Inquiry into Organ Donation in Victoria

Report

March 2012

Legislative Council

Legal and Social Issues References Committee

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Inquiry into Organ Donation in Victoria

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Chair's Foreword

I have pleasure in presenting this first report of the Legal and Social Issues References Committee. The Committee is one of three new Legislative Council Standing Committees which were established under the Standing Orders of the Legislative Council in late 2010.

This Inquiry into Organ Donation in Victoria has come at an opportune time to review the success to date of the 2008 national reform agenda on organ and tissue donation. Evidence suggests the reforms have had some success in increasing organ donation rates and raising community awareness on the importance of registering to donate. In particular, the Committee is pleased to note that Victoria's organ donation rate has doubled over the past few years and Victoria is now responsible for one-third of the nation's total annual organ donations.

Despite these positive signs, the Committee found there is a need for immediate action in order to capitalise on the recent growth in organ donation rates. Most importantly, evidence highlights the need for additional resources in Victorian hospitals in order to ensure transplantation activity can operate to maximum capacity now and into the future. Greater planning is necessary to enable future funding to be linked to projected organ donation growth. Further to the funding issue, Chapter 7 of this report highlights concern with respect to the Alfred Health's decision to temporarily halt its adult lung transplant program in September last year, and inconsistencies and gaps in evidence on this matter.

The overwhelming evidence received during the Inquiry did not support a move to a presumed consent (opt-out) model for organ donation in Victoria. Accordingly, the Committee recommends that the current system of informed consent (opt-in) be maintained.

Other issues that are identified as requiring action or continued support include:

- the need for families to have early discussions about their donation wishes
- a greater emphasis on raising awareness of tissue donation and the facilitation of timely tissue donations
- the continued implementation of donation after cardiac death programs
- consideration of living donor expense reimbursement schemes
- the possibility of establishing a coordinated organ retrieval service in Victoria
- and further strategic community awareness campaigns aimed at promoting the benefits of organ and tissue donation.

I would like to thank those organisations and individuals who contributed to the Inquiry, particularly individuals and families who provided personal experiences with the donation and transplantation processes.

This Inquiry had a number of complex components and I would like to thank the Committee members for their sustained work and commitment to the task. I particularly extend my appreciation to the Deputy Chairman, Mr Edward O'Donohue for acting during my absences for family reasons.

On behalf of the Committee, I would like to thank the Committee Secretary Mr Richard Willis, the Research Officer Ms Lisa Kazalac, and Research Assistant Mr Sean Marshall for their hard work on this Inquiry over the last year.

Finally, as the new Standing Committees continue to develop and undertake inquiries, I note that the Legislative Council Department is continuing negotiations with the Government to ensure adequate ongoing funding and resources. I trust the Government will provide the funds necessary for these new committees to continue their valuable work.

Matt Viney

Chairman

28 March 2012

Findings and Recommendations

Chapter 2: Organ Donation Statistics and Governance

Finding 1

Australia's organ donation rate remains low in comparison to other countries, however the number of organ donors has doubled over the past five years. Victoria's number of organ donors increased by 35 percent in 2010 and a further 8.5 percent in 2011.

Finding 2

Victoria leads the nation as the state with the highest number of organ donors. In 2011, Victoria had 107 donors, almost one-third of Australia's total of 337. Victoria's organ donor rate is now comparable to countries such as the United States and the United Kingdom.

Finding 3

International comparative measures based on donors per million of population do not take into account other measures of success including the number of organs retrieved per donor, the number of transplants per donor, and the long-term success of organ transplants.

Finding 4

Approximately 1700 Australians remain on organ transplant waiting lists. To date there is little evidence to suggest that the number of people on transplant waiting lists will decline as more organs become available for transplantation.

Finding 5

Since the first full year of implementation of the national reform agenda in 2008, there has been a significant improvement in organ donation rates in Australia. This would suggest that the new governance arrangements for organ and tissue donation throughout Australia have had some success in achieving its aims.

RECOMMENDATION 1

That the Victorian Government continue to support the ongoing implementation of the national reform agenda to increase organ donation rates.

Finding 6

Recent organ donation and transplantation activity in Victoria illustrates that Victoria has been the most successful state in implementing the national reform agenda. This success is largely due to a coordinated and collaborative approach across all key stakeholders in the organ donation sector, led by DonateLife Victoria.

Chapter 3: Legal and ethical framework

Finding 7

The Committee notes that seeking consent to organ donation often occurs at a difficult and tragic time for families. It requires those seeking consent to have an understanding of differing cultural and religious beliefs. Recognising this, it is important that undue pressure is not placed on the family of the recently deceased.

Finding 8

The Committee believes medical practitioners should continue to consult with families of potential donors when seeking consent. In particular, it is important that adequate support and information is provided to all families during the time of seeking consent for donation and after the donation process has concluded.

Finding 9

It is unclear to what extent the number of people that are on the Australian Organ Donor Register who are suitable to be donors at the time of death and are prevented from donating as a result of family objection to consent. The Committee believes there needs to be a greater understanding on the issue of family consent and the extent to which families actually object to organ donation proceeding regardless of organ donation registration.

Finding 10

It is important that families have early discussions about their organ donation wishes. Research suggests that families that know the donation wishes of their loved one support those wishes when consent is requested.

RECOMMENDATION 2

That existing medical practice be maintained and no change be made to the way in which consent is legislated in the *Human Tissue Act 1982*.

RECOMMENDATION 3

That relevant authorities investigate ways to collect data that may provide a greater understanding on the number of suitable registered organ donors that do not donate their organs as a result of family objection. This information would assist in understanding more clearly the family consent rate and could assist in targeted community awareness campaigns.

RECOMMENDATION 4

The definition of death within the *Human Tissue Act* 1982 is appropriate and should not be changed.

Finding 11

Existing ethical and clinical guidelines for organ donation and transplantation are appropriate and should be maintained to ensure the continued operation of a fair, transparent and safe sector.

Finding 12

National Health and Medical Research Council ethical guidelines ensure that the community can have faith and confidence in the organ donation and transplantation sector. It is essential that the integrity of these guidelines are maintained to ensure the ongoing community support for organ donation.

RECOMMENDATION 5

That the relevant bodies including Australia and New Zealand Intensive Care Society, Transplantation Society of Australia and New Zealand, Australasian Transplant Coordinators Association and the National Health and Medical Research Council continue to maintain clinical and ethical guidelines and periodically review as required.

Chapter 4: Consent models

Finding 13

High donor rates in countries with presumed consent models can be attributed to a range of factors including: reforms to the hospital sector, improvements to transplantation services and increase community awareness.

Finding 14

There is a lack of clear evidence internationally and within Australia to suggest that the introduction of presumed consent would directly lead to an increase in organ donation rates.

Finding 15

There is some community support for a move to presumed consent, most notably from individuals who have had a first-hand experience with transplant waiting lists, organ donation and transplantation.

Finding 16

The overwhelming evidence, including from government, medical and community groups, oppose the introduction of a presumed consent model in Victoria at this stage.

RECOMMENDATION 6

That the current system of informed consent (opt-in model) be maintained in Victoria.

Chapter 5: Tissue donation in Victoria

Finding 17

Tissue donation plays an important role in saving and improving the lives of Victorians. The location of the Donation Tissue Bank of Victoria and the Lions Eye Donation Service in Victoria creates significant advantages for the state.

Finding 18

Recent years have seen a decline in cadaveric tissue donors which is in contrast to the recent increases in organ donors.

Finding 19

Tissue donation has not benefited from the implementation of the national reform agenda in relation to public awareness to the same extent as organ donation. The importance of tissue donation should be included in all public awareness campaigns.

RECOMMENDATION 7

That DonateLife Victoria continue to work with the Donor Tissue Bank of Victoria to increase community awareness and the importance of tissue donation.

Finding 20

A potential impediment exists where the statutory requirements within the Victorian Coroner's Office may create time delays in facilitating tissue donation.

RECOMMENDATION 8

That key stakeholders including the Department of Health, Donor Tissue Bank of Victoria and the Victorian Coroner meet to clarify their respective roles, legislative requirements and processes in order to further facilitate timely tissue donations.

Finding 21

With respect to the identification and retrieval of tissues for donation, the lack of a legal requirement or process for the notification of deaths to the Donor Tissue Bank or Lions Eye Donation Service may in fact delay the opportunity for tissue donation to occur.

Finding 22

There exists a number of constraints on tissue donation in regional areas, including the collection of tissue, transportation costs and lack of facilities to collect and process tissues in regional Victoria.

RECOMMENDATION 9

That the Victorian Government examine ways to improve access to the collected tissues for donation throughout regional Victoria, including the need to process tissues more efficiently and minimise transportation costs associated with tissue donation.

Chapter 6: The clinical setting

Finding 23

Historically the main pathway to donation was through the brain death criteria. More recently the donation after cardiac death pathway has been introduced. This pathway is inherently more complex and differs significantly from the well understood processes of brain death donation. The community would benefit from further education on the different processes involved in donation after cardiac death.

Finding 24

The introduction of donation after cardiac death programs have substantially contributed to the recent increase in the organ donation rate in Victoria.

RECOMMENDATION 10

That the donation after cardiac death program continue to be implemented across appropriate Victorian hospitals to further improve the opportunity for deceased organ donation in Victoria.

