



***Kidney Health Australia Submission:
Legislative Council Inquiry into Organ
Donation in Victoria***

May 2011

Executive Summary

Kidney Health Australia, formerly known as the Australian Kidney Foundation, is a national not for profit organisation focused on saving lives and reducing the need for dialysis. Our work focuses on awareness, detection, prevention and management of kidney disease in Australia and surrounding regions.

Chronic Kidney Disease (CKD) refers to all conditions of the kidney, lasting three months or more, where a person has had evidence of kidney damage and/or reduced kidney function, regardless of the specific diagnosis of the disease or condition causing the disease¹. Dialysis or a kidney transplant is needed when the kidneys have stopped working. At the end of 2009 there were 2,531 Victorians receiving dialysis treatment² and 300 Victorians on the transplant waiting list (12% of those on dialysis)³.

Australia is recognised internationally as having one of the highest success rates for organ transplantation in the world⁴. However, Australia's rate of deceased organ donation has failed to keep abreast with demand for transplantation and remains below that of comparable industrialised nations⁵. System performance in organ donation and transplantation depends on successful coordination across systems, designated authorities, hospitals and individuals involved in donor detection and management, organ procurement, allocation, donor and recipient follow-up, monitoring and surveillance, and regulation⁶.

The Victorian Department of Health Renal Health Clinical Network recently commissioned a report on the renal transplant pathway identified blockages to patient access, flow, quality of care and efficiencies⁷. The Victorian Government will need to ensure that issues raised in the report are addressed and that there is capacity to cope with increased donation rates.

The number of deceased organ donors will never meet the demand, no matter how efficient the retrieval process⁸, therefore there is a need to increase the rates of kidney transplantation by increasing the number of living donors⁹. One of the barriers to live kidney donation is the financial cost to the donor. 45% of living donors experience some financial hardship¹⁰ and 24% of potential living donors chose not donate because of anticipated financial hardship¹¹. To ease the financial burden for living organ donors, experts advocate reimbursement of legitimate expenses, stating that it is just and ethically responsible, and should be considered a reasonable cost associated with treating living organ recipients. Many countries have some degree of government funded expense reimbursement programs for live donors including the following: Belgium, Canada, Chile, Czech Republic, Denmark, France, Israel, Netherlands, New Zealand, Norway, Saudi Arabia, Sweden, United Kingdom, United States¹².

¹ Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, 2009, cat no. PHE 111. Canberra AIHW, p. vi.

² Grace B, Excell L and McDonald S, 2010, *Stock and Flow*, Australia and New Zealand Dialysis and Transplant Registry.

³ Grace B, Excell L and McDonald S, 2010, *Stock and Flow*, Australia and New Zealand Dialysis and Transplant Registry.

⁴ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 77.

⁵ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 11.

⁶ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 41.

⁷ DLA Phillips Fox, 2011, *Report on renal transplant pathway project*, Department of Health, p. 3.

⁸ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgran B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

⁹ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgran B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

¹⁰ Stothers L, Gourlay W and Liu W, 2005, *Attitudes and predictive factors for live kidney donation: A comparison of live kidney donors versus nondonors*, Kidney International; 67: 1105-1111.

¹¹ Sickand M, Cuerden M, Klarenbach S, Ojo A, Parikh C, Boudville N and Garg A, 2009, *Reimbursing Live Organ Donors for Incurred Non-Medical Expenses: A Global Perspective on Policies and Programs*, American Journal of Transplantation; 9: 2825-2836.

¹² Sickand M, Cuerden M, Klarenbach S, Ojo A, Parikh C, Boudville N and Garg A, 2009, *Reimbursing Live Organ Donors for Incurred Non-Medical Expenses: A Global Perspective on Policies and Programs*, American Journal of Transplantation; 9: 2825-2836.

An opt-out model (also referred to as presumed consent) is consistently raised as a potential solution to increase organ donation in Australia. However, presumed consent alone is unlikely to explain the variation in organ donation rates between countries¹³. Legislation, availability of donors, organisation and infrastructure of the transplantation service, wealth and investment in healthcare, and public attitudes to and awareness of organ donation may all play a part, but their relative importance is unclear¹⁴.

¹³ Rithalia A, McDaid C, Suekarran S, Myers L and Snowden, A, 2009, *Impact of presumed consent for organ donation on donation rates: a systematic review*, British Medical Journal, p. 1.

