We seek your views on how to increase organ transplantation

People in NSW are dying because there is a shortage of organ donations that could save their lives.

It is not that people are not consenting to become donors. The NSW RTA donor register has the largest number of registered donors in Australia. But NSW compares poorly when measured against other states - in 2010 in Tasmania there were 19.7 donors per million population (dpmp), SA 18.8 dpmp, Victoria 17.7 dpmp, ACT 17.3 dpmp and NSW 12.4 dpmp.1

And while the transplantation rate has improved since the introduction of a National Reform Agenda for Organ and Tissue Donation in 2008, we can still improve when we consider other countries such as Spain where the rate is around 34 dpmp, Belgium 28 dpmp, France and USA 25 dpmp.2

National initiatives3

The key elements of the National Reform Agenda package include coordination mechanisms, funding and cost sharing arrangements, community education and awareness campaigns and consistent initiatives to maximise the availability of donated organs from deceased and living donors.

Factors influencing donation

Beside clinical appropriateness of donor organs, critical factors influencing donations include consent of individuals and their families and the capacity of the health system to retrieve and transport donated organs.

The NSW Government will continue to implement elements of the National Reform Agenda, but we want to do more to help people who wish to donate organs and those for whom it can mean a new life.

This discussion paper is intended to provide you, the public, with ideas that can make a difference to the organ donation and transplant rate in NSW.

We want your feedback on the questions posed on the following pages

Please write to us at NSW Health, PO Box 961, North Sydney NSW 2059 or submit your comments by email to organ@doh.health.nsw.gov.au by 31 January 2012.

With thanks for your interest and involvement.

Jillian Skinner MP
Minister for Health
Minister for Medical Research

3 See Appendix A page 8 for details
1. Changes to the Donation Register

The RTA or the Australian Organ Donor Register?

As in all other states, if you live in NSW you can ‘opt-in’ to become an organ donor in the event of your death.

NSW residents are able to register their intent or objection to organ donation via the RTA driver’s licence process and also by registering with the Australian Organ Donor Register. NSW is the only state to utilise both registers.

Community-based organ donation advocacy organisations (such as Transplant Australia and Kidney Health Australia), as well as the Australian Government support NSW moving to the Australian Organ Donor Registry (AODR) established in 2005 and managed by Medicare as a single national register of organ donation intent.

It has been suggested that the RTA registration process does not provide information to assist registrants in determining their decision. And while the RTA provides capacity to revise organ donation intention on line, and issues amended licenses free of charge where licensees elect to change their intent, it is claimed that the issue of a driver’s licence for a lengthy period of time (5 years) also provides a potential disincentive for registrants to update their consent to reflect changes in organ donation intent.

By comparison the AODR requires registrants to actively pursue registration and as such pre-supposes a deliberate and active behaviour on the part of the registrant to ensure that their wishes regarding organ and tissue donation are known and recorded.

Advance Care Directives

In addition there have been suggestions that alternate mechanisms such as Advance Care Directives – where a person may document instructions for the latter part of their life and arrangements after death – be promoted to indicate consent to donate.

‘Opt-in” or ‘Opt-out’?

The relative merits of ‘opt-in’ versus ‘opt-out’ (presumed consent) organ donation systems have been considered on a number of occasions since the late 1970s in NSW, other jurisdictions and nationally; and a process is currently under way in Victoria.

The consensus has not supported a change to an ‘opt-out’ system and internationally there have been mixed results for organ donation rates in countries that have changed from ‘opt-in’ to ‘opt-out’ models.

Spain introduced ‘opt-out’ legislation in 1979, however the country’s organ donation rate did not begin to improve until 1989 when it adopted a national system of organ donation coordination in hospitals. Since then, the donation rate per million population has increased from 14 to 35.

Other countries with an ‘opt out’ framework consistently rank below Australia in terms of organ donation. For example, in 2008 Greece, which has an ‘opt out’ framework, had a donation rate of 8.9 dpmp compared to Australia’s rate of 13.8 dpmp (based on 2010 figures).

