and honouring their wishes.

The discussion paper Increasing Organ Donation in NSW brought many difficult issues to light and I am most grateful to all the people and organisations whose contributions to that paper have helped us shape our new policies. It is by taking those into account that we have been able to develop Increasing Organ Donation in NSW: Government Plan 2012.

Our plan includes the following:

- Transferring existing donors from the state Roads and Maritime Services Register to the national Australian Organ Donation Register
- Increasing community education and awareness campaigns to encourage people to have discussions with their families about organ donation

- Employing specialists in hospitals to help families through the difficult decisions about consenting to organ donation
- Providing guidelines to doctors which help them uphold a person's desire to become an organ donor
- Promoting living donation programs

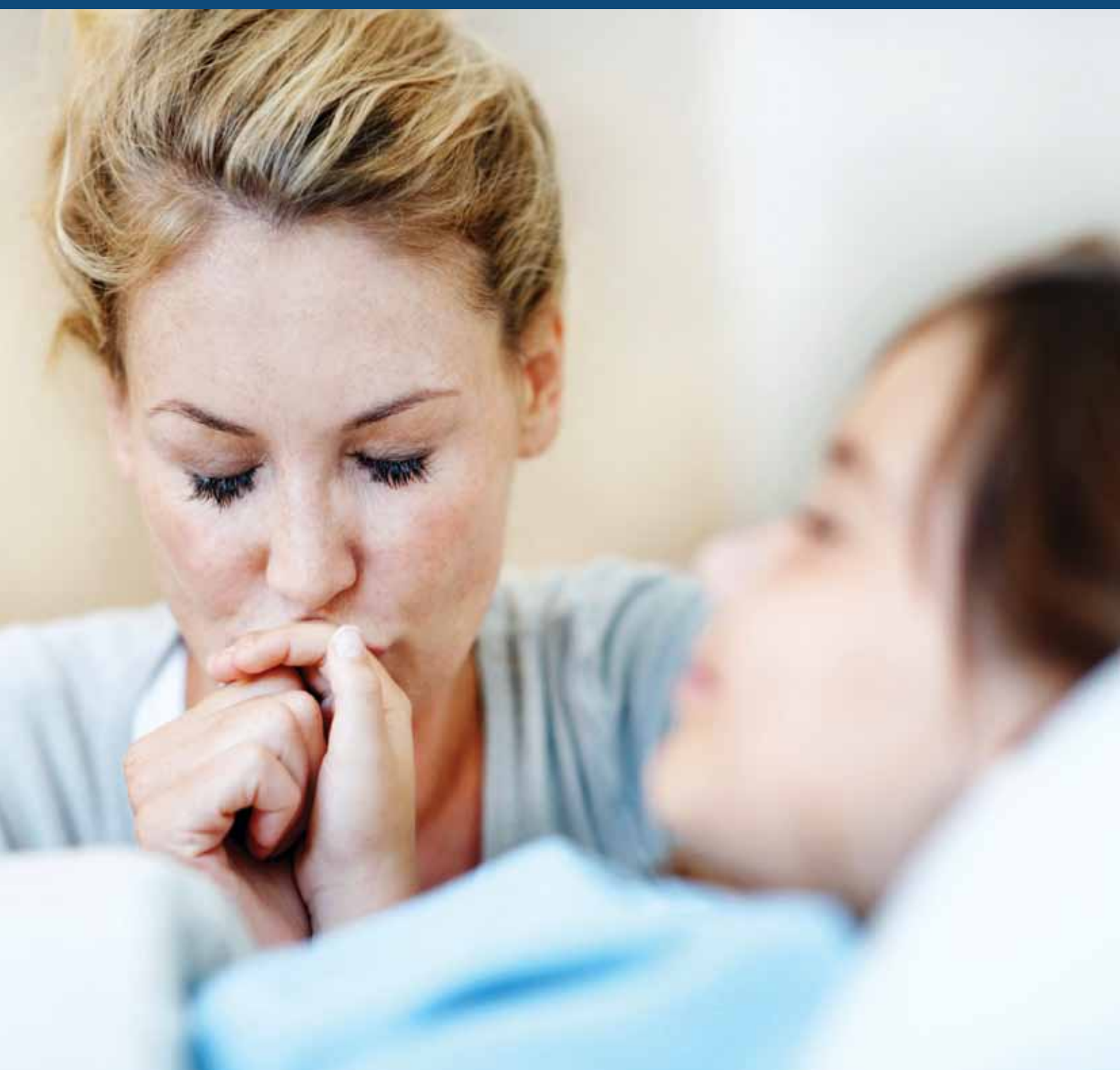
In my time as Minister for Health and previously as Opposition spokesperson, I have had the privilege of meeting many organ recipients and I know the extent to which they have an immeasurable gratitude to the individual and family whose decision has made their continued life possible. I have also met the special people who are the families of donors, people whose courage and determination to follow their deceased loved one's wishes, in a time of great stress, was so invaluable and life-saving.

Organ donation is life-changing and life-saving. I thank all of you who are already registered donors and I remind you of the importance of explaining and discussing your decision with your family. I urge those of you who are not donors to seriously consider enrolling.

What organ donation reminds us, perhaps a good thing about which we should be reminded in these often troubled times, is that in and underneath our skins we are truly just one family and we can look after each other.

A handwritten signature in black ink that reads "Jillian Skinner". The signature is fluid and cursive, with a large loop at the end of the last name.

Hon Jillian Skinner MP
Minister for Health
Minister for Medical Research



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Every year one in six people who could have been saved by an organ donation dies because a matching organ does not become available. It is a deplorable situation and one that must not be ignored.

Barry O'Farrell MP,
9th September 2006



1 Summary

Access to organ donation and transplantation is essential in the provision of quality healthcare in NSW, especially where providing organ transplant can be the difference between life and death.

The NSW Government is taking a proactive approach to organ and tissue donation and transplantation to ensure that the best outcomes are achieved for all patients in NSW – whether it be for people with end-stage disease (such as kidney, liver, heart, lung or pancreas failure) or for people receiving tissue donation (bone, corneas or skin) to improve the quality of their lives.

The Government's commitment to putting the patient first includes ensuring that the wishes of patients in relation to organ donation are respected and, as far as possible, upheld.

Significant progress has been made in partnership with the Commonwealth to reform and improve organ donation across Australian states.

Despite this, the rate of organ and tissue donation in NSW compares poorly with other states.

This low rate of organ donation motivated the release in December 2011 of a discussion paper *Increasing Organ Donation in NSW* and this policy document is based on feedback from that discussion paper.

The approach outlined in this policy document *Increasing Organ Donation in NSW: Government Plan 2012* lays out a local blueprint for the way forward. It maintains and strengthens existing Commonwealth strategies and outlines new initiatives for NSW. It is essential that national and state programs are co-ordinated and some of these ongoing initiatives are reflected in this document.

This ongoing partnership between NSW and the Commonwealth provides the best means of raising awareness about organ donation, improving

hospitals' capacity and expertise in managing organ donation, yielding increased organ donation rates, and improving clinical outcomes for patients and families.