¹⁴ Rithalia A, McDaid C, Suekarran S, Myers L and Snowden, A, 2009, *Impact of presumed consent for organ donation on donation rates: a systematic review*, British Medical Journal, p. 1.

Kidney Health Australia

Kidney Health Australia, formerly known as the Australian Kidney Foundation, is a national not for profit organisation focused on saving lives and reducing the need for dialysis. Our work focuses on awareness, detection, prevention and management of kidney disease in Australia and surrounding regions.

Kidney Health Australia provides a range of services and programs for consumers, health professionals and the community including:

- Health Information and Publications
- Kidney Health Information Service – free call 1800 number for health advice
- Kidney Check Australia Taskforce (health professional education)
- Kidney Kids Programs – National Camps and state-based programs
- Family Accommodation Initiative Transplant Housing
- Holiday Dialysis Programs
- Consumer Advocacy Opportunities
- Education Initiatives for Consumers, Carers and Health Professionals
- Support Programs including support groups
- Research and Grants Scholarship Programs.

Introduction

Chronic Kidney Disease (CKD) refers to all conditions of the kidney, lasting three months or more, where a person has had evidence of kidney damage and/or reduced kidney function, regardless of the specific diagnosis of the disease or condition causing the disease¹⁵. Many people do not know they have kidney disease, because up to 90% of kidney function can be lost before symptoms are evident¹⁶. One in nine Australians aged over 25 (approximately two million people) have at least one clinical sign of existing CKD¹⁷. The top three causes of CKD in Australia are:

- Diabetes (34% of new cases)
- Nephritis or inflammation of the kidney (22% of new patients)
- High blood pressure (14% of new cases)¹⁸

Risk factors for CKD can be grouped into three broad categories: fixed, behavioural and biomedical (Table 1). Many people have multiple risk factors, which can considerably increase the risk of developing CKD.

Table 1: Risk factors for chronic kidney disease

Fixed	Behavioural	Biomedical
Family history and genetics	Tobacco smoking	Diabetes
Increasing age	Physical inactivity	High blood pressure
Previous kidney disease or injury	Poor nutrition	Cardiovascular disease
Low birth weight		Overweight and obesity
Male		Systemic kidney inflammation

Source: Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, cat. no. PHE 111, Canberra, p. 6.

Dialysis or a kidney transplant is needed when the kidneys have stopped working. At the end of 2009 there were 2,531 Victorians receiving dialysis treatment¹⁹. The average cost of dialysis for one person on average is \$61,659 per annum (Hospital \$79, 072; Satellite \$65,315; Home haemodialysis \$49,137; and Peritoneal dialysis \$53,112)²⁰. The average unit cost of a kidney transplant in the first year is \$81,549 and \$11,770 in subsequent years²¹.

Kidney transplantation is the most effective treatment for end stage kidney disease for those people who are suitable. Compared with dialysis, transplantation is associated with improved life expectancy, superior quality of life and reduced healthcare costs. The financial benefits of a successful kidney transplant are enormous to both the recipient, society and government. Once recovered from surgery, transplant recipients can resume normal work schedules and care for themselves. The costs related to transplantation (such as surgery, anti-rejection medication, clinical follow up) are considerably lower than costs associated with dialysis (including equipment, consumables, salaries/wages, medications, clinical management, waste management)²². In 2010, the cost to the Australian Government of providing dialysis and kidney transplant services was almost \$1 billion²³.

¹⁵ Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, 2009, cat no. PHE 111. Canberra AIHW, p. vi.

¹⁶ Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, 2009, cat no. PHE 111. Canberra AIHW, p. 1.

¹⁷ Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, 2009, cat no. PHE 111. Canberra AIHW, p. 9.

¹⁸ McDonald S, Excell L and Dent H, 2009, *New Patients Commencing Treatment in 2008*, Australia and New Zealand Dialysis and Transplant Registry.

¹⁹ Grace B, Excell L and McDonald S, 2010, *Stock and Flow*, Australia and New Zealand Dialysis and Transplant Registry.

²⁰ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 27.

²¹ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 28.

²² Kidney Health Australia, 2006, *National Chronic Kidney Disease Strategy*, p. 71.

²³ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 27.

The mean waiting time for a kidney transplant is around 3.79 years from a deceased donor and 1.38 years from a living donor²⁴. On average one Australian dies each week while waiting for a transplant. The longer a patient is on dialysis prior to transplantation the worse the patient's outcome.