The US has an ‘opt in’ system similar to Australia’s and is able to achieve donation rates comparable to those of high performing European countries with ‘opt out’ legislation.

The Expert Committee of the Council of Europe, following its review of legislative options to increase organ donation, found that the most important factor in increasing organ donation rates was strong leadership by a central organisation; such a body sets standards, allocates organs, and supports local or regional retrieval arrangements.
Options to better address a donor’s wish to donate his or her organs

1.1 Should we switch to an ‘opt out’ model of presumed consent if a person dies without making his or her wishes known about the desire to donate organs?

1.2 Should we simplify the national arrangements for determining consent and making it easier for people to understand where to register, and do away with the NSW RTA register instead linking only with the Australian Organ Donor Register?

1.3 Should we promote the use of Advance Care Directives and other relevant legal documentation outlining end-of-life considerations made by a patient to act as indication of intent/consent in the absence of any indication on a national register?

2. Assisting families considering donor consent

Doctors initiating donor requests

Whilst many intensive care specialists agree that it is their responsibility to raise the issue of organ donation with families of recently deceased patients, doctors who lack specific training in organ donation, may be unable to provide families with enough information to ensure informed consent. Some are also uncomfortable requesting the donation and some are not familiar with the sensitivity of communication required to make such a request. It is also felt that there is a perceived ethical issue with doctor-initiated requests arising from a conflict between the primary-care giver role and the advocate for donation.

Where it is necessary for a doctor or other local clinician to initiate a request, it has been suggested that formal requests for organ donation should be made by staff not directly responsible for the clinical care of the potential donor.

Designated Requestors

Despite the specialist hospital staff measures adopted under the National Reform Agenda, it has been suggested that the employment of additional specially trained staff can help families dealing with consent issues.

Evidence from the United States shows that organ donation consent rates were markedly higher when an organ procurement organisation representative (designated requestor) approached family about potential donation compared with hospital staff undertaking that role.

Dual Advocacy

Best practices to increase organ donation identified through the US Organ Donation Breakthrough Collaborative saw donations increased by a cumulative 22.5% from October 2003 to October 2006. The Collaborative in the US identified that successful requestors act as “advocates for people on the organ transplant waiting list and are presumptive, not neutral” in their requesting. This type of requesting is commonly known as “dual advocacy”

This includes giving positive messages and endorsement of organ donation, as well as giving information that refutes the most common misconceptions about donation. These strategies also include the recommendation that requestors should approach a family a second time if they are initially unsure or not interested in donating because families often alter their original position with time and more information.

Collaborative requesting

Other positive results have come from collaborative requesting – involving using the skills of a number of health care professionals to ensure that the family is supported with appropriate emotional, psychosocial and medical information.

Families overriding patient consent

As mentioned previously, while NSW has the most extensive donor register in Australia, this does not translate to actual donation rates.

Even if you have listed your consent to becoming a donor the current practice is to allow family members to refuse to allow your organs to be donated.

In all cases, clinicians and/or transplant coordinators always seek final consent for donation from family where appropriate. It is clear then that whilst family members have the right of veto, moving from an “opt-in” to an “opt-out” system will have no impact. Current family refusal rates in NSW are over 45% of donation requests.

Options to help families dealing with consent while ensuring they uphold patient wishes

2.1 Should NSW consider trialling employment of Designated Requestors working in collaboration with other health care professionals?

2.2 If so, should they be trained in “dual advocacy” methods used in countries such as Spain and the United States?

2.3 While stressing the importance of clinicians communicating with family members about processes involved in transplantation, should we revoke family members right to refuse organ donation in circumstances where the deceased person has consented to it through a donation register?