Our goal is to increase the organ donation rate in NSW

We will do this through:

1. Enabling peoples' intentions regarding organ and tissue donation to be known to their family or significant others, and preferably documented and accessible by:

- Streamlining to a single national organ donation register.
- Reinforcing current national key messages around discussing wishes about organ donation with one's family or significant others.
- Encouraging healthy adults to consider and discuss their organ donation wishes at the same time as they plan who should make medical treatment decisions on their behalf as part of advance care planning for end of life.

2. Addressing information gaps about organ donation, including addressing myths and misperceptions by:

- Supporting current national key messages and forthcoming information campaigns about organ donation.
- Increasing understanding that two pathways to deceased donation are possible (by donation after brain death or by donation after cardiac death).¹
- Enhancing current education for culturally and linguistically diverse communities about organ donation and its benefits.
- Identifying clinical and community organ donation 'leaders' to encourage people to think about organ donation.

3. Identifying all opportunities for organ donation in NSW hospitals by:

- Developing a new model for hospital placement of specialist clinicians in facilities with a higher caseload of potential donors.
- Enhancing medical record audit of deaths in those referred as potential deceased donors.
- Making health professionals aware of the expanded eligibility criteria for donors that now exists.
- Enabling removal of cardiac tissue (such as heart valves) after death.
- Promoting a culture among all hospital staff that supports organ donation.

4. Supporting clinicians to have conversations with donor families which enable fully informed decisions about proceeding with organ donation by:

- Expanding specialist training for clinicians in conducting donor family conversations.
- Trialling a new model for approaching families for consent led by specially trained 'designated requesters' who are independent to the treating team.
- Maintaining the current 'opt-in' consent.
- Developing a Practice Guideline applicable to circumstances where doctors who accede to a family's refusal of donation despite prior patient consent must document the reasons for refusal.

5. Supporting living donor programs by:

- Participation in the national paired kidney exchange program.
- Making existing leave entitlements known to those recipients and their families who may be considering living donation (for more detail see Section 5).



Transplant Australia

Transplant Australia sees both the wonderful life-saving benefits of donation and transplantation and yet the heartache of those who wait for that second chance every working day.

As the national advocate for the 1,596 Australians currently on the transplant waiting list, we believe more must be done to ensure Australia reaches a rate of donation comparable with the world's leading nations.

We are a generous people. This is evident in how we help each other in times of fire or floods. Why this doesn't translate in terms of organ and tissue donation has long been a source of frustration.

Conversely NSW can and should be proud of its place in the history of transplantation in Australia. Wonderful transplant units such as those at St Vincent's, Westmead and Royal Prince Alfred Hospitals have helped save the lives of hundreds of Australians over the past 40 years.

For the first time in NSW, the Government has asked both the experts and the people what they believe can be done to improve donation.

Many of the answers lie within this plan. Fortunately we have avoided wholesale change but rather see the benefits of working with the Commonwealth in a structured and cohesive manner to achieve world's best practice.

There certainly needs to be greater effort in our clinical system in NSW. A donation rate of 36 per cent of all potential donors is something that must be improved. Ensuring we have the right mix of skills coupled with empathy and compassion at the time of that all-important consent discussion with the grieving family is paramount.

Simplifying the way the community supports donation is also important. There is no doubt we have confused the public both with the motor registry option and the national Australian Organ Donor Register. It needs to be made much easier to 'opt-in' to this important initiative.

We also look forward to working with the Government on addressing our multi-cultural audiences. It is concerning to note that of the 1,756 donors in Australia in the seven years from 2005, some 1,621 (92 per cent) were from traditional British and European ethnicities. Tailored messages to Australians with a multi-cultural background are crucial.

Finally the potential within this plan should not be underestimated. In 2011 NSW, with a donation rate of 36 per cent, was able to transplant a total of 228 people. That's 228 lives saved. With a goal of increasing the donation rate to 70 per cent it is possible that almost 500 people in NSW will achieve life-saving surgery every year. That will be something to celebrate.

Chris Thomas
Chief Executive Officer
Transplant Australia

2. The need for change: Current organ and tissue donation practice in NSW

Residents of NSW are supportive of organ and tissue donation. In fact the Roads and Maritime Services drivers' licence register has the largest number of registered donors in Australia. Despite this, the rate of organ donation compares poorly with other states (Figure 1).²

There is a significant difference between the number of people who indicate that they are willing to be organ donors on the Roads and Maritime Services register ('registered' donors) and the number who ultimately donate their organs.

NSW is significantly below the national target for organ donation rates. This target is 70 per cent of all potential donors³ going on to actually donate organs based on medical suitability and requisite prior consent of the person or their family (Figure 2).

Figure 1: Deceased Organ Donors Per Million Population: National and Jurisdiction Rates
2000-2008, 2009-2010 & 2011

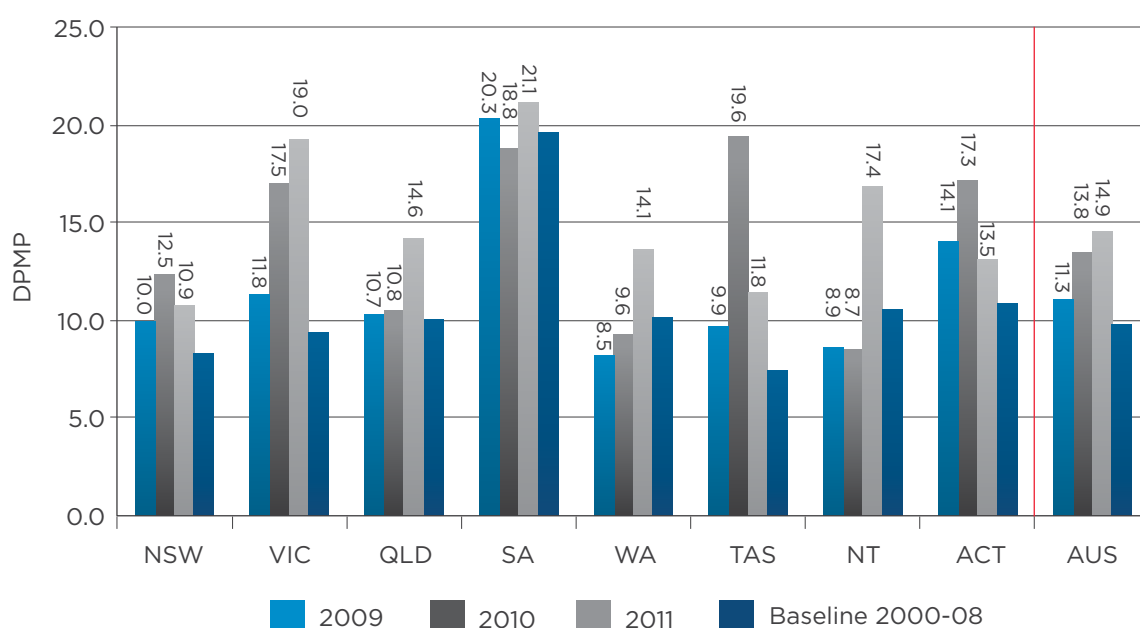


Figure 2: Request Rate, Consent Rate and Donation Rate
All Donors 2010 & 2011 NSW Performance vs. National KPI Targets