At the end of 2009, there were 300 Victorians on the transplant waiting list (12% of those on dialysis)²⁵. Kidney Health Australia believes that the waiting list is not an accurate reflection of those patients who would attain a significant medical benefit from a kidney transplant and for whom transplant would be a cheaper treatment option were a kidney to be available. In other words access to the potential for receiving a transplant by being placed on the waiting list is itself rationed as a result of the shortage of transplant organs. This is because nephrologists are reluctant to include patients that will be unlikely to receive kidneys due to the already long waiting list.

- Although the exact extent of this problem has not been documented, we believe that the waiting list is likely to be at least 50% more than what it is. In the United Kingdom the true waiting list is at minimum 50% more and is rising rapidly with changing demographics²⁶.
- The 45-54 years age group has the largest number of patients awaiting a kidney transplant²⁷. Older age groups are more likely to have kidney failure and to "need" a transplant but are less likely to be offered a transplant because of co-morbidities and other limitation on access.

In 2008 Victoria had the third highest kidney transplant rate (41 per million) in Australia²⁸. In 2008, 246 Victorians and Tasmanians received a kidney transplant²⁹. Transplants performed for people resident in Tasmania are included in figures for Victoria³⁰ (these regions share common waiting lists and allocation protocols).

²⁴ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 67.

²⁵ Grace B, Excell L and McDonald S, 2010, *Stock and Flow*, Australia and New Zealand Dialysis and Transplant Registry.

²⁶ Department of Health, 2008, *Organs for Transplants: A report from the Organ Donation Taskforce*, p. 4.

²⁷ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 67.

²⁸ Campbell S, McDonald S, Webster A, Excell L and Livingston B, 2009, *Transplantation*, Australia and New Zealand Dialysis and Transplant Registry.

²⁹ Campbell S, McDonald S, Webster A, Excell L and Livingston B, 2009, *Transplantation*, Australia and New Zealand Dialysis and Transplant Registry.

³⁰ Campbell S, McDonald S, Webster A, Excell L and Livingston B, 2009, *Transplantation*, Australia and New Zealand Dialysis and Transplant Registry.

1) The operation of existing legislative, procedural and governance frameworks and policies, including other jurisdictions.

Australia is recognised internationally as having one of the highest success rates for organ transplantation in the world³¹. However, Australia's rate of deceased organ donation has failed to keep abreast with demand for transplantation and remains below that of comparable industrialised nations³². Consequently, transplant rates are relatively low in Australia. From various audit studies it is estimated that organ donation is medically possible in around 2-3% of all hospital deaths³³. System performance in organ donation and transplantation depends on successful coordination across systems, designated authorities, hospitals and individuals involved in donor detection and management, organ procurement, allocation, donor and recipient follow-up, monitoring and surveillance, and regulation³⁴.

The Australian Government announced a new National Reform Package, *A World's Best Practice Approach to Organ and Tissue Donation for Transplantation* in 2008. Australia for the first time has a nationally coordinated approach to deceased donation and a central authority to oversee reforms intended to maximise donor potential. Although the 2010 deceased donation figures exceeded the total number of donations in any year in Australia's recorded donation and transplant history, Australia needs to significantly increase donation rates to make it comparable with leading nations. However, national reform requires negotiation, agreement and coordination between eight independently operating state and territory government health systems³⁵. Within each jurisdiction there is considerable variation in practice between individual hospitals and clinical units³⁶. In addition, increasing levels of transplants will require appropriate staffing levels to cope with the demand and theatre time. This has become an issue in at least two states of Australia, including Victoria.

The Victorian Department of Health Renal Health Clinical Network recently commissioned a report on the renal transplant pathway (living and deceased) in the five health services that currently provide renal transplant services in Victoria. The report identified blockages to renal transplantation patient access, flow, quality of care and efficiencies³⁷.

The report found that:

- Surgical waiting lists and an emphasis on elective surgical throughput impact on the availability of theatre time for live donor transplantation;
- There can be considerable delays in accessing tissue typing services;
- There is variation across the system and that some of the delays experienced by donor recipients are the result of process issues that are modifiable at the local level;
- A shared set of performance indicators for the renal transplantation system in Victoria does not exist; and
- All health services experience significant delays in facilitating access by their patients to assessments by specialists on a non-admitted basis³⁸.

³¹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 77.

³² National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 11.

³³ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 49.

³⁴ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 41.

³⁵ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 16.

³⁶ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 16.