3. Enhancing Organ Donation within Aboriginal & CALD Communities

It is widely recognised that Australia’s Aboriginal communities, and those in our society from culturally and linguistically diverse (CALD) backgrounds, face extra challenges in relation to chronic diseases.

Some of these chronic diseases increase the potential for the requirement of organ transplant.

Greater need, fewer organs available

It must also be recognised that those from Aboriginal communities experience disproportionately higher need for transplant than the general community, however a significantly lower number of Aboriginal people become organ donors.

Rates of end-stage renal disease among Aboriginal people are up to 8 times higher than those for non-Aboriginal people and they are less likely to receive a renal transplant prior to dialysis treatment and less likely to receive a well-matched transplant.5 There are several possible reasons for under-representation in transplantation for Aboriginal people including tissue matching issues that affect the long term outcomes of transplantation.

Historically there have been lower numbers of donors identified from Aboriginal and CALD communities and currently across Australia over 90% of donors are Caucasian – a figure echoed in the NSW donor statistics.

Recognised cultural differences include, but are not limited to:

- Taboo nature of end-of-life planning in some cultures.
- Experiences in home countries or cultures relating to the medical sector and beliefs about organ donation, more specifically confidence (or lack of) in professional conduct of medical doctors in home countries.
- Religious beliefs that appear to contradict or prevent organ donation.
- Recognition of other members in the community as having greater authority than legally recognised next-of-kin arrangements.

Options to increase organ donation and transplant for Aboriginal and CALD communities:

3.1 Do you support, where possible, the use of a healthcare worker or designated requestor from the cultural background of the potential donor?

3.2 Do you support cultural awareness training of all transplant staff including the adaptation of interviewing styles and consent seeking to accommodate Aboriginal community and CALD differences (such as not mentioning the deceased person’s name, culturally appropriate eye contact, etc)?

3.3 Should we actively promote the provisions in s5A of the Human Tissue Act 1983 that allow family members to voluntarily delegate their function as next of kin for the purposes of signing consent where another community member in a family, community or religious group has the cultural or religious authority to make such decisions?

3.4 Should we do more to engage Organ Donation “champions” who can better inform community members to assist with accurate information regarding organ donation and transplantation. This

3.5 Are Aboriginal and CALD communities/representatives able to suggest any other relevant measures that may assist in ensuring the greater success of organ donation for Aboriginal and CALD communities?

4 Further Enhancing the Living Donor Program

Since 1963, according to the Australian New Zealand Dialysis and Transplantation Registry (ANZDATA), there have been 18,817 kidney transplant operations performed on 15,612 patients. Of these, living donor transplants accounted for 23% of operations and 37% of functioning grafts.

In 2009, living kidney donation accounted for 42% of kidney transplantation performed in Australia and played a major role in the transplantation strategy of many centres in NSW.

The long term results of living kidney transplantation (both related and unrelated) are generally better than donation from a deceased donor (with the exception of zero mismatched donor/recipients). In the case of kidneys, living transplantation is generally superior for the following reasons:

- Closer tissue compatibility.
- Cold ischemic time is minimised.
- Procedures can be synchronised to best effect – the transplant can be carried out when the patient is in an optimum condition or pre-dialysis (the proportion of all primary living donor transplants performed “pre-emptively” in Australia in 2009 was 37%).
- There is usually a reduced need for immunosuppression.
- The organs of living donors are usually in a better condition than those of cadaveric donors.

Living donation raises ethical concerns different from that of deceased donors and comes with risks to the donors that are obviously not relevant in deceased donation. These include:

- Short term risks of morbidity or mortality to the donor.
- Longer term health risk to the donor who is left with only one kidney.
- Longer term psychological outcomes for the donors from living donation.

Advances in medicine expand capacity for living organ donations

Until recently, solid organ donation from living donors was almost exclusively confined to kidneys. Advances in medicine have meant that within Australia living liver transplantation (both adult to child and adult to adult) is now an established form of donation and transplantation.