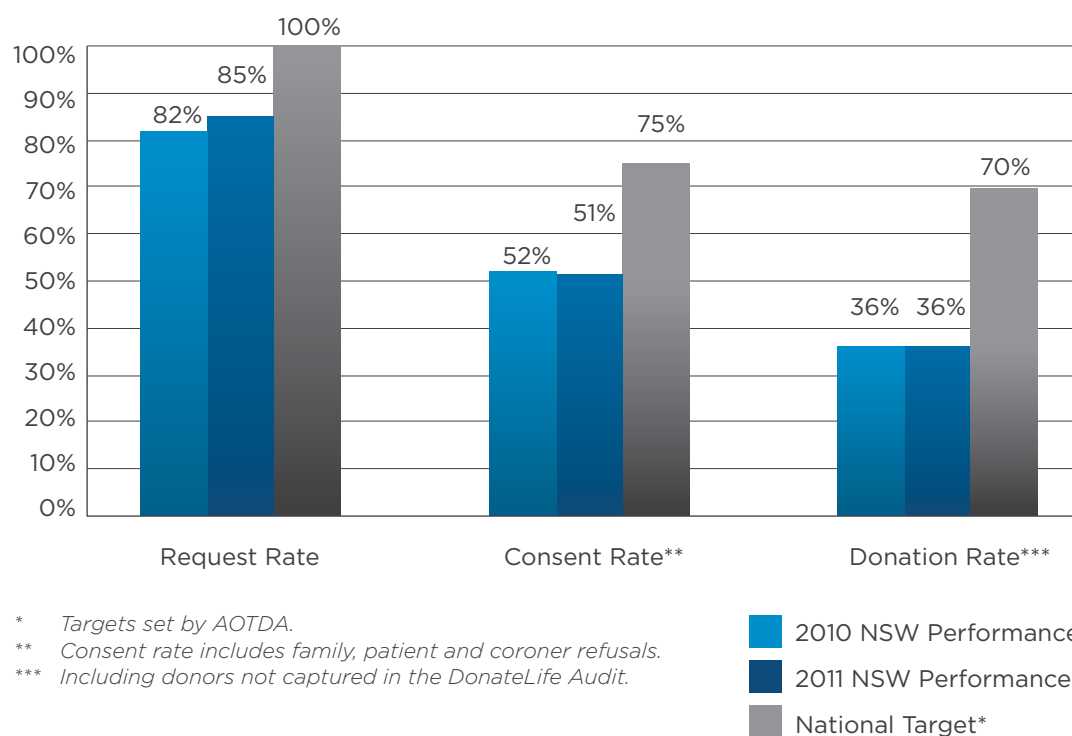
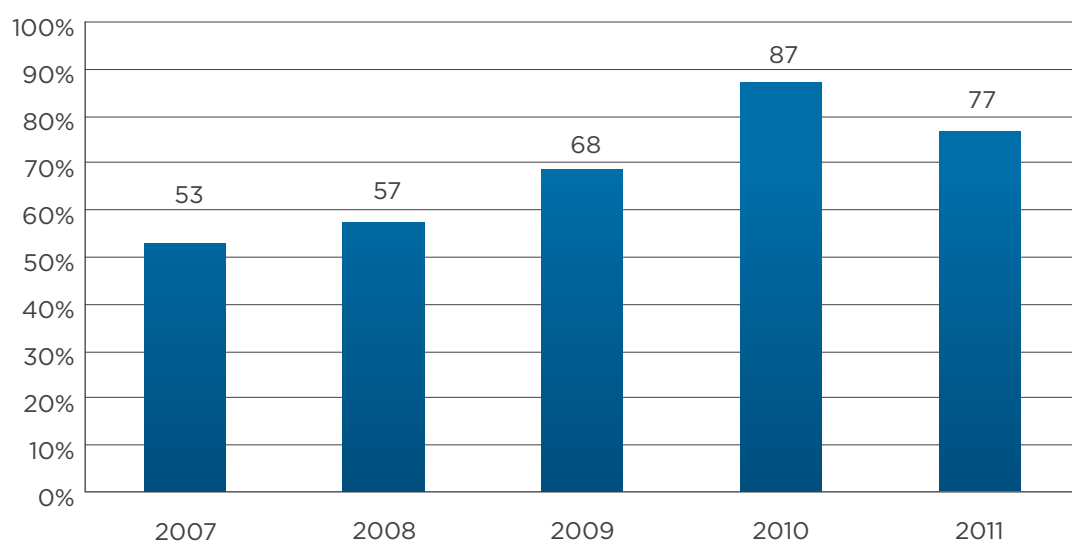


Figure 3: NSW Solid Organ* Donors 2007-2011



* Solid organs are kidneys, livers, hearts, lungs and pancreas

Figure 2 shows the difference between:

- i) the percentage of cases where the family is requested to consider organ donation (the 'request rate')
 - ii) the percentage of families that ultimately agree to donation (the 'consent rate'), and
 - iii) the percentage of potential donors who become actual donors (the 'donation rate').
- These NSW results are then compared with the national targets for these indices.

In 2011 there were 215 individuals identified in NSW hospitals as being potential donors and medically suitable to donate, of whom only 77 donated their organs. While a proportion of these will have

registered as willing to donate on the Roads and Maritime Services register, many will not have done so. These declining numbers underscore the need for policy changes to increase donation rates in NSW.

Family refusal to proceed with organ donation occurs in approximately half of all potential donor cases in NSW but it is important to note that the vast majority of family refusals occur where the person's wishes are unknown. However in NSW around seven to 10 families per year refuse donation where the person has given prior consent.

In 2010 there were 87 people who donated their organs while in 2011 there were 77 donors.



Limitations on organ donation related to the way people die

Meeting demand for transplantation is significantly limited by the availability of organs from deceased and living donors. However, while strengthened efforts are needed to optimise availability of organs for transplantation, deceased donation will always be limited to some degree as most people do not die in a way that makes organ donation feasible.

Of all deaths in hospital, fewer than two per cent occur in a way that makes deceased organ donation possible as this requires patients to be on a ventilator in an Intensive Care Unit in the period leading up to their death. Tissue donation, on the other hand, is possible in many more environments where patients die, including at home. It is essential then that all potential organ donors are identified so that donated organs and tissues can be most effectively used.

A number of other important factors adversely influence the number of organs available. These include:

- The number of patients who are medically suitable to donate who die in hospitals.
- Inaccuracy in identifying potential donors in hospitals.
- Ineffectiveness in how clinicians present the possibility of organ donation and support families in decision-making.
- The percentage of individuals who are identified as potential donors but who have previously expressed and /or documented refusal to donate their organs after death.





Jessica Sparks
with her mother, Kate
(photo courtesy The Illawarra Mercury)

Jessica's story

Jessica Sparks was born with cystic fibrosis and received a double lung transplant when she was 16.

"From the age of about 12, my illness got progressively worse, to the point where I was diagnosed with end-stage lung disease," Jessica said.

"I couldn't walk, talk or even breathe without help. At just 16, I was facing the reality that I could die."

Three years after her transplant, life could not be more different for the vibrant teenager who is now at university studying for a combined law/ journalism degree and a diploma in French.