³⁷ DLA Phillips Fox, 2011, *Report on renal transplant pathway project*, Department of Health, p. 3.

³⁸ DLA Phillips Fox, 2011, *Report on renal transplant pathway project*, Department of Health, p. 9.

It is evident that there is scope for improvements to be made in the five health services that currently provide renal transplants in Victoria. The Victorian Government will need to ensure that issues raised in the report are addressed and that there is capacity to cope with increased donation rates. Kidney Health Australia has been advised anecdotally that the system is at capacity. If this is the case, then adequate planning needs to be undertaken and resources provided to ensure that donated organs are not wasted as a consequence of resource constraints.

Deceased organ donation remains low by international standards, yet substantial regional variation in donor rates is a clear indication that improvement is possible³⁹. It is evident that opportunities for deceased donation are frequently missed through refusal of consent to donation and other critical factors preventing the conversion of potential donors to actual donors⁴⁰. Another key factor restricting access to transplantation is recipient suitability as the average age and comorbidity profile of dialysis patients continues to increase, a greater proportion of those on dialysis are deemed medically unsuitable for transplantation⁴¹.

Transplantation is the optimal and most cost-effective treatment for end-stage kidney disease⁴². Maximising deceased donation rates is therefore a priority to optimise the cost effectiveness of end-stage kidney disease treatment and to ameliorate the demand for living donation⁴³.

The ability of the Organ and Tissue Authority to implement the new organisational systems, additional intensive care unit beds and specialised staff necessary to support substantial growth of deceased donation rates will be, to some extent, dependent on the commitment of individual health services and state governments to those reforms⁴⁴.

The number of deceased organ donors will never meet the demand, no matter how efficient the retrieval process⁴⁵, therefore there is a need to increase the rates of kidney transplantation by increasing the number of living donors⁴⁶. Living organ donation is becoming more common, in a response to the shortage in deceased donor organs⁴⁷. Single kidney donation is the most frequent living donor procedure as most people can live a normal, healthy life with only one kidney⁴⁸. Transplantation without prior dialysis (known as pre-emptive transplantation) is becoming increasingly common as an alternative initial treatment option⁴⁹. Live donor recipients have an increased life expectancy by more than 12 years over deceased donor recipients⁵⁰.

The benefits of pre-emptive transplantation include reduced rates of death, longer duration of functioning of the transplanted kidney, and avoidance of the psychosocial and economic impact of dialysis. For patients who have the opportunity to receive a live donor kidney, shortening the assessment period increases the likelihood of achieving a pre-emptive transplant, with a significant

³⁹ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 12.

⁴⁰ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 12.

⁴¹ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 40.

⁴² Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 40.

⁴³ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 40.

⁴⁴ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 42.

⁴⁵ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgrn B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

⁴⁶ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgrn B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

⁴⁷ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁴⁸ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁴⁹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁵⁰ Humphries H, Conrad B, Berry R, Reed S and Jennings C, 2009, *Framing the Gift of Life: An Empirical Examination of Altruism, Social Distance and Material Incentives in Non-Directed Kidney Donor Motivation*, Journal of Nephrology Social Work; 31: 20-27.

positive impact on overall outcomes⁵¹. The survival rate following a kidney transplant from a live donor is even higher – 98% of recipients are alive at one year and 94% are alive at five years⁵².

The shortage of deceased donors has resulted in an increased interest in living donation, but it must be noted that living donation of a kidney is associated with a risk of death to the donor of about one in 3,000⁵³. Nothing demonstrates the critical shortage of deceased donors more clearly than the acceptance – by patients and clinicians – of such risks to the life of a fit, healthy person⁵⁴.

⁵¹ DLA Phillips Fox, 2011, *Report on renal transplant pathway project*, Department of Health, p. 12.

⁵² McDonald S, Excell L and Dent H, 2009, *New Patients Commencing Treatment in 2008*, Australia and New Zealand Dialysis and Transplant Registry.

⁵³ Department of Health, 2008, *Organs for Transplants: A report from the Organ Donation Taskforce*, p. 4.

⁵⁴ Department of Health, 2008, *Organs for Transplants: A report from the Organ Donation Taskforce*, p. 4.