Finding 25

As organ transplant waiting lists remain high, living kidney and liver donation has become more common. Evidence suggests that living organ transplants are likely to have improved success outcomes.

Finding 26

It is important that guidelines and hospital practices and processes that pertain to living donation contain safeguards for the potential living donor. The health and safety of the living donor is paramount. These guidelines and practices should not be eased in order to increase the number of living organ donors.

Finding 27

Personal expenses associated with living donation, including cost of travel, meals, accommodation, loss of income and childcare, are limiting factors to people becoming living donors.

RECOMMENDATION 11

That the Victorian Government consider, in consultation with DonateLife Victoria, the introduction of a reimbursement scheme for living donors which would cover reasonable associated expenses such as, accommodation, transport, meals, loss of income from time off work and childcare.

Finding 28

Evidence presented to the Committee proposed that Victoria would benefit from a centralised organ retrieval service.

RECOMMENDATION 12

That the Victorian Government consider the proposal to establish a coordinated organ retrieval service in Victoria.

Finding 29

There are a number of barriers which impact on the ability of regional areas to support organ donation programs including lack of expertise in organ retrieval and resources to implement organ donation programs in hospitals as well as transportation costs.

RECOMMENDATION 13

That the Victorian Government work with hospitals and DonateLife Victoria to establish an effective and sustainable organ donation programs in regional Victoria.

Finding 30

The Committee recognises the importance of data collection for organ and tissue donation and transplantation and notes the future implementation of the Electronic Donor Record by the Organ and Tissue Authority.

RECOMMENDATION 14

That the Victorian Government monitor the implementation of the Electronic Donor Record in Victoria to ensure future effectiveness in improving the processes of organ and tissue donation.

Chapter 7: Hospital funding and resourcing

Finding 31

Existing hospital funding and staff levels are inadequate to effectively meet current demands required within transplantation units in Victoria.

Finding 32

National and Victorian initiatives to increase organ donation rates must be supported with additional resourcing. There is potential for negative outcomes or a withdrawal of community support for organ donation, if organ donation or transplantation does not occur as a result of funding or resourcing constraints. This will be worsened by the prospect of willing donors not being utilised due to a lack of resources.

Finding 33

The establishment of future organ donation targets will assist the Government in determining appropriate levels of funding to meet transplant outcomes and this needs to be prepared by the Department of Health as a priority planning issue.

Finding 34

Insufficient investment and planning within Alfred Health's transplantation programs created unsustainable workload capacities which lead to the temporary closure of the Alfred Health's adult lung transplant program in September 2011.

Finding 35

A situation exists within Alfred Health where investment levels are a year behind actual donation and transplant numbers is not sustainable and has the potential to undermine efforts to improve donation levels and damage public and patient confidence in organ donation more generally.

RECOMMENDATION 15

That the Victorian Government review existing resourcing levels within hospitals to ensure organ transplantation activity can operate to maximum capacity in order to meet current and future increases in organ donation and transplant rates.

Chapter 8: Community awareness

RECOMMENDATION 16

The importance of family consent and early discussion within families on organ donation should continue to be a priority focus of national community awareness campaigns.

Finding 36

The Committee acknowledges the positive contribution of the not-for-profit sector and other community organisations in their involvement in raising awareness in the community on organ and tissue donation.

RECOMMENDATION 17

That organisations involved in awareness raising campaigns coordinate their efforts to ensure a consistent and collaborative national campaign to the extent that they wish to be involved.

Finding 37

Promoting the benefits of organ and tissue donation through community awareness and education campaigns is a vital strategy to encourage more people to register as an organ and tissue donor.

Finding 38

The profile of organ and tissue donation in Victoria would be enhanced through further campaigns directed at schools and through sporting organisations. In particular, Victoria would benefit from hosting the Australian Transplant Games.

RECOMMENDATION 18

That additional resources be directed to strategic community awareness and education campaigns aimed at demystifying and promoting the benefits of organ and tissue donation.

RECOMMENDATION 19

That the Victorian Government should meet with Transplant Australia and other relevant stakeholders with a view to Victoria hosting a future Australian Transplant Games.

RECOMMENDATION 20

That the Victorian Government consider ways to acknowledge and recognise the altruistic act of organ donation including the possibility of suitable acknowledgement on the donor's death certificate.

RECOMMENDATION 21

That the Victorian Government, in association with health organisations and donor families, give consideration to any potential protocol issues in relation to contact between donor recipients and donor families.

Acronyms

ACT – Australian Capital Territory

ADAPT – Australasian Donor Awareness Program

ANZDATA – Australia and New Zealand Dialysis and Transplant Registry

ANZICS – Australian and New Zealand Intensive Care Society

ANZOD – Australia and New Zealand Organ Donor Registry

AODR – Australian Organ Donor Register

APX – Australian Paired Kidney Exchange Program

COAG – Council of Australian Governments

DCD – Donation after cardiac death

DPMP – Donors per million of population

DTBV – Donor Tissue Bank of Victoria

FOI – Freedom of information

FTE – Full time equivalent

EDR – Electronic donor record

HOTA – Human Organ Transplant Act 1987

ICUs – Intensive care units

NHMRC – National Health and Medical Research Council

ODHSF – Organ Donation Hospital Support Funding

ONT – Organizacion Nacional de Trasplantes

TSANZ – Transplantation Society of Australia and New Zealand

UK – United Kingdom

USA – United States of America

VPTAS – Victorian Patient Transport Assistance Scheme

VTIS – Victorian Transplantation and Immunogenetics Service

1. Introduction

1.1 Terms of Reference

On 10 February 2011, the Legislative Council agreed to the following resolution:

> That this House requires the Legal and Social Issues References Committee to inquire, consider and report on options and mechanisms to increase organ donation in Victoria including:
>
> (1) the operation of existing legislative, procedural and governance frameworks and policies, including in other jurisdictions;
>
> (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;
>
> (3) identification and assessment of various possible mechanisms to increase organ donation in Victoria;
>
> (4) an appropriate ethical framework for decision-making, procedures and safeguards regarding organ donation, including the rights of prospective donors and family members; and
>
> (5) any other matters that should be considered in relation to mechanisms to increase organ donation in Victoria;
>
> and that the Committee present its final report to Parliament no later than 12 months after this reference is given to the Committee.

On 9 February 2012, the Legislative Council agreed to extend the Committee's final reporting date to 30 March 2012.

1.2 Receipt of evidence

On 11 March 2011, the Committee advertised its terms of reference in *The Age* newspaper calling for written submissions. The Committee also wrote to a number of key stakeholders throughout Australia inviting written submissions. At the close of submissions on 20 May 2011, a total of 36 written submissions were received. A list of submissions is provided in Appendix A.

Following receipt of written submissions, the Committee proceeded to take evidence in public hearings on 25 August, 8 September, 21 September and 2 December 2011. Public hearings concluded on 8 February 2012 with evidence from the Minister for Health. A full list of witnesses who appeared before the Committee is provided in Appendix B.

The Committee's evidence covered a wide range of organisations and individuals with an interest in organ and tissue donation and transplantation. Key government agencies provided background to the existing governance frameworks and policies dealing with organ and tissue donation.[1] Alfred Health and the Austin Hospital, who undertake organ donation and transplantation procedures, also gave evidence to the Committee. Further

[1] Throughout this report, the Committee's reference to organ donation will generally be taken to include tissue donation except where otherwise stated, particularly in relation to organ statistics.

input was received from other medical professionals including surgeons, physicians, and peak medical professional associations.

Various community and not-for-profit organisations with a focus on promoting organ donation also provided valuable evidence, as did a number of religious groups and ethicists. The Committee was particularly appreciative of the input received from families and individuals who have been directly affected by the donation process; their evidence conveyed the social and emotional impacts upon people. This includes family members who have lost loved ones who have given the gift of life, individuals who have been fortunate enough to have successfully received an organ transplant and others who patiently remain on organ transplant waiting lists.

The Committee gratefully acknowledges the valuable contributions made by all submitters and public hearing witnesses.

1.3 Focus of the Inquiry

As discussed in Chapter 2, in July 2008, the Council of Australian Governments (COAG) endorsed the national reform agenda to create a coordinated approach to organ and tissue donation. The Organ and Tissue Authority and the DonateLife network were established in January 2009. Since the implementation of the national reform agenda, Victoria's organ donation rates have increased by over 50 percent.

The Standing Committee Inquiry presents a timely opportunity to review the success to date of the national reform and to consider ways to further increase donation rates in Victoria. This is of particular interest as Australia continues to have a comparatively low rate of organ donation compared to other developed countries.

While the Committee's terms of reference related to organ donation, the Committee believes any examination and discussion on organ donation should also include tissue donation. While much of the public awareness surrounds organ donation and the gift of life, it is important to note that tissue donation can not only save lives but significantly enhances the lives of thousands of Australians. Consideration of tissue donation in this report is also consistent with the aims of the Organ and Tissue Authority and DonateLife Victoria.

The first part of this report sets the scene for organ donation in Australia and Victoria. It outlines the 2008 national reform agenda and sets out the legislative and governance frameworks, and clinical and ethical frameworks within which the organ donation and transplantation sector operates. The second part of the report addresses methods to increase organ donation. It considers different consent models, alternative pathways to organ donation, the capacity of hospitals to accommodate further donation and transplantation procedures, and closes with a discussion on the clinical issues and the role of community awareness.