"The world has once again opened and I've claimed back my dreams," she said.

Jessica said it's not just about the big things, like studying at university and competing in the World Transplant Games in Sweden.

It is the small things – things people without a chronic illness take for granted – that give her the greatest thrill.

"Things like being able to go grocery shopping with my mum and walking on the beach mean so much to me."

Jessica said she and her family will be forever grateful to the organ donor who gave her a second chance at life.

And now Jessica is on a crusade to see an improvement in Australia's organ donation statistics.

"It's so important to maximise Australia's organ donation rates so that more of the desperately sick people on the transplant waiting list can have another chance of life.

"Australia is world class in successful transplant outcomes, but we continue to have one of the world's lowest donation rates," she said.

3. What we do well:

Organ and tissue donation and transplantation in NSW

Optimal use of donated organs

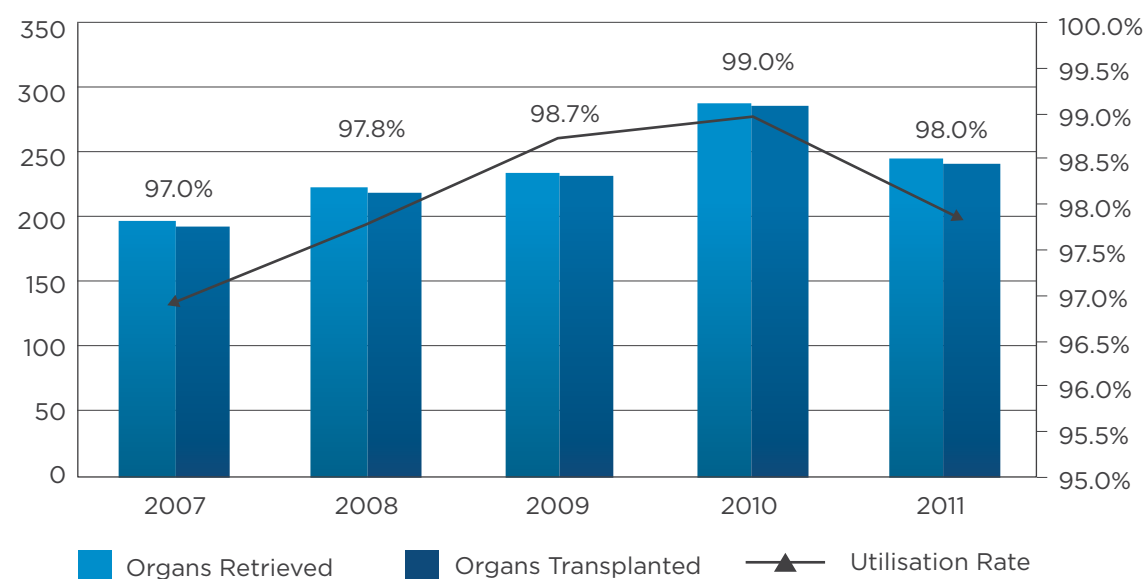
While overall organ donor numbers are low in comparison with other states, the utilisation rate for donated organs in NSW has ranged from 97 per cent to 99 per cent over the last five years (Figure 4). This reflects high levels of clinical expertise in donor identification and clinical management, surgical processes and retrieval standards in NSW.

Transplantation outcomes

NSW, and Australia more broadly, have clinical outcomes for patients who receive organ and tissue transplants that are among the best in the world. However in order to improve clinical outcomes and quality of life for all patients waiting for transplantation, ways need to be found to increase the availability of organs and tissue.

Australia has a world class reputation for successful transplant outcomes, both in terms of survival rates of recipients and in the number of organs transplanted from each donor. Since 1965, more than 30,000 Australians have received life-saving or life-preserving organ transplants. More than 900 organ transplant operations are performed each year. Many more tissue transplants/grafts are performed, including about 1,500 corneal transplants each year.

Figure 4: NSW Organ Utilisation Rate (excluding islets*) by Calendar Year



* Pancreatic islet cells

Due to thorough review of a potential donor's current and past medical, social and lifestyle factors, only three per cent of all kidneys retrieved in Australia for the purpose of organ donation were not able to be transplanted compared to 17 per cent in the United States.⁴

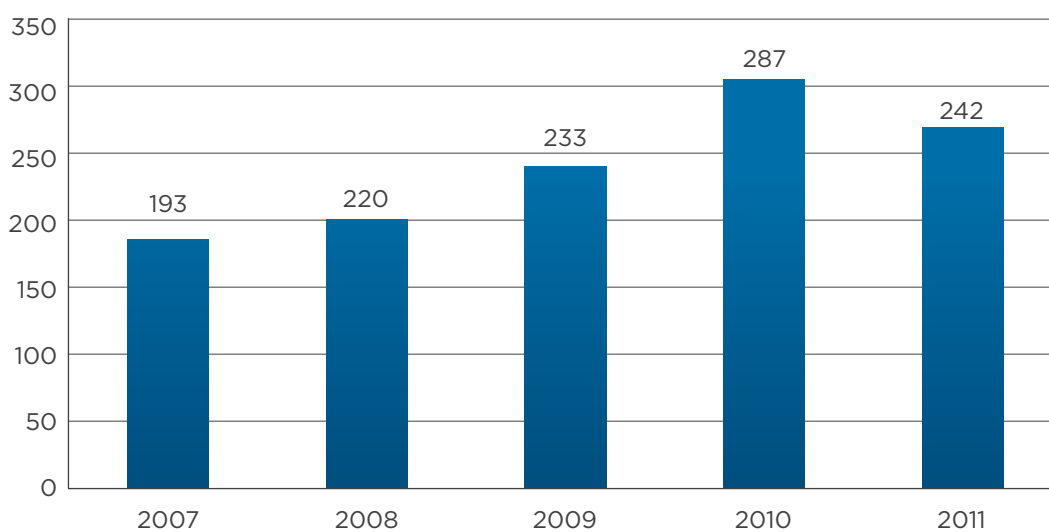
St Vincent's Hospital's heart-lung transplantation program is one of the largest and longest running programs in Australia, with survival rates which exceed international figures.⁵

Despite these outstanding results, in 2011 the number of organs transplanted declined from 287 to 242, reflecting the reduced number of available deceased donor organs (Figure 5).

Contribution to tissue donation programs nationally

The contribution of NSW to tissue donations such as corneal transplants and bone grafts is high, with the state providing one third of all Australian tissue transplants, including one third of all corneal transplants in Australia.

Figure 5: NSW Total Transplants 2007-2011 (excluding islets)





Chandana and Ishita Guha

A Mother's perspective

Chandana Guha's daughter Ishita was just two years old when she was diagnosed with a rare kidney condition that saw her miss a lot of schooling because of repeated hospitalisations.

By 2008, when a donor kidney became available, Ishita's own kidneys had failed completely and she was relying on daily dialysis to survive.

"I did the dialysis for her at home. It was heartbreaking," Chandana said. "There's nothing worse for a mother than watching your child go through something like this.

"She was literally tied to the machine every night for eight to 10 hours. I would untie her in the morning so she could go to school. She would come home, do some homework and then get back onto the machine.