Disincentives currently exist however, specifically related to the need for donors to potentially take extensive sick or unpaid leave, creating financial difficulties for many donors. Current legislation however restricts financial, material gain or incentive. Whilst the principles of donation should be based on consensual and altruistic giving, free of coercion through obligation or benefit, living donation does give rise to the need for special consideration in order to ensure that potential donors are not discouraged by these regulations.

Options to further increase the rates of living donation:

4.1 Should we change the NSW Human Tissue Act 1983 to allow living donation to be promoted without contravening current legal restrictions?

4.2 Should we develop workplace policies to support business and agencies with Human Resource changes, such as paid Living Donation leave (such as in the ACT)?

4.3 Should we provide additional support to living donors whilst taking leave to donate and provide special considerations within the Isolated Patient Travel and Accommodation Assistance Scheme to ensure that living donors are not out of pocket in order to donate?

4.4 Do you have other ideas that may encourage further community engagement with living donor programs?
APPENDIX A

The National Reform Agenda

On 3 July 2008, the Council of Australian Governments (COAG) endorsed the Australian Government’s reform agenda to implement a world’s best practice approach to organ and tissue donation for transplantation. The Australian government committed $151 million over four years to increase organ and tissue donation rates through:

- Establishing a national Australian Organ and Tissue Donation and Transplantation Authority (AOTA) to oversee the implementation of the measures and initiatives funded by the National Reform Agenda. AOTAs primary responsibilities are outlined in the Australian Organ and Tissue Donation and Transplantation Authority Act 2008.
- Funding a network of 8 Organ and Tissue Donation Agencies (OTDAs) operating across each state and territory known as the DonateLife network; and 163 medical and nursing specialists dedicated to organ and tissue donation in 76 hospitals around Australia led by a State/Territory Medical Director in each jurisdiction.
- Coordinating and funding national community education and awareness programs.
- Implementing a range of national initiatives and protocols to increase opportunities for donation and transplantation such as the Australian Paired Kidney Exchange program and a national protocol for Organ Donation after Cardiac (circulatory) Death.

The COAG commitment regarding implementation of the National Reform Agenda included acknowledgement that the Australian Government’s funding allocation is directed towards donation system improvements, with downstream services required to operate the retrieval, tissue typing and transplantation surgeries remaining the responsibility of States and Territories, along with cost sharing arrangements for jurisdictional OTDAs.

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In February 2011 Health Ministers, in noting a progress report on the National Reform Agenda and managing an integrated donation and transplantation service within their jurisdictions, committed to manage retrieval, tissue typing and transplant issues pre-emptively so that all transplant opportunities presented by increased donation rates are realised.

A midpoint review of the implementation of the National Reform Agenda, commissioned by the AOTA was released on 23 September 2011. The Report focuses on progress in implementing the national organ and tissue reform agenda and assessing the impact and potential for future growth, as well as opportunities to improve implementation strategies.

In 2010, the first full year of implementation, the reviewers found that 309 organ donors saved and improved the lives of 931 Australians; this was the highest donation rate since national records began. The increase is substantial, being a 51% increase on the baseline of 205 organ donors (average 2000-2008), and a 25% increase on the 2009 outcome (247 organ donors). The Report acknowledges that the increase in organ donation in 2010 can be largely attributed to a substantial increase in performance by a relatively small number of hospitals within two jurisdictions, New South Wales and Victoria.