The Committee's terms of reference is based on the assumption that chronic disease is increasing and may lead to end-stage organ failure, and therefore the need for organ transplants will continue to rise. The Committee's report therefore examines ways to increase donation rates to meet a growing demand.

The Committee notes there are broader preventative health issues that state and federal governments will need to address which may in turn reduce chronic disease. While there are many individuals who suffer from organ failure by virtue of family genetics or other factors beyond their control, unfortunately end-stage organ failure often may be the result of poor nutrition, obesity, smoking and alcohol consumption. Excellent work is carried out by organisations such as VicHealth, the Heart Foundation, Kidney Health Australia, the Australian Lung Foundation, and the Australian Liver Foundation. It is outside the Committee's terms of reference to consider these broader health issues; nevertheless, the Committee urges all governments to continue to focus on disease prevention and health promotion.

2. Organ donation statistics and governance

2.1 History of organ donation and transplantation

Australia has a proud history of medical achievements which is evident in its success in the field of organ and tissue transplantation. In 1965, the first successful living kidney transplant was performed in Australia; by the 1980s, transplantation of hearts, lungs and livers became available. Within the last decade, Australian medical teams have achieved successful transplants on newborn infants and have achieved a world first kidney/liver/pancreas transplant.

These achievements demonstrate how the progress of transplantation procedures and medical research has improved dramatically over the years, making transplantation the most sought-after procedure for end-stage organ disease. The donation of organs for transplantation is life saving and significantly improves the lives of transplant recipients who would otherwise require less than satisfactory and expensive ongoing treatments. Chapter 5 further illustrates the life-saving benefits from tissue donation.

Medical innovation and progress has also improved the clinical outcomes and success rates of transplantation procedures. Australia is recognised as having some of the best survival outcomes in transplantation worldwide. For example, five years after receiving a kidney transplant, a recipient has an 89 percent survival outcome from a deceased donor and 94 percent from a living donor.[2] Australia also boasts a comparatively high number of organs retrieved per donor with an average of 3.2 organs transplanted per donor (See Section 2.3).[3]

2.2 Organ donation statistics

Performance measurement was identified as an issue by the Committee, in particular how success of organ donation programs are measured both within Australia and internationally. The Committee identified that the donor per million of population (dpmp) measure may not be the best way to measure the success of organ donation and transplantation activity in Australia. This view was confirmed in the work of the National Clinical Taskforce on Organ and Tissue Donation in their 2008 report.[4]

The Taskforce's final report identified that the 'best measure of performance for deceased organ donation is based on the conversion rate of the number of potential deceased organ donors who become actual organ donors.'[5] This type of measure would remove 'differences in population demographics and mortality patterns and [focus] attention on infrastructure and public policies.'[6]

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[2] P Clayton, L Excell, S Campbell, S McDonald and S Chadban, 'Transplantation' *ANZDATA Registry Report 2010*, Australia and New Zealand Dialysis and Transplant Registry, 2011, p. 8-25, p. 8-30.

[3] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, Australia and New Zealand Organ Donation Registry, 2011, p. 1.

[4] Department of Health and Ageing, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally,* 2008, p. 112-113.

[5] K Hornby et al, 'Measuring organ donation performance internationally: modelling the effects of available denominators for organ donation rates', 2007 Organ Donation Congress of the International Society of Organ Donation and Procurement (ISODP) and the International Transplant Coordinators Society (ITCS), 11–14 November 2007, in Department of Health and Ageing, *National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally,* 2008, p. 113.

[6] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p 112.

Unfortunately, the number of potential deceased organ donors is often not collected in other countries and can therefore not be used as a comparator for deceased organ donation performance. Instead, 'population is used as the proxy for potential donors'[7] resulting in the measure of donors per million of population used for international comparisons.

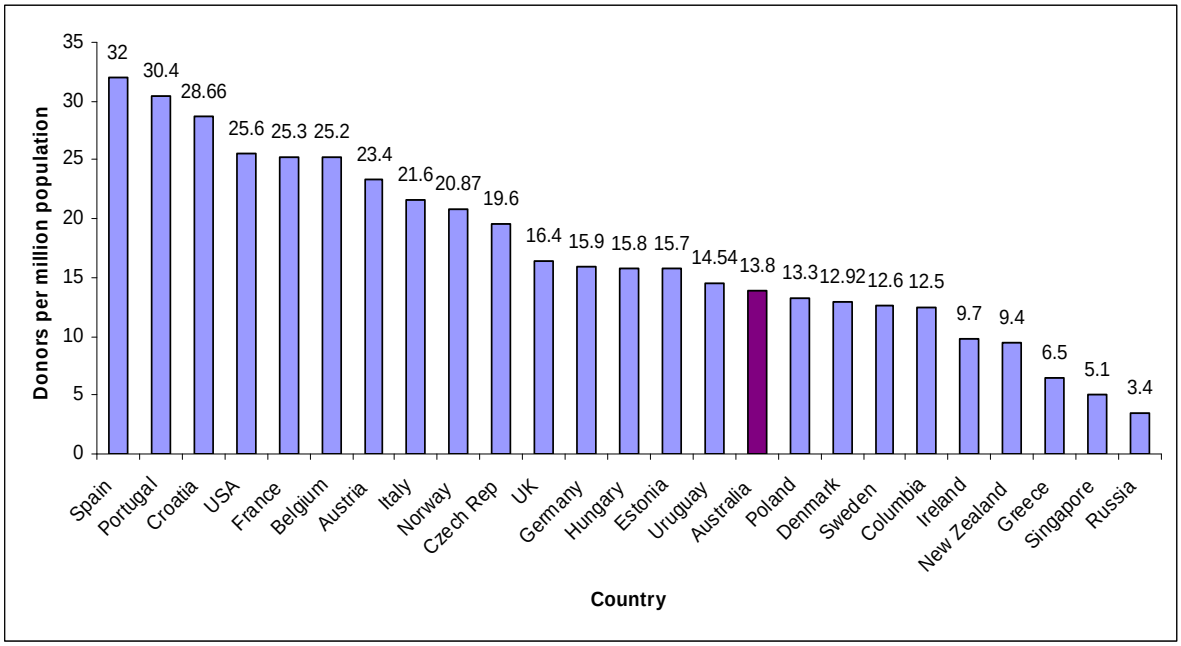
While the Committee acknowledges there are other measures of success including the number of organs retrieved per donor, the level of transplant activity and the long term success of transplants, for the purpose of international and state data comparisons, the Committee will refer to the donor per million of population measure.

Despite Australia's medical capabilities and international reputation in transplant procedures, Australia has had one of the lowest organ donation rates among developed countries. This shortage of organs and the increased demand for transplantation procedures has created sizeable transplant waiting lists.

Figure 1 illustrates the ranking of Australia and other developed countries in terms of donors per million of population in 2010. It is evident that Australia's organ donation rate is comparatively low compared with other developed countries, only recording 13.8 dpmp in 2010 compared with 32.0 dpmp in Spain and 25.6 dpmp in the United States. In 2011, Australia's donor rate increased to 14.9 dpmp, a positive improvement but still comparatively low internationally.

Spain has consistently maintained the highest organ donor rates in the world since it implemented the equivalent of a national reform to the organ donation and transplantation sector in 1989.

Figure 1. International donor statistics 2010[8]



The Taskforce report highlighted that in 2005 Spain retrieved 2.6 organs per donor compared to 3.2 retrieved in Australia and 3.5 retrieved in the United States.[9] In addition,

[7]Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p. 112.
[8]International Registry of Organ Donation and Transplantation, <http://www.tpm.org/secciones/irodat.swf> accessed 12 January 2012.
[9]Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p.114.

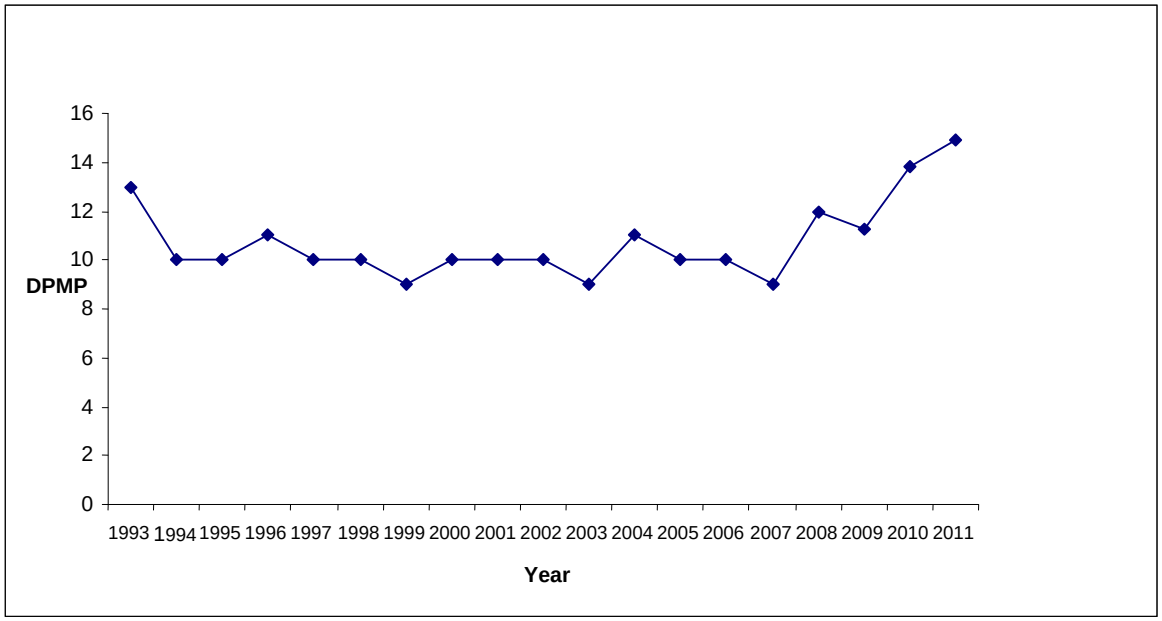
Australia had 3.6 transplants per donor compared to 2.4 in Spain and 2.7 in the United States.[10]

In the 15 years prior to 2008, Australia had a relatively static rate of organ donation, ranging between 9 to 11 donors per million of population (Figure 2). This is in contrast to a relatively large increase in the number of organ donors in Australia since 2008.