"By the time she received her transplant she had undergone 14 surgeries in the space of four months."

As a side effect of the condition, Ishita was also obese. This led her to be bullied at school.

"She was so obese I joined a sewing class so that I could make clothes for her," said Chandana, a qualified statistician who gave up her profession to care for her daughter at home.

"Until the transplant, Ishita's childhood was hard. What with the absences when in hospital, and the bullying, she missed the opportunity to integrate normally with other kids.

"And it was hard for us as a family too. We wondered whether we'd ever be able to be like other families. To go out to dinner, and to smile and laugh."

These days life is very different for the now 17-year-old, a size 8 who is loving school, planning to be an artist, and recently competed in the Balmoral Burn.

Life is also different for her mother, who has returned to work as a statistician.

"We owe so much to the donor family," Chandana said.

4. What we will do:

Response to recent community and professional consultation

In response to concerns over relatively low organ donation rates in NSW, the Government released a Discussion Paper *Increasing Organ Donation Rates in NSW* in December 2011. The purpose of the paper was to encourage local community discussion and seek views on how to improve performance in NSW.

A total of 76 submissions were received. The majority of submissions were from individuals, with 11 received from groups, including Transplant Australia and other clinical and organ donation

advocacy organisations, the NSW Health Clinical Ethics Advisory Panel, the NSW Medical Services Committee and the Australian Medical Association.

The following section includes brief comment about the consultation results, as well as an outline of how we will achieve our objective of increasing organ donation rates in NSW.



OUTCOME 1:

Enabling people's intentions regarding organ donation to be known by their family or significant others, and preferably documented and accessible

1.1 Streamlining to a single national organ donation register

What we learnt in consultations

NSW is the only state in Australia to maintain a separate state-based organ donor register – the Roads and Maritime Services drivers' licence-enabled register. There was strong support for closing this donor register on the basis that a drivers' licence renewal process is not the best way of registering organ donation intentions.

This is because the process of drivers' licence renewal in NSW affords minimal opportunity to provide detailed information to potential registrants about donation and the importance of discussing these wishes with one's family. The Roads and Maritime Services register operating in parallel with the Australian Organ Donation Register run by Medicare has caused confusion for clinicians when checking on potential donors' intentions.

A single national register will address these concerns; allow greater focus on important issues such as proper consent; and allow doctors to more readily access information about a person's wishes regarding organ donation should they have travelled to another state or territory and become a potential organ donor.

What we will do

NSW will close the Roads and Maritime Services register and transition to the Australian Organ Donation Register. The NSW drivers' licence register will be closed in November 2012 for acceptance of new organ donor registrations and/or amending existing organ donation consent. From that time, anyone wishing to register their organ donation intent will be directed to the Australian Organ Donation Register.

The Commonwealth Government has agreed to work with the NSW Government to support decommissioning of the Roads and Maritime Services organ donor register.

A 'snapshot' database of the NSW drivers' licence organ donation register will be retained by the NSW Organ and Tissue Donation Service for five years (the maximum period for which licences are valid) to allow for reasonable inquiries to be made by health professionals involved in decision-making, in particular regarding a person's objection or consent to organ donation should organ donation become a possibility. The 'snapshot' database will allow the wishes of people who have either consented or objected to organ donation, but not informed their families, to be respected. The information on the database will be able to be overridden should more recent information be available indicating an individual has changed their view about organ donation.

Registrations of consent on the NSW Roads and Maritime Services organ donor register will be made available to the Commonwealth Government for inclusion in the Australian Organ Donation Register. A regulation will be made under the Health Records and Information Privacy Act 2002 to enable the disclosure of information to the Australian Organ Donation Register.

An information campaign involving radio, print and digital (web-based) information for the community will inform residents of NSW about the changes, encourage family discussion, direct individuals who wish to register organ donation intent to the Australian Organ Donation Register, and promote the positive benefits of organ donation and transplantation. The Ministry of Health and the NSW Organ and Tissue Donation Service will develop this campaign.

The closure of the Roads and Maritime Services register is also an opportunity to explore innovative ways to encourage more Australians to register on the Australian Organ Donation Register.

Some submissions to the Discussion Paper expressed concern that the Register and the methods of joining it had not kept pace with today's changing technology, and it is in fact surprising that in a period of intense media and public promotion of organ and tissue donation over the past three years, the number of Australians registering on the Australian Organ Donation Register have at best stagnated and in some states fallen.

NSW understands the importance of family discussion but believes a joint message of discussion and registration optimises our community's participation in this important initiative.

The National Health Service Organ Donor Register in the UK has recently trialled text messaging registration. The service, supported by a mobile

response company, has given UK residents the opportunity to register as donors by texting the word 'GIVE' to a special number. A number of privacy safeguards were necessary to ensure accuracy of the data.

NSW will partner with Transplant Australia and liaise with the Commonwealth to explore opportunities for innovation, in order to encourage more people to register on the Australian Organ Donation Register. This includes opportunities afforded by today's rapidly changing technology and social media.

Drivers' licences issued after closure of the NSW Roads and Maritime Services drivers' licence register will not include any information regarding organ donation.

The Australian Organ Donation Register can be accessed at www.humanservices.gov.au/customer/services/medicare/australian-organ-donor-register.

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Australian Organ Donor Register Registration

If you wish to change any of your registration details, please call 1800 777 203 or contact us by Email ADQR@medicareaustralia.gov.au

I hereby give my permission for the details I have listed below to be included on the Australian Organ Donor Register.

*Indicates a required field

Personal Details:

*Medicare Card Number: (10 numerals required)

*Reference Number: (This is the number next to your name on your Medicare Card)

Title:

*First Name: As per your Medicare card

Second Initial:

*Surname:

*Date of Birth: Day Month (eg. 31 Jan 1971)

1.2 Reinforcing current national key messages around discussing wishes about organ donation with one's family

What we learnt in consultations

Family refusals to proceed with donations are high in circumstances where the wishes of the individual in regard to organ donation are unknown. In the first six months of this year, there were 32 family refusals in this circumstance. This underscores the importance of encouraging people to discuss their wishes with their family in advance of the need to make a decision about proceeding with organ donation.

What we will do

We will support national and local social marketing campaigns which promote family discussion of organ donor intent. Two national DonateLife campaigns '*DonateLife, discuss it today, OK?*' and '*DonateLife, know their wishes. OK?*' have encouraged Australians to 'discover, decide and discuss' their wishes or decisions with their family members regarding organ donation.

Promoting key messages is an important priority for the NSW Organ and Tissue Donation Service in 2012. The Organ and Tissue Donation Service will partner with a range of community organisations, including Transplant Australia, in campaigns targeted to a range of culturally and linguistically diverse communities via language-specific media outlets.

1.3 Encouraging healthy adults to consider and discuss their organ donation preference at the same time that they make plans about who should make treatment decisions on their behalf should they lose capacity to do so (part of advance care planning for end of life)

What we learnt in consultations

There was support for raising organ donation as an option for individuals to consider early in chronic disease or when people are still healthy.

What we will do

Advance care planning involves thinking about, discussing and documenting preferences for care in anticipation of future deterioration in health and inability to make one's own decisions, often at end of life.