While the report found that there has been solid progress to date and that this progress equals or betters progress seen in other nations at an equivalent stage in the reform journey, it identifies the following factors as key to the next stage of implementation:

- driving improvements in clinical practice and establishing a Clinical Governance Framework;
- enhancing national performance measurement; and
- expanding a professional education program for DonateLife Network and broader hospital staff.
Nine Measures of the National Reform Agenda

There are nine measures comprising the National Reform Agenda that the AOTA and all States and Territories are required to implement and report progress against:

Measure 1: A new national approach and system, a national authority and network of organ and tissue donation agencies

Measure 2: Specialist hospital staff and systems dedicated to organ donation

Measure 3: New funding for hospitals

Measure 4: National professional education and awareness

Measure 5: Coordinated, ongoing community awareness and education

Measure 6: Support for donor families

Measure 7: Safe, equitable and transparent national transplantation process

Measure 8: National eye and tissue donation and transplantation network

Measure 9: Additional national initiatives, including living donation programs

NSW implementation of the National Reform Agenda

Measure 1:
A new national approach and system, a national authority and network of organ and tissue donation agencies

The NSW Organ and Tissue Donation Service (NSW OTDS) was established on 1 July 2009 and responsibility for statewide coordination of organ donation was transferred to it from the Australian Red Cross Blood Service. The NSW OTDS is a stand-alone clinical business unit which is currently managed by the South Eastern Sydney Local Health District. The NSW OTDS is also known as DonateLife NSW.

The Australian Government, via the AOTA, provided funding of $22,589,853 for the NSW OTDS for the 3 year period 2009/2010 to 2011/2012. As noted previously, continuation of funding beyond 2011/12 will be determined following consideration of the findings and recommendations of the midterm review of implementation of the National Reform Agenda.

NSW Health allocated $3,720,246 for that period, which incorporates a recurrent allocation of $1.2 million per annum. Enhancement funding for the NSW OTDS of $931,500 from 2011/12 will provide capacity to accommodate projected growth in organ donation.

Measure 2:
Specialist hospital staff and systems dedicated to organ donation

Dedicated clinical specialist positions have been established in hospitals across NSW with the funds provided by the Australian Government. The role of the staff in those positions is to promote and support organ donation at the sites at which they are located and to provide outreach to other hospitals (both public and private) in their geographic area of responsibility. There are 10.5 FTE Staff Specialists located in 14 hospitals and 18.0 FTE nursing staff located in 19 hospitals – 7 clinical nurse consultants and 11 clinical nurse specialists.

Like hospitals are compared in relation to nationally agreed key performance indicators (KPIs). The KPIs are request rate, consent rate, and donation rate. National targets for these are 100%; 75%; 70% for brain death (BD) donors and 50% for Donation after Cardiac Death (DCD) respectively. The donation rate target is lower for DCD as not all potential DCD donors die within the required timeframe after withdrawal of cardio-respiratory support for viable organs to be retrieved.

The NSW request rate increased in the period January 2010 to March 2011, and for 2010 the rate was 83% compared with the national rate for 2010 of 86%. The NSW consent rate for 2010 was 54% and the national consent rate for
2010 was 57%. The NSW donation rate for 2010 was 35%, and the national donation rate for 2010 was 40%. All rates are below the national targets, and NSW rates are marginally less than the current national rates for Requests and Consent.

**Measure 3:**
**New funding for hospitals**

In addition to the provision of funding for hospital-based positions (Measure 2), from 1 July 2009 the Australian Government, provided a new funding stream - Organ Donation Hospital Support Funding - to address the additional costs associated with organ donation activity within hospitals. This funding is to offset the costs incurred as a result of the assessment and maintenance of the potential organ donor - for example, maintenance of a brain dead donor in ICU prior to transfer to the operating theatre for organ retrieval. It is not necessary for an organ donation to proceed for a hospital to receive funding. The funding stream is only for solid organ donation. It does not cover tissue donation which is a post-mortem activity.

NSW hospitals received reimbursement totalling $1,114,548 in 2009-2010 under this measure, and for the first 3 quarters of 2010 - 2011 will receive $1,223,336. To date 29 individual hospitals, including all major metropolitan hospitals, John Hunter Hospital and Wollongong Hospital have received funding.

The initiative is a significant step towards alleviating or eliminating potential barriers to solid organ donation.