In 2010, there was a 50 percent increase in Australia's dpmp rate (over the rates observed in the mid-2000s), reaching a total of 309 donors.[11] Continued growth was achieved in 2011 when organ donors totalled 337 (Figure 2).[12]

The Committee's evidence attributes the recent increases in Australia's organ donor rate to the implementation of the *National Organ Donor Collaborative* (from mid-2006 to mid-2009) and the national reform agenda, *A World's Best Practice Approach to Organ and Tissue Donation and Transplantation* in 2010 (refer to Section 2.5).

Figure 2. Donors per million of population for Australia 1993 to 2011[13]



The *National Organ Donor Collaborative* created an opportunity for a previously fragmented sector to come together and share learnings and best practice. Evidence received from Dr Helen Opdam, State Medical Director of Organ and Tissue Donation in Victoria highlighted that –

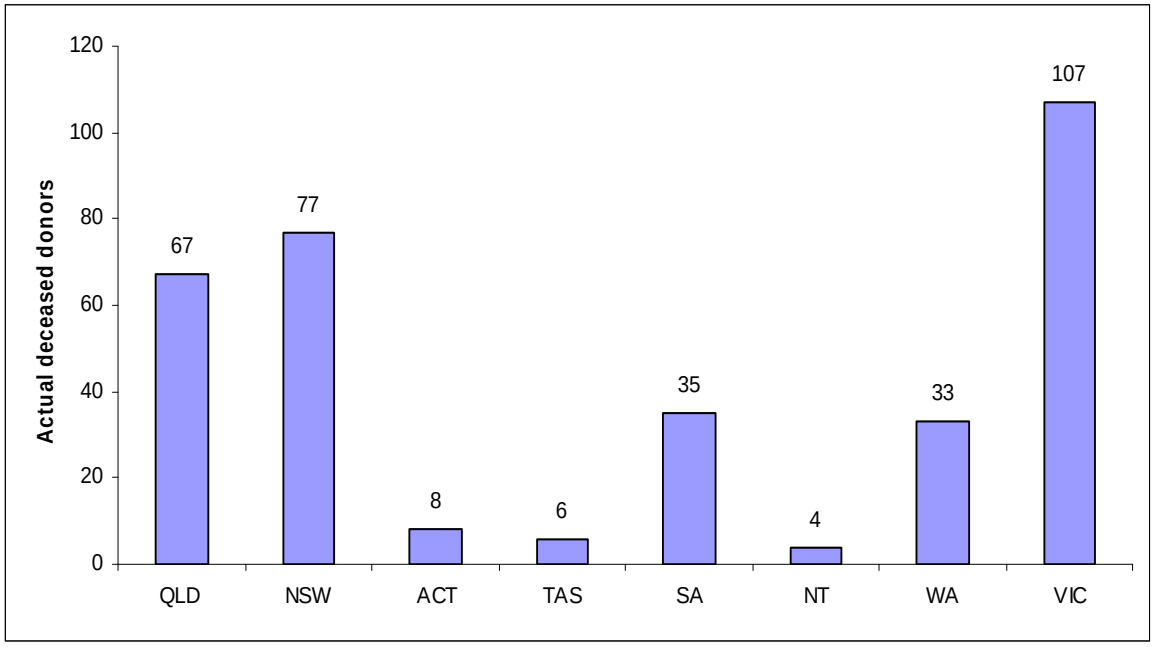
> … in 2005, 2006 and 2007 we had about 200 deceased donors in Australia per year. This increased to about 250 in 2008 and 2009. I believe the reason behind that was what was called a national organ donation collaborative, whereby we had 26 hospitals across the country through a nationally funded program have staff members attend regular meetings and share best practice about donation over a

[10] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p.114.
[11] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 2.
[12] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report on Deceased Organ Donation in Australia*, December 2011, Australia and New Zealand Organ Donation Registry.
[13] L Excell, K Hee, and G Russ, 'Appendix 1', ANZOD Registry Report 2011, Australia and New Zealand Organ Donation Registry, 2011, p. 3 and ANZOD 2011 *Summary of Organ Donation and Transplantation*, released January 16, 2012.

> three-year period. That ran from mid-2006 until mid-2009. That was, I think, influential in that increase.[14]

A state breakdown of Australia's organ donors illustrates that Victoria is leading the nation in the total number of donors and is second only to South Australia on a donor per million of population comparison. Of the 337 organ donors in 2011, Victoria had 107, followed by New South Wales with 77.[15] Victoria's donor rate per million of population is now 19.0, well above the national average of 14.9 and more favourable on an international comparison (see Figure 1). Figure 3 below shows the total number of actual deceased donors for each state and territory in 2011.

Figure 3. Total actual deceased donors all states and territories 2011 [16]



Victoria's recent level of success in organ donation rates is in contrast to the years prior to 2008 when Victoria's donor rates were static and relatively low in comparison with other states. Figure 4 illustrates Victoria's total deceased donors each year since 2005. The period 2005 to 2007 experienced little movement from 46 to 55 donors,[17] however in 2008 total donors had risen to 67. The most significant increase occurred in 2010, with total donors rising to 98 (a 35% increase from the previous year) and reaching 107 in 2011.[18]

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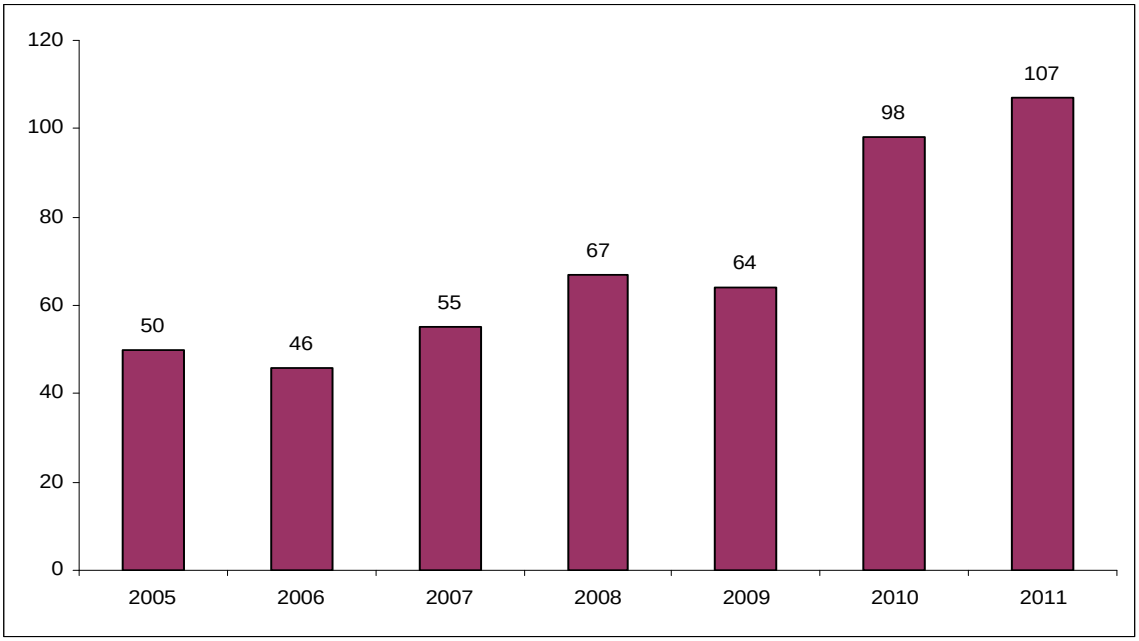
[14] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 42.
[15] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report,* December 2011, Australia and New Zealand Organ Donation Registry.
[16] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report,* December 2011, Australia and New Zealand Organ Donation Registry.
[17] L Excell, K Hee, and G Russ, 'Appendix 1', ANZOD Registry Report 2011, 2011, p. 3 and ANZOD monthly updates <http://www.anzdata.org.au/anzod/v1/summary-org-donation.html>, accessed 3 October 2011, (data compiled from Annual Reports 2011, 2006 and 2001 and monthly updates in 2011).
[18] L Excell, K Hee, and G Russ, 'Appendix 1', ANZOD Registry Report 2011, 2011, p. 3 and ANZOD monthly updates <http://www.anzdata.org.au/anzod/v1/summary-org-donation.html>, accessed 3 October 2011. (Data compiled from Annual Reports 2011, 2006 and 2001 and monthly updates in 2011).