- 2) **Assessment of available national and international evidence on the effectiveness and efficacy of policies to increase donation rates, including the operation of various disclosure and consent arrangements such as presumed consent.**

And

- 4) **An appropriate ethical framework for decision making, procedures and safeguards regarding organ donation, including the rights of prospective donors and family members.**

As at 31 March 2011 there were 358,392 Victorians who had registered their decision in regard to organ and tissue donation on the Australian Organ Donor Register⁵⁵. A benefit of a positive registration, whether it be recorded as 'intent' or 'consent', is that it greatly assists the family in making the decision to donate if they are aware of their loved one's wishes and, in so doing, also helps to increase the number of donors⁵⁶. While 98% of Australians agree that organ and tissue donation has the potential to save and improve lives and 77% are generally willing to become organ and tissue donors only 58% of families give consent for organ and tissue donation to proceed⁵⁷. This is a contributing factor to low rates of transplantation⁵⁸. However, the support expressed in surveys may be higher than that felt by newly bereaved individuals facing the reality of making the decision on behalf of a family member⁵⁹.

An opt-out model (also referred to as presumed consent) is consistently raised as a potential solution to increase organ donation in Australia. Australia's legal system governing consent is based on the 'opt-in' principle, where informed consent is explicitly sought for each potential donor⁶⁰. The National Clinical Taskforce on Organ and Tissue Donation recommended against the introduction of a presumed consent (opt-out) approach by any Australian State or Territory⁶¹. The Taskforce stated the following:

*"It is not expected that legislative change in isolation can bring about a substantial increase in donation rates, as there are other relevant factors that influence donation rates. For example, a number of countries with a presumed consent system also adopt a presumptive approach to the decision about donation made by the family. Other factors, such as health care resourcing decisions and variations in mortality rates (such as road accident fatalities and strokes), also have an effect on donation rates. In the Australian context, such a move would most likely be destabilising. Surveys have indicated that there is a pre-existing element of medical mistrust with the Australian community, which in relation to organ, eye and tissue donation needs to be countered through education and awareness campaigns... The Taskforce considers that a presumed consent system may feed these fears and most likely lead to clinicians being less likely to proceed with initiating the donation process. When Australia's predominant social attitudes and legal traditions are considered, the principle of informed consent model better balances individual rights with the community's need for organ, eye and tissue donation"*⁶².

⁵⁵ <http://www.medicareaustralia.gov.au/provider/patients/aodr/stats.jsp#N1045E>

⁵⁶ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, pp. 126-127.

⁵⁷ <http://www.donatelife.gov.au/Resources/Facts-and-Statistics-on-Organ-and-Tissue-Donation.html>

⁵⁸ Cass A, Chadban S, Gallagher M et al, 2010, *The economic impact of end-stage kidney disease in Australia: Projections to 2020*, Kidney Health Australia, Melbourne, Australia, p. 41.

⁵⁹ Opdam H and Silvester W, 2006, *Potential for organ donation in Victoria: an audit of hospital deaths*, Medical Journal of Australia, volume 185 number 5, 4 September 2006.

⁶⁰ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 15.

⁶¹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 157.

⁶² National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, pp. 157.

Spain has by far the world's highest rate of organ donation from deceased donors (approximately 34-35 per million of population)⁶³. Spain introduced presumed consent legislation for organ donation in 1979, and the Spanish system is therefore universally described as an "opt-out" system⁶⁴. The appeal of presumed consent legislation is based on the belief that if consent is a problem, presuming it will solve the problem⁶⁵. The misconception underlying this belief is that presumed consent equates with organ donation⁶⁶. In fact, presumed consent equates simply with the presumed consent of the potential donor – the actual decision to donate rests with the potential donor's family⁶⁷. In Spain, the family consent rate is 85%⁶⁸. The family bases its decision on many factors, such as trust in the medical profession, understanding of the organ donation process, the professionalism of the approach for donation, and, most importantly, the expressed wishes of the potential donor (for example, through donor register, donor card, or conversations)⁶⁹.

In February 1997 Brazil introduced presumed consent that did not require consent of the family⁷⁰. In response to widespread public and medical disquiet, the legislation was amended to make consultation with the family mandatory, but by then the damage had been done and the legislation was entirely revoked in October 1998⁷¹. Although Spain introduced presumed consent legislation for organ donation in 1979, the rate of organ donation from 1979 to 1989 did not change remarkably⁷². In 1989 Spain introduced a comprehensive, nationally organised organ donation system that included many innovations⁷³ which is credited with raising the organ donation rate to the highest in the world.