**Measure 4:**
**Coordinating an ongoing, nationally consistent and targeted program of recognised professional development and training**

The OTDS employs an Education Coordinator to manage and report on all educational activity within the DonateLife NSW Network. This includes managing the Australasian Donor Awareness Program Training (ADAPT) which provides specialised clinical training for medical officers to enhance their capacity to identify and certify brain death; and understand the clinical management of a potential organ donor. ADAPT also targets nursing, allied health and other relevant staff to enhance their capacity to support organ donation.
**Measure 5:**
**Coordinated, ongoing community awareness and education**

An ongoing, coordinated and evidence based national community education and awareness program has been implemented to increase knowledge about organ and tissue donation and transplantation and build public confidence in Australia’s donation system. The national program aims to give Australians regular, clear, factual and relevant information about organ and tissue donation, and how they can make a difference. Key elements of the national approach include a national community awareness framework and a national community awareness charter.

The first phase of the ongoing National DonateLife campaign *DonateLife, discuss it today, OK?* ran from 23 May to 3 July 2010. The campaign’s call to action was for Australians to discuss their organ and tissue donation wishes with family/next of kin, in preparation for a situation when they will be asked to confirm the wishes of relative who is a potential organ donor.

The evaluation of the first phase of the campaign found that it achieved significant increases in public awareness and behavioural change as follows:

- the level of actual family discussion increased by 10% to 58%;
- awareness of family members’ donation wishes increased by 7% to 58%; and
- awareness that family consent is sought before donation can proceed increased by 9% to 73%.

Subsequent market research has found that the increases have been sustained and that more Australians are discussing organ and tissue donation wishes, up 9% over the past 12 months. However, 1 in 3 Australians are unsure about how to start the conversation about organ donation with their family and family consent rates remain less than 60%.

Based on that market research, the second phase of the ongoing campaign is currently being implemented - *DonateLife, Know their wishes*. The current campaign further seeks to normalise family discussion and increase family knowledge of donation wishes, as international evidence shows this is essential to increasing the family consent rate and the availability of deceased donor organs.

The NSW OTDS Communications Manager provides local support for the national initiatives and for dedicated local activity. The specialist hospital-based clinical staff also make a contribution to community education and awareness.

**Measure 6:**
**Support for Donor Families**

Organ and tissue donation is dependent on the decisions made by families at a very difficult time. The Bereavement Aftercare Program managed by the NSW OTDS acknowledges the generosity of donors and their families.

NSW was the first, and until recently, only jurisdiction with a designated Donor Family Support Coordinator. Building on the NSW expertise AOTA established a National Donor Family Support Group tasked with developing a consistent, evidence based and standardised program of bereavement aftercare for families involved in the organ and tissue donation process.

All families of potential solid organ donors are offered support, including bereavement counseling, whether or not the potential donor progresses to donation. Support includes the provision of bereavement literature, correspondence, telephone support, counseling, memorial gatherings and events to honour and remember donors.

**Measure 7:**
**Safe, equitable and transparent national transplantation processes**

Currently the number of patients who may benefit from transplantation is higher than the number of organs donated from deceased and living donors each year in Australia. This limitation requires that robust criteria and protocols are applied to both the listing of patients for transplantation and to the allocation of deceased donor organs to patients on the waiting list. A review of the national eligibility criteria for listing recipients for transplantation and criteria for allocation of deceased donor organs was completed in 2010 with the formal publication of nationally consistent protocols by the Transplantation Society of Australia and New Zealand (TSANZ).

Implementation of the protocols is the responsibility of the States and Territories.

NSW has since established a local policy - *Policy Directive 2011_026 Organ Transplantation From Deceased Donors: Eligibility & Allocation Protocols* to guide implementation of the protocols ensuring that eligibility and allocation decisions include assessment of all relevant factors such as medical need, urgency, capacity to benefit and donor-
recipient matching criteria. The policy requires that patients deemed ineligible for transplant are provided with a rationale for their ineligibility and offered the option of requesting a review of the decision making process.