Figure 4. Total actual deceased donors 2011[19]



In evidence to the Committee in August 2011, Ms Yael Cass, Chief Executive Officer, Organ and Tissue Authority, highlighted that –

> …if Victorian [donor] rates are sustained and projected for this full calendar year and turned into a donor per million [of population] rate for this state, we expect that you will achieve around 20.7 donors per million [of] population which is comparable with rates currently being achieved in the US which is a very strong international performance.[20]

Finding 1

Australia's organ donation rate remains low in comparison to other countries, however the number of organ donors has doubled over the past five years. Victoria's number of organ donors increased by 35 percent in 2010 and a further 8.5 percent in 2011.

Finding 2

Victoria leads the nation as the state with the highest number of organ donors. In 2011, Victoria had 107 donors, almost one-third of Australia's total of 337. Victoria's organ donor rate is now comparable to countries such as the United States and the United Kingdom.

Finding 3

International comparative measures based on donors per million of population do not take into account other measures of success including the number of organs retrieved per donor, the number of transplants per donor, and the long-term success of organ transplants.

[19] L Excell, K Hee, and G Russ, 'Appendix 1', ANZOD Registry Report 2011, Australia and New Zealand Organ Donation Registry, 2011, p. 3 and ANZOD monthly updates <http://www.anzdata.org.au/anzod/v1/summary-org-donation.html>, accessed 3 October 2011. (Data compiled from Annual Reports 2011, 2006 and 2001 and monthly updates in 2011).

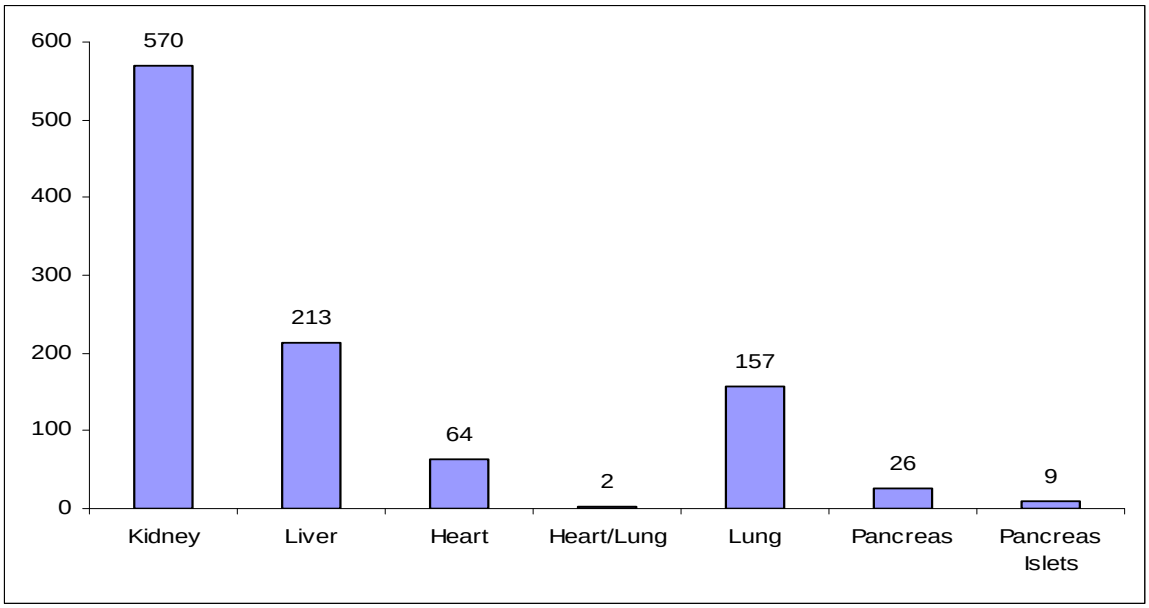
[20] Ms Yael Cass, Organ and Tissue Authority, *Transcript of Evidence*, 25 August 2011, p. 4.

2.3 Transplant statistics

As indicated earlier, Australia has a comparatively high number of successful transplants per donor. In 2011, there were a total of 1,001 recipients transplanted with organs from a total of 337 donors.[21] Victoria's recent increase in deceased donors has had a corresponding positive impact on transplantation activity in the state. In 2011 there were 322 organs transplanted in 309 transplant recipients.[22]

Kidneys are the most common organs donated and transplanted, followed by livers, lungs and hearts. Figure 5 illustrates total organs transplanted from all donors in 2011.

Figure 5. Organs retrieved and actually transplanted in Australia for 2011[23]

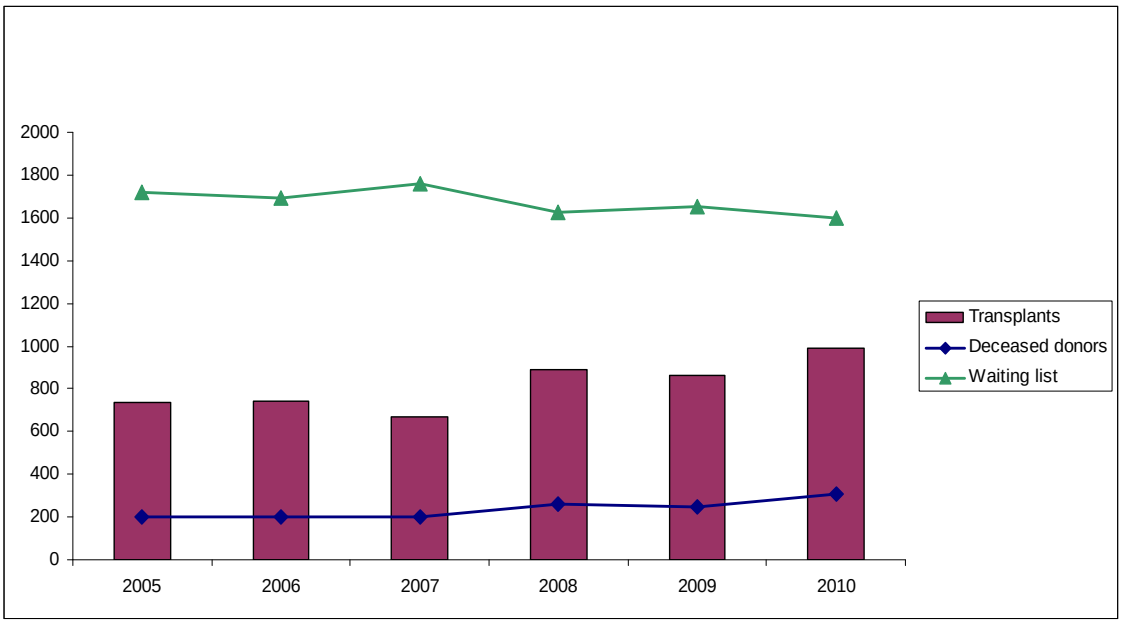


Transplant waiting lists have been a reality ever since the first successful transplantation procedure. In Australia, there have consistently been approximately 1700 people on all solid organ waiting lists, including, kidney, liver, heart, pancreas, lungs and intestines.[24]

Figure 6 shows the number of people on the transplant waiting list, the number of deceased donors and the number of transplants conducted over the period 2005 to 2010 in Australia. It is clear there is a large gap between the number of people on the transplant waiting list and the actual number of transplants completed each year. Over the last six years, the waiting list has remained fairly static even though there has been a marked increase in the number of deceased donors during that time.

[21] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report,* December 2011, Australia and New Zealand Organ Donation Registry.
[22] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report,* December 2011, Australia and New Zealand Organ Donation Registry.
[23] L Excell, K Hee, and G Russ, *ANZOD Registry Monthly Report,* December 2011, Australia and New Zealand Organ Donation Registry.
[24] DonateLife, *Facts and Statistics*, <http://www.donatelife.gov.au/index.php?option=com_content&view=article&id=672&Itemid=159>, accessed 12 January 2012.

Figure 6. Number of deceased donors, solid organ transplants and patients on the waiting list in Australia 2005 to 2010[25]



At January 2011, there were 1,599 people waiting for transplants across Australia. The breakdown by solid organ waiting list is outlined in Table 1.

Table 1. Waiting list for organs by transplant region as at 1 Jan 2011[26]

Organs	QLD	NSW/ACT	VIC/TAS	SA/NT	WA	AUST
Kidney	141	572	370	49	91	1,223
Liver	23	65	49	18	12	167
Heart	5	18	13	-	10	46
Heart/Lung	1	4	1	-	-	6
Lung	24	22	53	-	11	110
Pancreas/Kidney	-	21	14	-	-	35
Pancreas only	-	1	-	-	-	1
Pancreas Islets	-	4	3	2	-	9
Intestines	-	-	2	-	-	2
Total	194	707	505	69	124	1,599

The kidney waiting list is the largest waiting list of all organs. At 1 January 2011, there were 1,223 people in Australia waiting for a kidney.[27] On average, people can be on the transplant waiting list anywhere from six months to four years.[28]

[25] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 3.
[26] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 3.
[27] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 3.
[28] DonateLife, *About Transplantation*, <http://www.donatelife.gov.au/discover/about-transplantation> accessed 5 December 2011.