The UK Organ Donation Taskforce conducted an extensive assessment of presumed consent and concluded that this approach was unlikely to improve organ donation in the UK. Moreover, it suggested that the costs of implementing presumed consent – approximately £45m (€53; \$70m) in establishment costs, and several million pounds per annum thereafter – might divert resources away from more effective initiatives⁷⁴.

Presumed consent alone is unlikely to explain the variation in organ donation rates between countries⁷⁵. Legislation, availability of donors, organisation and infrastructure of the transplantation service, wealth and investment in health care, and public attitudes to and awareness of organ donation may all play a part, but their relative importance is unclear⁷⁶. A British Transplantation Society working party suggested in the mid-1990s that a potentially important difference between the UK and many European countries, including Spain, was the relatively low provision of intensive care facilities⁷⁷. Current figures—excluding intensive care beds associated with coronary care, neonatal, and burns units—are around 27 intensive care beds per million of population in the UK, and 87.5 beds per million of population in Spain⁷⁸.

While Australia has one of the lowest rates of organ donation it needs to be recognised that there are different international deceased organ donor definitions. Countries vary in how they classify an organ donor and this affects reported donation rates and influences international comparisons⁷⁹. For example in Australia the definition is 'Retrieval operation commenced for the purpose of

⁶³ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁴ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁵ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁶ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁷ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁸ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁶⁹ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁷⁰ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 923.

⁷¹ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 923.

⁷² Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁷³ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 922.

⁷⁴ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, pp. 923-924.

⁷⁵ Rithalia A, McDaid C, Suekarran S, Myers L and Snowden, A, 2009, *Impact of presumed consent for organ donation on donation rates: a systematic review*, British Medical Journal, p. 1.

⁷⁶ Rithalia A, McDaid C, Suekarran S, Myers L and Snowden, A, 2009, *Impact of presumed consent for organ donation on donation rates: a systematic review*, British Medical Journal, p. 1.

⁷⁷ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 923.

⁷⁸ Fabre J, Murphy P and Matesanz R, 2010, *Presumed consent is unnecessary*, British Medical Journal, volume 341, 30 October 2010, p. 923.

⁷⁹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 112.

transplantation' whereas in Spain the definition is 'Transferred to the operating theatre from whom at least one organ has been retrieved'⁸⁰.

International comparisons can be problematic and depend to a significant extent on the nature of the country's health system and the level of medical care that is provided⁸¹. Australia's available organ donor pool is decreasing with a changing profile of potential donors (older and medically compromised) due to a number of factors including:

- High quality healthcare in Australia with improved control of blood pressure, effective treatment of trauma and intracerebral haemorrhage and excellence of intensive care; and
- Decreasing incidence of road traffic accidents and injury as a consequence of mandatory wearing of seat belts and successful campaigns to reduce the incidence of speeding and drink driving⁸².

⁸⁰ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 112.

⁸¹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 112.

⁸² National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 112.

3) Identification and assessment of various possible mechanisms to increase organ donation in Victoria.

Living organ donation expense reimbursement program

Although there have been significant improvements recently, the number of deceased organ donors will never meet the demand, no matter how efficient the retrieval process⁸³, therefore there is a need to increase the rates of kidney transplantation by increasing the number of living donors⁸⁴. One of the barriers to live kidney donation is the financial cost to the donor. 45% of living donors experience some financial hardship⁸⁵ and 24% of potential living donors chose not to donate because of anticipated financial hardship⁸⁶. To ease the financial burden for living organ donors, experts advocate reimbursement of legitimate expenses, stating that it is just and ethically responsible, and should be considered a reasonable cost associated with treating living organ recipients.

Many countries have some degree of government funded expense reimbursement programs for live donors including the following: Belgium, Canada, Chile, Czech Republic, Denmark, France, Israel, Netherlands, New Zealand, Norway, Saudi Arabia, Sweden, United Kingdom, United States⁸⁷.

The current movement towards donor reimbursement is motivated by two main factors:

- The belief that reimbursing donors for their out-of-pocket costs, a concept different from payment for financial gain, is justified and ethical; and
- The scarce availability of kidneys combined with the growing need for transplantation⁸⁸.

Living organ donation is becoming more common, in response to the shortage in deceased donor organs⁸⁹. Single kidney donation is the most frequent living donor procedure as most people can live a normal, healthy life with only one kidney⁹⁰. Transplantation without prior dialysis (known as pre-emptive transplantation) is becoming increasingly common as an alternative initial treatment option⁹¹.