Implementation of the policy in NSW has produced positive outcomes for some specific groups on the waiting list, in particular by recognising previous waiting time for older paediatric renal patients who move from the Paediatric to the Adult waiting list.

**Measure 8:**
**National eye and tissue donation and transplantation network**

Historically, tissue banks in NSW and other jurisdictions have developed as a result of specialist individual interests, and have been not well linked to other health services. Promotion of tissue donation and its benefits has been similarly fragmented.

As part of implementing the National Reform Agenda, NSW reviewed the eye and tissue bank services located within the then South Eastern Sydney Area Health Service in 2009. The recommendations of the review are currently being implemented. Whilst there is some overlap between tissue donation and solid organ donation this discussion paper will be confined to in depth consideration of solid organ donation.

**Measure 9:**
**Additional national initiatives, including living donation programs**

This measure supported the development of a national protocol for Organ Donation after Cardiac (Circulatory) Death and the introduction of an Australian Paired Kidney Exchange Program (AKX).

**Australian Paired Kidney Exchange Program**

The AKX program increases access to donor kidneys for transplantation by offering opportunities for living donors who are biologically incompatible with a recipient to whom they are related or connected in some way. A national pool of pairs of incompatible donors and recipients is assessed for matching and in the event that compatibility is identified in the national pool, simultaneous surgeries are planned to exchange kidneys. Potential matches are identified through computer matching of the results of tissue typing tests.

The likelihood of a successful exchange is dependent upon the number of donor-recipient pairs entered into the pool of potential matches. It is anticipated that up to 100 pairs will be entered in to the national program in the first year. Enrolment of potential matched pairs commenced in August 2010.

NSW has enrolled a total of 23 pairs in the AKX Program to 31 July 2011. To date 6 NSW recipients have received a transplant from the AKX process

AKX requires synchronized donor-recipient surgery and national coordination of transport of donated organs to ensure the best outcomes for patients. Chief Executives of LHDs are responsible for ensuring that participating institutions understand the need for flexibility in surgical scheduling to accommodate synchronised donor-recipient surgery.

**National Donation after Cardiac (Circulatory) Death (DCD) Protocol**

The aim of developing DCD guidelines was to provide increased donation opportunities for people who wish to be organ donors after their death, but whose illness or injury means that they do not meet the brain death criteria. As such, DCD also provides a means of potentially increasing the availability of deceased donor organs within current accepted ethical and legal requirements. However, DCD also creates challenges, as the clinical management of donors is a critical factor in ensuring that organs which are retrieved following circulatory death are clinically appropriate for transplantation and maximise the beneficial outcomes for transplant recipients.

In 2007, prior to the establishment of the National Reform Agenda, NSW Health published the first protocol on DCD - Organ Donation After Cardiac Death: NSW Guidelines - following collaboration with the NSW Transplant Advisory Committee. Those initial guidelines underwent State and National stakeholder consultation in 2006.

Following the NSW publication the need for a consistent National DCD protocol was identified. The National DCD protocol was developed by the National Health and Medical Research Council and published in July 2010.

There is an emerging evidence base regarding clinical management of potential DCD donors to enhance the clinical appropriateness of donated organs, and the range of organs which can be retrieved following cardiac death.
For example, at present use of hearts from DCD donors is not recommended in Australia as the evidence is not regarded as sufficient to support their use. Further there is evidence that administration of anti-coagulant medications such as heparin enhances the clinical utility of DCD organs. However, there are some legal barriers to obtaining consent for administration of medications prior to cardiac death that are not of therapeutic benefit to the potential donor. Resolution of these issues, via enhancement of information provided to people at the time that they register for organ donation, is being progressed with the AOTA.

Other NSW initiatives to enhance organ donation

Organ retrieval capacity

Effective organ retrieval is critical to maximise the benefits of increased organ donation and recent increases in donor rates have impacted retrieval resources, which under the National Reform Agenda are the responsibility of jurisdictions.