This may involve, but is not limited to, use of advance care directives. Advance care planning is currently being implemented in the NSW public health system. Eliciting organ donation preferences will be encouraged and incorporated into early phase advance care planning discussions with patients and families.

Developments are underway to both promote advance care planning generally, and to include a person's organ donation decision specifically, into evolving electronic documentation systems, such as the Commonwealth's Personally Controlled Electronic Health Record.

Advance care planning was considered a preferred method of honouring a person's intentions regarding organ donation over suggested legislative changes preventing a family from overriding the deceased person's wishes.

1.4 Respecting the most recent wishes of potential organ donors

What we learnt in consultations

People were concerned about situations where a deceased person had registered an objection to organ donation and had subsequently changed their mind without going through the administrative process of changing their details on either the Roads and Maritime Services register or the Australian Organ Donation Register.

The *Human Tissue Act 1983* currently requires compliance with written objection to organ and tissue donation in those cases, which means that donation is not possible.

What we will do

The *Human Tissue Act 1983* will be amended so that information can be considered about the deceased person changing their mind after recording an objection to organ and tissue donation.

This means that organ and tissue donation will be able to proceed if a deceased person has told a relative or friend that they want to be a donor after having previously registered an objection.





Sumith Abkari

Sumith's story

Sumith Abkari was 33 when he had a new liver transplanted at RPA in 2008. Now 37, with a four-week-old baby at home, life couldn't be more different.

"I was lucky. I only waited nine months. Some people have to wait two years or more."

And some die waiting.

"I was in really bad shape before the organ transplant," Sumith said. "I was very yellow, with no energy. I hadn't worked for five months because I was too sick."

Everything went smoothly and he was back at home three weeks after the surgery.

"It gives you a different perspective on life. I used to work in the corporate world, now I work for a not-for-profit organisation. It was just something I felt I wanted to do."

Sumith said the idea of becoming a father was a distant hope when he was so sick. The birth of his child is an "added bonus" to his second chance at life.

"I am as normal as I can be. I am working as hard as I can. We have our new baby."

"Before the transplant it was just about surviving, about getting through it day by day."

Sumith believes people are still not aware of what a difference organ transplantation can make to the recipient.

"People don't really realise how important it is. How it can change a person's life and how it can also change the lives of that person's family."

He was a believer in the importance of organ donation long before he needed one of his own.

"When I migrated to Australia I registered as a donor."

But actually needing a donated organ himself was not something he had ever considered.

"It's a gift. At the end of the day it's just the most fantastic gift."

OUTCOME 2:

Addressing information gaps about organ donation, including addressing myths and misperceptions

2.1 Supporting current national key messages and forthcoming information campaigns about organ donation

What we will do

NSW will continue to build on key national messages in innovative ways. In 2012 the NSW Organ and Tissue Donation Service will partner with a range of community, government, education and corporate agencies to promote factual information, normalise the conversation, and discourage misconceptions about donation and transplantation. These partnerships and strategies will include engagement with NSW Department of Education and Communities, under- and post-graduate nursing courses, NSW Youth Road Trauma Forum, and a program of national grants to filmmakers to produce short films related to the theme 'Discover, Decide and Discuss'.

The forthcoming community information campaign surrounding changes to registration of organ donation for NSW residents also provides a significant opportunity to raise community awareness about donation and its benefits.

2.2 Increasing understanding that two pathways to deceased donation are possible (by donation after brain death or by donation after cardiac death)

Whether a person can become a deceased donor is dependent on how, when and where a person dies. This is often referred to as the "pathway" to donation. When a person dies in an Intensive Care Unit, it may be possible for organ donation to

occur after brain death is determined, or after the person's circulation has stopped. Tissue donation may be possible in many settings outside Intensive Care Units including a hospital ward, hospice or home.

What we will do

Health professionals' understanding about the different pathways to deceased donation is important for identifying potential donations across all units of a hospital and will promote the message that consent to tissue donation (such as eye and/or bone donation) is a possibility that all individuals in the community should consider.

The NSW Organ and Tissue Donation Service will include information on these pathways to donation in all relevant education sessions and forums given by its personnel.

2.3 Enhancing current education for culturally and linguistically diverse communities about organ donation and its benefits

What we learnt in consultations

There was support for the existing proposals to introduce targeted strategies for promoting organ donation for Aboriginal and culturally and linguistically diverse communities.

Research commissioned by the Commonwealth's Australian Organ and Tissue Donation and Transplantation Authority found that culturally and linguistically diverse audiences are less likely to have made decisions about organ and tissue donation or held family discussions about donation wishes.



What we will do

NSW will build sustainable partnerships with agencies such as Transplant Australia and key community groups to enhance education awareness of organ donation within their communities. This will include the development of innovative programs which target the younger generations within these communities. Throughout 2012/13 this will include the launch of targeted and tailored resources addressing potential barriers to understanding organ and tissue donation across a range of cultural groups.

Community initiatives developed and/or launched to date include national educational resources and partnerships with the Chinese, Indian, Latino, Orthodox Greek and Serbian communities in NSW. Further groups will be identified and brought into similar partnerships. Targeted resources developed for and with Aboriginal communities will be launched soon. Examples include *Orthodox Communities in the Illawarra: Discovering and Discussing Organ and Tissue Donation Together and Donate Life* and *Give Our People a Second Chance at Life* brochure and posters developed by Aboriginal Elders of the NSW North Coast.

As part of our national commitment, NSW will continue to work with the Australian Organ and Tissue Donation and Transplantation Authority through the Community Awareness Grants program to ensure effective resourcing of these projects.

2.4 Identifying clinical and community organ donation 'leaders'

What we will do

There is considerable evidence that a positive response to organ donation messages occurs when they are provided by a well known individual or spokesperson from the relevant community group, religious leaders, a person within that community in need of a transplant, or from a donor family member. NSW Organ and Tissue Donation Service in partnership with the Australian Organ and Tissue Donation and Transplantation Authority also supports the NSW '*DonateLife Ambassadors*' program. This is now well established with nationally recognised community and media personalities promoting donation both within the state and across Australia.

The NSW Organ and Tissue Donation Service will continue to identify and encourage local leaders and high profile individuals within the community to participate as organ donation champions both within NSW and as part of the national *DonateLife Network*. They will act as role models and advocates, encouraging those within their communities to have a family discussion.

Clinical leaders are those specialist trained organ donation doctors and nurses in hospitals who are already active in providing organ donation advocacy, education and clinical expertise in our hospitals. The Organ and Tissue Donation Service will work with clinical leaders to promote a culture among all hospital staff that supports organ donation.

OUTCOME 3:

Identifying all opportunities for organ donation in NSW hospitals

3.1 Developing a new model for hospital placement of specialist clinicians in organ donation at facilities with higher caseload

What we will do

There is evidence that specialist medical and nursing staff in hospitals across NSW contribute to improving the skills of other clinical staff in identifying potential donors and managing their care. Specialist organ donation clinicians are a key feature of the successful models in Spain and the United Kingdom and have been implemented in Australia in recent years.

From 2012/13 the NSW Government is placing specialist clinicians in hospitals where the Intensive Care Units and Emergency Departments care for high numbers of potential donors due to the nature of the patient presentations and/or the population density.