The Western Australia Country Health Service (WACHS) is the only jurisdiction in Australia to have a Live Kidney Donor Travel Reimbursement Scheme. The scheme was introduced in 2006 and provides for reimbursement of reasonable travel expenses incurred by suitable regional donors travelling to Perth for kidney donation assessment, retrieval and one-post operative visit⁹². The scheme applies only to those who reside within the WACHS. This is an excellent scheme which should be considered by all jurisdictions in Australia.

The problematic State and Territory Government assisted travel schemes require urgent attention. The Commonwealth Government established the Isolated Patients' Travel and Accommodation and Assistance Scheme (IPTAAS) over 30 years ago to provide financial assistance to people who needed to travel more than 200km to obtain specialist medical treatment and oral surgery. In 1987 the

⁸³ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgrn B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

⁸⁴ Barniech L, McLaughlin K, Manns B, Klarenbach S, Yilmaz S and Hemmelgrn B, 2010, *Barriers to living kidney donation identified by eligible candidates with end-stage renal disease*, Nephrology Dialysis Transplantation; 1.

⁸⁵ Stothers L, Gourlay W and Liu W, 2005, *Attitudes and predictive factors for live kidney donation: A comparison of live kidney donors versus nondonors*, Kidney International; 67: 1105-1111.

⁸⁶ Sickand M, Cuerden M, Klarenbach S, Ojo A, Parikh C, Boudville N and Garg A, 2009, *Reimbursing Live Organ Donors for Incurred Non-Medical Expenses: A Global Perspective on Policies and Programs*, American Journal of Transplantation; 9: 2825-2836.

⁸⁷ Sickand M, Cuerden M, Klarenbach S, Ojo A, Parikh C, Boudville N and Garg A, 2009, *Reimbursing Live Organ Donors for Incurred Non-Medical Expenses: A Global Perspective on Policies and Programs*, American Journal of Transplantation; 9: 2825-2836.

⁸⁸ Clarke K, Klarenbach S, Vlaicu S, Yang R and Garg A, 2006, *The direct and indirect economic costs incurred by living kidney donors – a systematic review*, Nephrology Dialysis Transplantation; 21: 1958.

⁸⁹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁹⁰ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁹¹ National Clinical Taskforce on Organ and Tissue Donation, 2008, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally*, Commonwealth of Australia, p. 51.

⁹² <http://www.wacountry.health.wa.gov.au/default.asp?documentid=512>

responsibility for IPTAAS was transferred from the Commonwealth Government to the States and Territories because it was thought they would be better able to administer the scheme.

There are a range of issues with the current arrangements including:

- Lack of equity
- Inadequate level of coverage
- Lack of uniformity
- Escorts and carers are not covered
- Limited awareness of the schemes
- Onerous paperwork
- Delays in payment

Four recent Senate inquiries have produced recommendations to comprehensively improve the operation of travel schemes:

- *Public hospital funding (2000)*
- *Services and treatment options for persons with cancer (2005)*
- *Gynaecological cancer in Australia (2006)*
- *Highway to health: better access for rural, regional and remote patients (2007)*

The National Health and Hospitals Reform Commission (NHHRC) in its final report 'A Healthier Future for All Australians' stated the following:

"We also strongly support increased funding for patient travel and accommodation for patients and their families on a nationally consistent basis. Patient travel and accommodation is an essential requirement of guaranteeing access to health services for many country patients and should be funded as such. The accommodation or travel expenses allowance you receive should not vary according to which state or territory you live in. This is one important aspect of all Australians having equal access to 'one health system'"⁹³.

The NHHRC made the following recommendation:

"We recommend that a patient travel and accommodation assistance scheme be funded at a level that takes better account of the out-of-pocket costs of patients and their families and facilitates timely treatment and care"⁹⁴.

As part of the National Health and Hospitals Network, the Government's response to the NHHRC recommendation was as follows:

"The Government notes this recommendation and supports the development of an improved national approach to patient assisted travel. On 20 April 2010, COAG agreed, with the exception of Western Australia, to further work in regards to Patient Assistance Transport Schemes, with a view to higher and more consistent national standards"⁹⁵.

The Victorian Patient Transport Assistance Scheme reimburses patients who travel more than 100km one way or 500km for a minimum of five consecutive weeks⁹⁶.

⁹³ National Health and Hospitals Reform Commission, 2009, *A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission*, p. 89.

⁹⁴ National Health and Hospitals Reform Commission, 2009, *A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission*, p. 25.