Prof. Bob Jones, Head of the Liver Transplant Unit, Austin Hospital described these transplant waiting lists in his evidence to the Committee –

> .... if you look at liver transplantation, we do vary it a little bit depending on the organ donor supply — for example, we know there is no use putting people on the list who are never going to get transplanted, so there is a slight reduction in numbers of patients who go onto the list because we know that they are not going to get done. If the organ supply increased, we would be able to increase the number of transplants, but having said that, there is a finite limit. This is not something that is just going to exponentially increase and cost a fortune.[29]

The Transplantation Society of Australia and New Zealand (TSANZ) released the first national consensus statement on eligibility criteria and allocation protocols for organ transplantation from deceased donors.[30] This document outlines the relevant criteria for people to be placed on a transplant waiting list. Whilst each organ has specific eligibility criteria, there are some overarching ethical principles for all organ waiting lists. (Refer to Section 3.4 for a further discussion on the consensus statement.)

Finding 4

Approximately 1700 Australians remain on organ transplant waiting lists. To date there is little evidence to suggest that the number of people on transplant waiting lists will decline as more organs become available for transplantation.

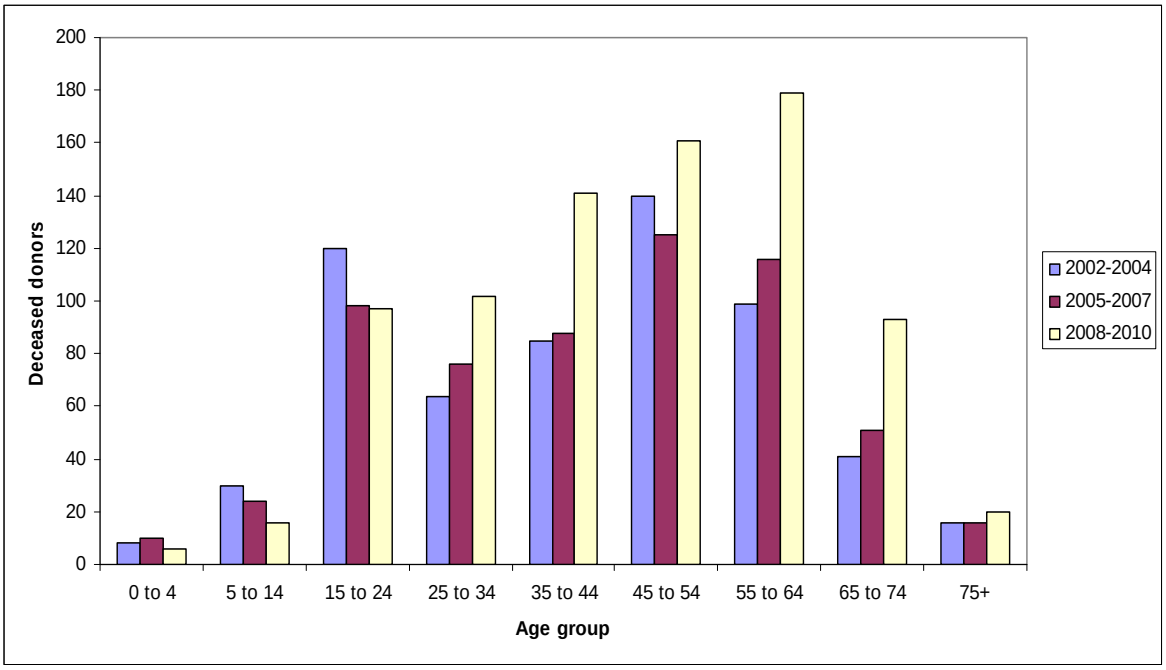
2.4 Deceased donor profile

In the past decade, the deceased donor profile has changed with the average age of donors increasing and the causes of donor death varying. The gender split of deceased donors has been relatively consistent over the last decade, however generally there is a greater proportion of donors who are male than female.[31]

Of particular interest is the changing age profile of deceased donors. Figure 7 illustrates that in the years 2002-2004, the majority of deceased donors were predominantly in the age groups 15-24 or 45-54. By the mid-2000s deceased donors were spread across three age groups, 15-24, 45-54 and 55-64. By the end of the decade there had been a notable change to the age profile, with more donors reported in the 55-64 age range and a marked increased in the 65-74 range. The expansion of medical suitability criteria to include more older donors is clearly reflected in this data.

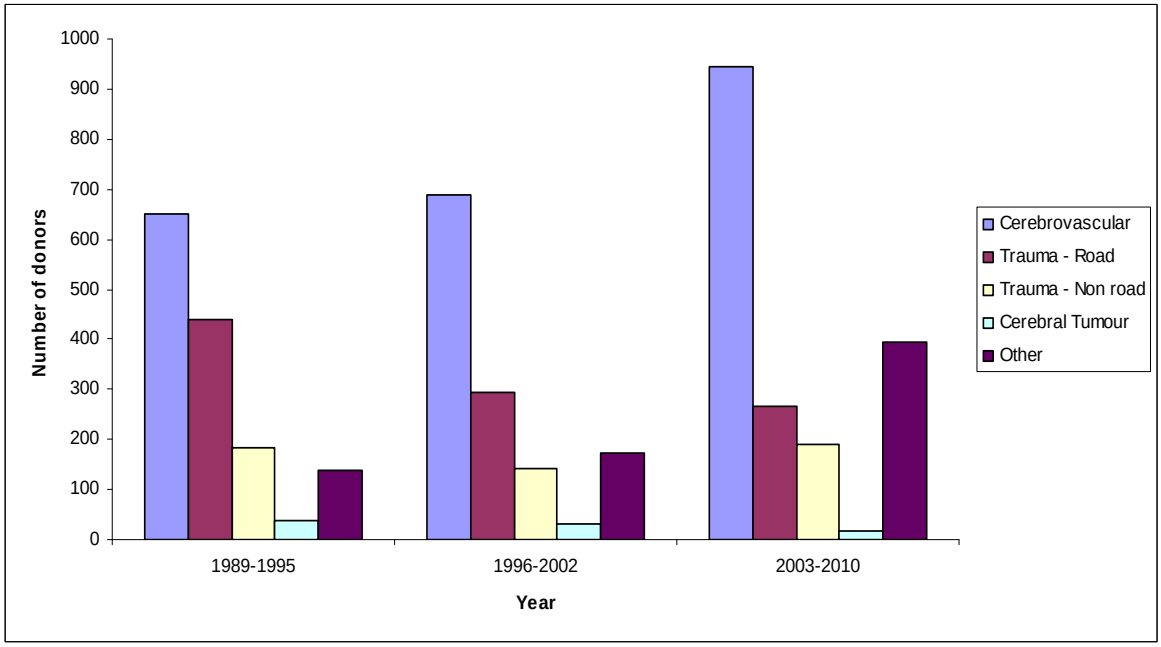
[29] Prof Bob Jones, Austin Hospital, *Transcript of Evidence*, 8 September 2011, p. 88.
[30] Transplantation Society of Australia and New Zealand, *Organ transplantation from deceased donors: consensus statement on eligibility criteria and allocation protocols*, 2011.
[31] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 5.

Figure 7. Age group of deceased donors Australia 2002 to 2010[32]



Historically the main cause of death of deceased donors in Australia has been by cerebrovascular means, which remains the case today. During the period 2003 to 2010 (Figure 8), cerebrovascular death accounted for 52 percent of donor deaths.

Figure 8. Cause of donor death in Australia 1989 to 2010[33]



[32] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 5.
[33] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 8.

Improvements in road safety have had a significant effect on the donor pool. In the late eighties and early nineties, road trauma accounted for 30 percent of donor deaths.[34] From 2003 to 2010, road trauma contributed only 15 percent to donor deaths in Australia, representing a 50 percent decline over a 20 year period.[35]

This change in the deceased donor profile was identified in the Taskforce's 2008 report. The report cited the following reasons for the dramatic changes in the demographic profile:

- high quality health care in Australia with improved control of blood pressure, effective treatment of trauma and intracerebral haemorrhage and excellence of intensive care.
- 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 driving.[36]

This places a greater emphasis on the need to explore and implement pathways to organ donation. The introduction of donation after cardiac death programs into metropolitan hospitals is one way to increase organ donation rates and is discussed in more detail in Section 6.3.

2.5 Organ donation governance

The organ donation sector in Australia is governed by state and territory human tissue legislation and is managed by the respective state departments of health and organ donation agencies. In 2009, the governance framework underwent a major change to include the establishment of a national Organ and Tissue Authority and network of donation agencies: the DonateLife network. The new framework occurred as part of the national reform agenda, *A World's Best Practice Approach to Organ and Tissue Donation*.