Specialist medical positions will be located in hospitals which are major treatment centres for people in NSW. Rather than a single individual appointment (as has been the case to date), positions will be split to include a range of experienced medical practitioners. This has the benefit of increasing the likelihood that a dedicated medical practitioner is on duty at the time of admission of a potential organ donor, as well as developing capacity in less experienced clinicians across a range of medical and nursing specialties. From all the evidence across Australia, this is the most profound structural change that we can undertake to move towards best practice for organ and tissue donation. Specialist nursing positions will also be retained in these hospitals.

In addition, specialist nursing positions will be located in selected rural areas to support clinical and community education, improve donor identification, and complement dedicated medical positions in major coastal treatment and population centres.

3.2 Enhancing medical record audit of deaths in those referred as potential deceased donors to better identify potential donors in the future

What we will do

The NSW Organ and Tissue Donation Service already audits deaths in large hospitals to assess the number of patients who may have been potential organ donors. In 2011 only 133 patients were identified as brain dead potential donors. As the potential donor pool is so small, it is essential that all potential donors are identified so that organ donation can be considered. Enhanced auditing of deaths will be conducted in all NSW hospitals with specialist nursing and medical staff to measure and report on actual and potential organ donation activity and to identify missed opportunities for organ donation.

Audit findings will be used to:

- Inform case review meetings and quality of care
- Raise staff awareness across clinical specialties and care settings
- Determine how to overcome local barriers to organ donation.

3.3 Engaging health professionals around the expanded eligibility criteria for deceased donors that are now in place

What we will do

Along with the promotion of family discussion, the NSW Organ and Tissue Donation Service will continue to work with the Commonwealth to discourage misconceptions about organ donation. Recent initiatives include promoting the message that age and previous health issues, such as cancer or some chronic diseases, are not necessarily a barrier to organ donation. Organ or tissue donation by those who are older or with chronic illnesses may still confer significant health benefits to recipients.

The Organ and Tissue Donation Service will hold regular forums with transplant surgeons and physicians about the suitability of organs from a broader spectrum of donors.

3.4 Enabling removal of cardiac tissue (such as heart valves) after death

Heart valve transplants are life saving operations and are used to repair congenital heart defects in children and to correct acquired disease of the heart valves in adults. Where the whole of the heart is viable for transplant, it is essential for a medical practitioner to remove the heart. However there are situations where the whole of the heart is not viable for transplant but in

such cases, and provided the appropriate consents have been given, parts of the cardiac tissue, particularly the heart valves, can still be used for transplant purposes.

The *Human Tissue Act* currently requires medical professionals to remove cardiac tissue. However, in practice, this limits removal of cardiac tissue to the context of multi-organ retrieval. As the state's clinical need for heart valve transplants increases, the current restrictions in the *Human Tissue Act* will continue to cause great potential loss to the community.

What we will do

To this end, the *Human Tissue Act* will be amended to allow trained and authorised non-medical practitioners to retrieve cardiac tissue after death has occurred. Such an amendment has the potential to significantly increase the number of cardiac tissue donations and brings the removal of cardiac tissue into line with removal of corneal and musculoskeletal tissue after death.

3.5 Promoting a culture among all hospital staff that supports organ donation

The NSW Organ and Tissue Donation Service and the Agency for Clinical Innovation will work together on models to promote a culture in hospitals that is supportive of organ and tissue donation and to identify and remove barriers to organ donation. A whole-of-hospital approach will maximise donation rates.



The clinician's perspective

My daily work consists of caring for patients who are in hospital dying from liver failure.

I find it distressing that they have to wait so long for transplantation, but when it does finally happen the effect of transplantation on their lives is dramatic. It not only saves their life, it transforms their physical, mental and social lives too.

The impact of transplantation on the patient and their family is truly amazing.

But public awareness and information is only part of the story. We need to have the structure right because it's the structure that will allow us to identify organ donors in hospital systems on a whole-of-hospital basis.

My concern is that Australia is still concentrating too much on awareness and information, rather than making the necessary structural change.

Public awareness is important, but we have to get the right structure in place.

Professor Geoff McCaughan
Director, Liver Transplant Unit
Royal Prince Alfred Hospital

OUTCOME 4:

Supporting clinicians in having conversations with donor families that enable fully informed decisions about proceeding with organ donation

4.1 Expanding specialist training for clinicians in conducting donor family conversations

What we learnt in consultations

There was support for trialling different approaches to consent conversations with families than are currently used in NSW. Proposed models included using 'designated requesters' who are doctors or nurses independent from the treating team and for using 'collaborative' approaches where medical and nursing professionals engage together in the donor family conversation.

What we will do

The skills of specialist organ donation doctors and nurses in requesting organ donation are currently being enhanced as part of national quality improvement reforms through access to specialist training designed by the Gift of Life Institute Philadelphia, USA.

This training focuses on the most appropriate way to approach these donor family conversations and how best to provide the necessary information to families at a time of great stress and sadness. An integral part of the Gift of Life Institute program will be training clinicians in how to approach the donor family conversation in a way that reflects the legal framework around organ donation and champions pre-existing donor consent in donor family conversations.

Currently 90 clinicians have received initial training and a practical workshop involving simulation training using actors is being rolled out nationally. Doctors and nurses from around NSW will continue to participate in this training to ensure that staff who care for potential organ donors have the particular skills required in as many hospitals as possible where potential organ and tissue donations arise.

4.2 Trialling a new model for approaching donor families for consent (specially trained 'designated requesters' who are independent from the treating team)

What we will do

Currently in NSW, in addition to providing the treatment of a dying patient, it is also the role of the treating Intensive Care Unit specialist to discuss with the family, at an appropriate time, the organ donation wishes of their loved one.

The NSW Organ and Tissue Donation Service will trial the 'designated requester' model in selected Intensive Care Units from 2012/13. Intensive Care Units were chosen because of the high number of deaths in such units (10 to 20 per cent of admissions).

The trial will be based on an international model which uses specialist requesters who are separate from the treatment team of the potential donor. This model is associated with specialist support for families and higher consent rates for organ donation (compared with current rates in NSW). There is no high quality evidence to evaluate the benefit of this approach in Australia yet, but the trial in NSW will help build knowledge about the best way to work with families who are considering organ donation.

The NSW Organ and Tissue Donation Service will also continue to run Australasian Donor Awareness Program workshops for nursing and medical staff to provide introductory training on the clinical processes involved in organ and tissue donation, the grief experienced by families facing the death of a loved one, and principles of sensitive communication.

4.3 Maintaining the current 'opt-in' consent model

What we learnt in consultation

Overall there was support for retaining the existing 'opt-in' consent model for organ donation which exists in all other states and territories. This means that organ donation only proceeds when that person consents in advance, or their family decides on their behalf at the time of decision-making. The alternative 'opt-out' approach presumes that everyone is willing to be a deceased donor unless they explicitly register a refusal. Reasons for keeping the current approach included that:

- There is little or no evidence^{6,7} internationally to show that the 'opt out' approach alone (without also instigating other significant contributors) leads to increased donations
- Family refusals may still occur in an opt-out system and, in some cases, warrant being supported (families already do not have legal right to refuse in NSW)
- An 'opt-out' approach where everyone is presumed to be an organ donor unless they specifically refuse may be viewed by the community as unacceptably coercive and paternalistic, and
- An 'opt out' system may have a different impact across the community with an unfair burden placed on those who may not as readily exercise their right to opt out e.g. those with lower literacy levels or with limited English language skills

What we will do

There is insufficient international evidence at this time that moving to an 'opt-out' system is the only determinant in improving organ donation. Nor is there local support in NSW for such a change in practice.