Organ retrieval is a state-wide service in NSW undertaken by three hospitals – Royal Prince Alfred (RPA), Westmead and St Vincent’s - but serving a larger number of transplant units, and directly benefiting patients from across NSW and the ACT.

Abdominal organ retrieval services are currently provided by RPA and Westmead Hospitals.

The retrieval procurement teams from these hospitals perform multi-organ abdominal retrievals, with organs allocated to transplant units according to national protocols. In NSW, livers are allocated to the National Liver Transplant Unit (based at RPA and The Children’s Hospital at Westmead), pancreata to the National Pancreas Transplant Unit (based at Westmead Hospital) and kidneys to one of the six renal transplant units (John Hunter, Prince of Wales, Royal North Shore, RPA, The Children’s Hospital Westmead, and Westmead). St Vincent’s Hospital is the sole heart and lung retrieval service in NSW and all organs are transplanted at St Vincent’s Heart and Lung Transplant Unit, which is a state-wide service.

In 2010 NSW Health undertook a review of organ retrieval capacity and identified resourcing issues related to reimbursement of donor retrieval surgical staff and technical support staff capacity and coordination issues for both abdominal and heart/lung retrievals. The service delivery and funding models have developed differently over time and the increase in organ donation was found to be impacting them in different ways.

Processes are currently in train to implement a model for funding retrieval which accommodates projected growth in organ donation and transplantation.

Tissue typing services

Tissue typing services, which are essential to support matching of recipients with donated organs and tissues, have also been reviewed in the context of the substantial increase in demand for the service driven by increased transplantation activity, including bone marrow and living and deceased organ donation. Tissue typing services are provided by the Australian Red Cross Blood Service laboratory.

During consultations for the review of organ retrieval, renal transplant physicians strongly supported the inclusion of new more effective and more expensive Luminex testing in the tissue typing protocol for patients on the deceased donor waiting list and in the testing algorithm for live renal transplant, including the AKX Program, in order to ensure consistency with current practice nationally.

Recurrent enhancement funding of $1.3 million has been allocated from 2011/12 to accommodate growth in demand for and cost of tissue typing.

Managing risk of disease transmission via organ transplantation

Organ transplantation is associated with a risk of transmission of some infectious diseases including HIV, hepatitis B, hepatitis C and other blood borne viruses. There is also a risk of transmission of malignancy. While it is possible to reduce the risks of transmission of infectious and other diseases it is not possible to completely eliminate the risk. The risk of transmission of disease must be balanced against the need to perform some transplants urgently. The medical urgency of transplantation for some potential recipients may mean that transplanting organs from donors with increased risk is contemplated at times.

NSW is the only jurisdiction which has a requirement for prospective Nucleic Acid Testing (NAT) of high risk potential organ donors for HIV, hepatitis C and hepatitis B and is one of the few jurisdictions with capacity for such testing. Mandatory medical and blood borne virus risk exposure
history is a nationally consistent requirement for all potential donors. In NSW routine NAT for HIV, HBV and HCV is performed on all donors, but only high risk donors are tested prospectively.

In NSW this investment in prospective NAT testing for BBVs over a 12 month period from 2009 to 2010 resulted in 69 organs being retrieved that otherwise would have been discarded from 27 increased-risk donors, including a significant proportion of hepatitis B core antibody positive donors who were found to be HBV DNA negative.

**The NSW Kidney Transplant Program Hepatitis C Register and use of hepatitis C positive donors**

To increase access to kidney transplantation a Policy Directive (PD2010_067) has been developed to enable NSW hepatitis C positive recipients to be allocated kidneys from a hepatitis C positive donor. Such an arrangement has been in place for many years for liver transplantation, where chronic hepatitis C is a major cause of end stage liver failure.

The NSW protocol provides the framework for participation in the TSANZ National Hepatitis C Register for renal transplantation.