The national reform agenda was the culmination of findings from the National Clinical Taskforce on Organ and Tissue Donation, established by the then Federal Minister for Health in October 2006. The Taskforce's role was 'to provide evidence-based advice to the government on ways to improve the rate of safe, effective and ethical organ, eye and tissue donation for transplantation in Australia'.[37]

The Taskforce comprised experts and key stakeholders from the organ, eye and tissue sectors. Their role was to identify and propose solutions to the key issues in relation to the Taskforce's terms of reference. The Taskforce produced 51 recommendations and identified the following six action areas:

- community awareness and donor registration
- hospital processes and procedures
- eye and tissue banking
- information collection and activity reporting
- transplant waiting lists and organ allocation systems
- reform of the national organisational infrastructure.[38]

[34] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 8.
[35] L Excell, K Hee, and G Russ, *ANZOD Registry Report 2011*, 2011, p. 8.
[36] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p. 112.
[37] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p. 25.
[38] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p.18.

Following the release of the final report of the Taskforce in January 2008, a national reform agenda was proposed at the July 2008 Council of Australian Governments (COAG) meeting where *A World's Best Practice Approach to Organ and Tissue Donation for Australia* was presented and endorsed by all state and territory governments.[39] The national reform agenda focussed on providing funding for a network of specialist doctors and clinical nurse educators in public and private hospitals to focus solely on organ and tissue donation, funding for hospitals for additional staffing, bed and infrastructure costs, and an independent national authority for organ donation and transplantation.[40]

A World's Best Practice Approach to Organ and Tissue Donation provided $136.4 million over four years to boost organ donation rates. Key elements of the reform package were:

- $67 million to fund dedicated organ donation specialist doctors and other staff in public and private hospitals
- $46 million to establish a new independent national authority to coordinate national organ donation initiatives
- $17 million in new funding for hospitals to meet additional staffing, bed and infrastructure costs associated with organ donation
- $13.4 million to continue national public awareness and education
- $1.9 million for counselling for potential donor families.[41]

Other significant measures included enhanced professional education programs, consistent clinical protocols and 'clinical trigger' checklists and data collection for organ transplants in hospitals were endorsed.[42]

The Organ and Tissue Authority (the Authority) was established on 1 January 2009 under the auspices of the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008*. The Authority's main roles are to provide 'national leadership to the organ and tissue sector and to drive, implement and monitor national reform initiatives and programs in partnership with states and territories, clinicians, consumers and the community sector.'[43] The Authority is also responsible for managing grants to non-government organisations which provide essential services to the community in relation to organ and tissue donation.

The objectives of the Authority are to:

- increase the capability and capacity within the health system to maximise donation rates; and
- raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation.[44]

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[39] K Rudd, N Roxon, and J McLucas, '$136.4 million plan to boost organ donation and save lives', Department of Health and Ageing, 2008, <http://health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr08-nr-nr100.htm?OpenDocument&yr=2008&mth=7>, accessed 12 January 2012.

[40] Council Of Australian Governments, 2008, *Council of Australian Governments' Meeting 3 July 2008,* <http://www.coag.gov.au/coag_meeting_outcomes/2008-07-03/index.cfm#health>, accessed 12 January 2012.

[41] K Rudd, N Roxon, and J McLucas, '$136.4 million plan to boost organ donation and save lives', Department of Health and Ageing, 2008.

[42] K Rudd, N Roxon, and J McLucas, '$136.4 million plan to boost organ donation and save lives', Department of Health and Ageing, 2008.

[43] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2008-2009*, 2009, p. 13.

[44] Organ and Tissue Authority, presentation to Committee at 25 August 2011 public hearing, slide 3.

In order to achieve these objectives, the Council of Australian Governments endorsed the following nine measures:

- 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 network.
- Measure 8: National eye and tissue donation and transplantation network.
- Measure 9: Additional national initiative, including living donation programs.[45]

The Organ and Tissue Authority leads a coordinated approach to organ and tissue donation as well as a national network of organ donation agencies, the DonateLife network. This was effectively a unification and rebranding of all existing state organ donation agencies.

While the organ and tissue donation sector now has a national focus, it is still governed by state and territory legislation and encompasses many stakeholders throughout states and territories. Key stakeholders include the various DonateLife agencies, professional medical bodies, regulatory bodies, community and not-for-profit organisations and transplant units within hospitals. (Refer to Appendix D for a list of some of the key stakeholders in the organ donation and transplantation sector.)

A review of the first full year of implementation of the national reform agenda was released in July 2011. The review found that 'overall, the reform package had achieved notable success by the end of 2010, though the progress in implementation of each of the nine measures of the reform package has varied.'[46] The review found 'there is significant capacity to see continued growth in national deceased donor organ donation performance',[47] citing deceased donor rates of 23 to 25 donors per million of population are 'potentially achievable'.[48]

Finding 5

Since the first full year of implementation of the national reform agenda in 2008, there has been a significant improvement in organ donation rates in Australia. This would suggest that the new governance arrangements for organ and tissue donation throughout Australia have had some success in achieving its aims.

Recommendation 1

That the Victorian Government continue to support the ongoing implementation of the national reform agenda to increase organ donation rates.

[45] Organ and Tissue Authority, presentation at 25 August 2011 public hearing, slide 4.
[46] Australian Healthcare Associates, *Organ and Tissue Donation Reform Package: Mid-point review report*, 2011, p. 1.
[47] Australian Healthcare Associates, *Organ and Tissue Donation Reform Package: Mid-point review report*, 2011, p. 2.
[48] Australian Healthcare Associates, *Organ and Tissue Donation Reform Package: Mid-point review report*, 2011, p. 2.

2.6 Implementing the national reform in Victoria

The Minister for Health is a signatory to the COAG-endorsed national reform agenda on organ and tissue donation. In 2009, the Department appointed Dr Helen Opdam as the inaugural Victorian Medical Director of Organ and Tissue Donation. Dr Opdam also works in a part-time capacity as an intensive care specialist at the Austin Hospital.

In its submission to the Inquiry, the Department of Health noted that:

> The leadership role of the State Medical Director is pivotal in achieving sustained increases in organ and tissue donation for transplantation and in accordance with the objectives of the national reform agenda.[49]

DonateLife Victoria coordinates organ donation in Victoria and Tasmania and works with the Donor Tissue Bank of Victoria and Lions Eye Bank to gain consent from potential donor families. The team works with hospitals and hospital-based organ and tissue donation medical specialists and nurses across Victoria to provide professional donation services and encourage best practice to increase donation performance. DonateLife Victoria also helps raise community awareness and understanding about organ and tissue donation to encourage all Victorian families to discuss donation, know each other's wishes and register their decision to be an organ and tissue donor.

Funding for organ and tissue donation and transplantation is derived from both Commonwealth and State Governments and is discussed in detail in Chapter 7.

In Victoria, there are twenty five organ and tissue donation hospital-based medical directors (8.4 full time equivalent) (FTE) are appointed across the following 13 Victorian Hospitals:

- Alfred Health – 1.5 FTE
- The Royal Melbourne Hospital – 1 FTE
- Austin Hospital – 1 FTE
- St Vincent's Hospital – 0.8 FTE
- Monash Medical Centre – 0.8 FTE
- Dandenong Hospital – 0.5 FTE
- Box Hill Hospital – 0.5 FTE
- Maroondah Hospital – 0.3 FTE
- The Royal Children's Hospital – 0.5 FTE
- Frankston Hospital – 0.5 FTE
- The Northern Hospital – 0.5 FTE
- Western Hospital – 0.5 FTE
- The Geelong Hospital – 0.5 FTE

In addition to hospital medical directors, 33 organ and tissue donation hospital-based nurses are appointed across 24 Victorian hospitals, including a number of regional hospitals.

The statistics referred to earlier in this chapter clearly demonstrates Victoria's recent success in increasing organ donation rates and transplantation activity. The Committee

[49] Department of Health, Submission No. 26, p. 2.

notes this is largely due to the work of DonateLife Victoria and the dedicated organ and tissue donation hospital networks within the state. This builds on Victoria's status as the nation's leading organ and tissue donation state and is consistent with its broader successes in medical capabilities and research.

Ms Yael Cass, Chief Executive Officer of the Organ and Tissue Authority, particularly highlighted the leadership and contribution of Dr Helen Opdam, State Medical Director for Organ and Tissue Donation and DonateLife Victoria for their engagement of experts in the public hospital system for contributing to Victoria's success.[50]

The Committee received evidence from Dr Opdam which outlined some of the success factors of Victoria. They included:

- Embedding hospital staff responsible for organ donation in major hospitals in metropolitan Melbourne and in regional hospitals
- Sharing the single salary available among three senior specialists to focus on organ donation
- Implementing an effective volunteer program, [to] undertake community education and awareness activities
- Working closely and effectively with the Department of Health and the Victorian Red Cross Blood Service
- Dedicating a full-time position to donor family support.[51]

Whilst Victoria is doing well in implementing the national reform agenda, the Committee received evidence that there is more which can be done to address some of the existing challenges to organ donation and transplantation. In particular, Chapter 7 highlights the need for the establishment of organ donation rate targets, improved planning and appropriate resource levels.

Finding 6

Recent organ donation and transplantation activity in Victoria illustrates that Victoria has been the most successful state in implementing the national reform agenda. This success is largely due to a coordinated and collaborative approach across all key stakeholders in the organ donation sector, led by DonateLife Victoria.