⁹⁵ Australian Government, 2010, *A National Health and Hospitals Network for Australia's Future*, p. 147.

⁹⁶ <http://www.health.vic.gov.au/ruralhealth/vptas/patients.htm>

Travel assistance includes:

- subsidies for private car travel - a reimbursement of 17 cents per kilometre is paid where a private vehicle is used;
- full concession fare reimbursements for public transport;
- air travel only if the journey exceeds 350 kilometres one way and a commercial flight is used;
- taxi travel only to the nearest public transport and only when a patient has no other means of transport available⁹⁷.

Accommodation assistance is paid at a maximum of \$35 per night for a patient and an approved escort staying in commercial accommodation⁹⁸. Although the Victorian Government provides assistance, the travel and accommodation reimbursements are very minimal and are not sufficient.

The Renal Social Workers Group of Victoria and Tasmania has provided specific examples of patients who are unable to proceed with donating a kidney to a loved one due to financial reasons. Many patients have tried unsuccessfully in their application for patient transport funding through State and Territory patient accommodation and transport schemes:

1. Resident of Cairns. Traveled to Melbourne with wife via car to donate kidney to his sister. Rejected by Qld patient travel scheme (PTS) for subsidy because: traveled interstate, location of treatment wasn't donors closest hospital, required pre-approval to claim.
2. Resident of Brisbane. Traveled to Melbourne alone via plane to donate kidney to his sister. Rejected by Qld PTS for subsidy because: traveled interstate, location of treatment wasn't donors closest hospital. Did attempt to claim prior to travel.
3. Resident of Kalgoorlie. Traveled to Melbourne with partner to receive a kidney from his mother. Provided subsidy for himself and partner for flights and accommodation via the Department of Health (Western Australia) Interstate Patient Travel Scheme.
4. Residents of Darwin. Patient and partner (also will be donor) wish to have transplant in Melbourne as family support is here. As part of the work up process, advised by social worker at Monash Medical Centre to speak to the Northern Territory Patient Assisted Travel Scheme. They advised patient that she and partner (donor) will receive subsidy for travel and accommodation.
5. Resident from Tasmania. Traveled to Melbourne via plane to donate a kidney to friend. Received subsidy support from Tasmanian PTS for flights and accommodation.

⁹⁷ <http://www.health.vic.gov.au/ruralhealth/vptas/patients.htm>

⁹⁸ <http://www.health.vic.gov.au/ruralhealth/vptas/patients.htm>

5) Any other matters that should be considered in relation to mechanisms to increase organ donation in Victoria.

ACT Public Service policy on living organ donation

Living organ donors typically will be required to be absent from work for up to eight weeks. People who do not have accumulated sick leave would have to take leave without pay (if approved by their employer) to donate a kidney. A mechanism to overcome this is to provide paid leave for employees who donate an organ. The ACT Government provides up to three months full pay in any 12 month period for employees who donate an organ. Classified as 'Other Leave – Donate an Organ', is included in all ACT Government Enterprise/Collective Agreements. We would encourage the Victorian Government to provide additional leave for employees who donate an organ. This may also encourage private sector employees to follow the public sector on this issue.

eHealth

The draft concept of operations for the personally controlled electronic health record (PCEHR) system outlines the proposed consolidated view of a person's record. The PCEHR system will have the capability to connect to the Australian Organ Donor Register⁹⁹. The introduction of the PCEHR from July 2012 will provide an opportunity to increase the number of people registered on the Australian Organ Donor Register through awareness. The PCEHR will provide health professionals with patient information in a more timely, convenient and reliable manner. This should assist in the renal transplantation pathway. In addition, electronic clinical information systems will streamline administrative and clinical processes associated with organ transplants. The process for organ donation includes an Organ and Tissue Donor Coordinator spending a considerable amount of time populating a substantial paper-based organ referral document with de-identified information contained within the deceased person's medical record¹⁰⁰. The referral documents contain as many as 27 pages¹⁰¹.

⁹⁹ Department of Health and Ageing, 2011, *Draft Concept of Operations: Relating to the introduction of a personally controlled electronic health record (PCEHR) system*, p. 32.

¹⁰⁰ James S, 2011, *DONORtrak system to streamline organ transplant process*, Pulse IT Magazine, Issue 21, March 2011, pp. 18-19.

¹⁰¹ James S, 2011, *DONORtrak system to streamline organ transplant process*, Pulse IT Magazine, Issue 21, March 2011, pp. 18-19.

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