We will retain the current 'opt-in' model of consent to organ donation in NSW while monitoring international trends and emerging evidence around effective and innovative approaches to increasing and improving organ and tissue donation.

4.4 Developing a practice guideline applicable to circumstances where doctors accede to a family's refusal of donation despite prior patient consent (documenting reasons for refusal)

While this issue elicits strong community comment, through the discussion process it emerged that there are less than a handful of cases each year where a family in NSW overrides a potential donor's informed consent wishes. In other words, when a person has given informed consent through the Australian Organ Donor Register or the Roads and Maritime Services register, and that consent is known by the family, it nearly always results in donation proceeding. What needs to change is where the donation wishes are not known and many families decline the opportunity to donate.

There are a number of factors that influence family consent to organ donation. These include the health professional's level of comfort seeking consent, the relationship with the family and their involvement in the treatment of the potential donor, and the timing of the request. On average seven to 10 donor families per year in NSW refuse donation where the person had given prior consent. It is clear that education, not legislation, is the answer. In addition it is believed more sophisticated consent conversations in the clinical setting will reduce this number further.

What we will do

We will develop a Practice Guideline referenced in the *Human Tissue Act 1983* requiring doctors to document why the deceased's prior consent was overridden when acceding to family refusal. This is likely to occur in around 10 cases per year and is generally related to a family's extreme grief response. This Guideline will help dispel potential misinformation about family refusals and clarify clinicians' responsibilities in these difficult scenarios.



A donor family's story

It's nearly 10 years now since Michelle Bradley's mother, Enid Bradley, died of a subarachnoid haemorrhage and her family decided to donate her organs.

It was an easy decision, because Enid and her husband had already had the conversation about organ donation.

"Some years before Mum died, she and Dad told all four of us of their wishes to be organ donors. So when the time came there was no decision to make. It had been made for us."

The only problem for Michelle and her family was convincing the registrar that Enid, who was 71 when she died, was not too old to be an organ donor. They sorted that however and Enid's wish to be an organ donor was honoured by her family.

Four people were helped by Enid's decision to donate her organs. A child and an adult received kidney transplants and two further people had corneal transplants to restore their sight.

"I'd urge all families to have this discussion because when the time comes you are in such shock and grief that making such a big decision is the last thing you want to have to do," Michelle said.

OUTCOME 5:

Supporting living donor programs

5.1 Supporting participation in the national paired kidney exchange program

What we will do

NSW participates in the national paired kidney exchange program. This program enables patients who are seeking a kidney transplant, but whose willing living donor is unsuitable to donate to them due to blood group and/or tissue incompatibility, to have their donor matched to a recipient in another pair. If a compatible match is found on the program's database then two or more simultaneous transplants can occur by exchanging donors' kidneys.

NSW Health policy supports and enables recruitment of willing donor and recipient pairs into this program, as well as 'altruistic' kidney donors.

5.2 Make existing leave entitlements known to those recipients and their families who may be considering living donation

What we learnt in consultations

A small number of respondents supported the proposal to introduce new workplace and income support strategies for living organ donors.

What we will do

NSW already has a range of financial support for living donors e.g. the NSW Isolated Patients Travel and Assistance Scheme and various types of leave arrangements through existing Workplace Awards. Potential transplant recipients and their families who are considering living organ and tissue donation may be unaware of existing financial and leave arrangements to support the living donor during surgery and convalescence. Ensuring these provisions are better understood and their use encouraged is appropriate at this time.





Brian Myerson

Brian's story

Brian Myerson is 59. It's been 13 years since he received a new kidney and pancreas and he's still eternally grateful to the donor and the donor's family who agreed back in June 1999 to transplantation.

After spending three years on dialysis before his organ transplantation, Brian said it's "beyond indescribable" how wonderful it is just to lead a normal life.

Brian did home dialysis three days a week. This involved five hours hooked up to the machine and an extra two hours setting up and coming off the machine... a seven hour process all up.

He considers himself incredibly lucky to have been able to receive his new organs.

"You just can't imagine what it's like. I'd been diabetic from the time I was 11 years old and as a result of that I developed kidney failure. I was always the sick person."

Dialysis takes a terrible psychological toll on those who need it to stay alive, with 15 per cent of dialysis patients dying every year.

"You know your time is coming up and the only thing that will save you is for someone else to die.

"It's very debilitating mentally."

He's concerned that NSW continues to have the lowest organ donation rate in Australia, and that Australia's rate is also low compared to the rest of the world.

"I don't think people really understand the impact of it."

Brian said it's not about more public awareness; it's about what happens in the hospital when a loved one is dying that determines whether organ transplantation occurs.

"The evidence from here and overseas suggests that it is how the family of that dying person is managed in the hospital that is most important.

"If the people in the hospitals are well trained and do their jobs, we will get the organs. That's the beginning and the end.

"Australians are amazing people. If they're approached in the right way in the hospital, the families will agree."

Endnotes

- 1 Definitions: "Donation after death may be possible where the individual's brain function is irreversibly lost but ventilation is still maintained by a machine – this is referred to as donation after loss of all brain function (or 'donation after brain death'). Donation after death may also be possible when it has been agreed by all parties that ongoing treatment is no longer in that individual's best interests and they will die shortly after withdrawal of life-sustaining treatments – this is referred to as donation after loss of circulation (or 'donation after cardiac death')." *AMA Position Statement on Organ and Tissue Donation and Transplantation 2012*.
- 2 Figures in this document are sourced from the *NSW Organ and Tissue Donation Service – Progress Report July – December 2011* with statistics for calendar year 2011, NSW Health Organ and Tissue Donation Service.
- 3 Definition: 'Potential donors' are defined as patients with confirmed brain death, or those who were likely to progress to brain death within 24 hours if supportive treatment continued, and who were medically suitable for organ donation. This includes potential donors who proceed to donation through either of the pathways to deceased donation: through donation after brain death or donation after cardiac death.
- 4 www.anzdata.org.au/anzod
www.optn.transplant.hrsa.gov
- 5 <http://www.stvincents.com.au/assets/files/pdf/C/c2%20heart%20lung%20interntnal%20survival%20comp%20as%20at%20april%202008.pdf>
- 6 Spain and Italy are the two countries which have shown the greatest improvement in their donor per million population rates since the early 1990s. Both countries had presumed consent legislation introduced in the 1970s. Neither countries' donor rates grew until the introduction of more efficient organisational structures to support donation (Abadie A, Gay, S The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross Country Study, *Journal of Health Economics* 2006; 25:599 – 620).
- 7 Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic analysis. *British Medical Journal* 2009; 338:a3162.