2.7 State Overview

Part of the Committee's terms of reference required an examination of the relevant organ donation legislative, procedural and governance frameworks and policies in other jurisdictions. Any such examination is in the context of all state and territory governments working together in the implementation of the national reform agenda. Interstate consideration of presumed consent is discussed in Chapter 5.

The following section provides a brief outline of recent relevant organ donation reviews in other Australian states.

2.7.1 Queensland

In 2008, the Queensland Legislative Assembly established a Select Committee to investigate the relatively low organ and tissue donation rates in Queensland.[52] It

[50] Department of Health, Submission No. 26, p. 2.
[51] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 49.

considered whether presumed consent should be introduced and other ways to improve organ donation rates. In 2007, Queensland's donation rates were nine donors per million of population with a total of 39 deceased organ donors. The Queensland Inquiry was conducted during the time of the National Clinical Taskforce on Organ and Tissue Donation and endorsement of the national reform agenda.

The Queensland Committee made a number of recommendations aimed at improving donor rates including the need to make donor registration more accessible, improving donor consent and processes, an emphasis on community education and awareness and funding for intensive care units (ICUs) to accommodate an increase in organ transplants.

The report set the Queensland Government a target of at least doubling the number of organ donors from 39 in 2007 to 60 by 2011 and 80 by 2013. Data released up to December 2011 shows Queensland has surpassed its 2011 target with a total of 67 deceased donors for the year.

2.7.2 Tasmania

From 2007-2008, a Tasmanian Legislative Council Select Committee conducted an inquiry into organ donation.[53] The Inquiry considered the adequacy of the Tasmanian approach to identifying potential donors; the causes leading to Tasmania's relatively low organ donation rates; the relationship between organ donation and wishes of families' involved; and the suitability of the current education and promotion program.

Key recommendations related to greater community education, the need to employ a Tasmanian organ donation coordinator within hospitals to facilitate the donation process, improvements to data collection, greater consistency in the legal definition of death and a formal audit of deaths to identify where organ donation may have been possible.

The Legal and Social Issues Committee received a written submission from the Tasmanian Minister for Health, Michael O'Byrne MP, where he outlined how DonateLife Tasmania works in conjunction with DonateLife Victoria –

> Tasmania is not a provider of organ retrieval, tissue typing or organ transplantation services. Most of these services are provided by Victorian based services. For example, there is a Memorandum of Understanding between the Department of Health and the Human Service (the Agency) and the Australian Red Cross Blood Service whereby funding is provided for organ donor coordination services provided by DonateLife Victoria.
>
> We are therefore reliant on the continued engagement and cooperation from DonateLife Victoria to maximise opportunities for organ donation and transplantation. This includes the development of a hybrid model for organ donor coordination and the implementation of donation after cardiac death.[54]

2.7.3 Western Australia

In 2000, the Western Australia Parliamentary Standing Committee on Uniform Legislation and Intergovernmental Agreements conducted an inquiry into organ donation and transplantation.[55] The Committee investigated a wide range of issues including legislative processes, consent models, factors influencing organ donation, the need for medical

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[52] Legislative Assembly of Queensland, *Organ and Tissue Donation: Report of the Review of Organ and Tissue Donation Procedures Select Committee,* 2008.
[53] Parliament of Tasmania, Legislative Council Select Committee, *Organ Donation,* 2008.
[54] Minister for Health, Tasmanian Government, Submission No 5, p. 1.
[55] Western Australia Legislative Assembly, Standing Committee on Uniform Legislation and Intergovernmental Agreements, *Organ Donation and Transplantation,* Report No. 25, 2000.

donor coordinators and a national effort to standardise and streamline the donation process (the report predated the national reform agenda on organ donation).

More recently, a special committee released a discussion paper which investigated an opt-out model to organ donation. The paper was in response to a request by the Minister for Health to consider the adoption of an opt-out consent model of organ and tissue donation as a means of increasing donation rates in Western Australia.

The Western Australian discussion paper highlights the need to secure ongoing Commonwealth funding and notes the need to ensure such an initiative can be introduced in parallel with the current national reform agenda. (Refer to Section 4.2 for a further discussion on presumed consent models.

2.7.4 New South Wales

In December 2011, the New South Wales Ministry of Health released the discussion paper *Increasing organ donation in NSW*.[56] The discussion paper seeks views on specific issues from interested parties including: changes to the donation register; assisting families considering donor consent; enhancing organ donation within Aboriginal and Culturally and Linguistically Diverse Communities, and further enhancing the living donor program. Public consultation on this document closed on 31 January 2012.

2.7.4 Other States and Territories

In calling for written submissions to the Inquiry, the Committee wrote to all state and territory governments seeking feedback on the relevant legislation, policies and practices for organ donation and transplantation in their jurisdictions. As part of this process, the Australian Health Minister's Advisory Council also wrote to each minister seeking their response to the Inquiry. Several state and territory governments provided written submissions outlining their existing practices and involvement in the national reforms. All state and territory governments continue to support the implementation of the national reform agenda.

[56] NSW Ministry of Health, Increasing organ donation in NSW: discussion paper, December 2011.

3. Legal and ethical framework

3.1 The law and organ donation

In Victoria, organ and tissue donation is governed by the *Human Tissue Act 1982.* Key aspects of the legislation include how consent is obtained for organ and tissue donation (s.26), providing the definition of establishing death (s.41), describing consent by the coroner (s.27) and prohibiting the trade of human tissue (s.38 and 39).

All states and territories have similar legislative frameworks which govern the removal of organs and tissues, however, there are some variations. In Western Australia there is no definition of death provided for in the legislation; instead tissue may be removed once two medical practitioners certify that irreversible cessation of all brain function has occurred.[57] In South Australia, the definition of death is contained in the *Death (Definition) Act 1983* rather than the relevant human tissue legislation.

The legislated informed consent model requires that individuals must explicitly provide consent during their lifetime to donate organs upon their death. Alternatively, the senior available next of kin can consent to organ donation. In the absence of such prior consent, organ donation will not proceed.

Historically, registrations of consent in Victoria were held by the State's road authority (VicRoads) and an individual would receive notification on their driver's licence indicating their consent to donate. This approach was replicated throughout Australia creating multiple consent registers. In a move to centralise the consent registers, the Australian Organ Donor Register (AODR) was established in 2000. All consent registers are now coordinated by the AODR, however, New South Wales is the only state to continue with a driver's licence card registration system.

The AODR was initially established to enable individuals to register their intention to donate their organs after death. In effect, this was a register of intent only. Following a review in 2004 to 2005, the register was altered to a register of legally binding consents to donate. The AODR is now the national register for organ and tissue donation and is an important part of the legislative framework. This register is consulted at all times when a potential donor is identified in hospital. Importantly, individuals can register their objection to donate any organs as well. At the end of October 2011, there were 1,535,293 legally valid consents registered in Australia on the register. Of these, 376,676 registrations came from Victoria.[58]

The reality of medical practice in Victoria is that the family is always consulted with respect to the potential donation of organs from a recently deceased relative. However, this practice within Victorian hospitals is not strictly consistent with the purpose of Section 26 of the *Human Tissue Act 1982* which outlines the consent process (refer to Appendix C for a copy of section 26).

Current practice results in the senior available next of kin or family member being able to revoke an individual's informed consent at the time of death. For example, if at the time of seeking consent from the senior available next of kin they indicate their objection to donation, the medical practice is such that the donation will not proceed, even if the individual has registered their consent to donate on the AODR. The practice of seeking family consent in Victoria is consistent with practices in all states and territories.

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[57] Department of Health and Ageing, *National Clinical Taskforce Final Report,* 2008, p. 43

[58] Australian Organ Donor Register, *Statistics*, <http://www.medicareaustralia.gov.au/provider/patients/aodr/stats.jsp>, accessed 6 December 2011.

Evidence from Alfred Health highlights a contrast between a strict legal interpretation of the consent process within the *Human Tissue Act*, and the current clinical practices of obtaining family consent. In its submission, Alfred Health notes –

> There is no legal requirement that family members as a group consent to organ donation. They might well make their views known to the senior available next of kin but ultimately consent is a matter for the deceased person in their lifetime or the senior available next of kin.
>
> In addition, family members have no right to veto consent that has been validly given by the donor or the senior available next of kin.
>
> Alfred Health agrees with the current law that no-one (other than a court or tribunal) should have the right to overrule a validly-made consent to donate organs.
>
> However, the practice of seeking family consent is widespread, even where consent has been validly given by the donor in their lifetime or the senior available next of kin after death. Many health professionals mistakenly believe that organ donation cannot proceed without the consent of the donor's family. Even DonateLife promotes the misleading message that 'your family will have the final say.[59]

Alfred Health's legal counsel, Mr Stephen Taffe, further noted that –

> Parliament could address this problem [of consent] by strengthening the current law to help ensure that an individual's lawful choices are respected. Alfred Health suggests that a new subsection should be inserted into section 26 of the *Human Tissue Act* that says, 'For the purposes of this section, a wish, consent or objection made or expressed by a deceased person or the senior available next of kin is not affected by the contrary views of any other person.'[60]

However, Alfred Health's medical directors hold a different opinion on consent, which stems from a practical point of view. Dr Steven Philpot, a medical director for organ donation at Alfred Health, noted –

> The fact of the matter is that the current clinical practice is not in keeping with that law. When we speak to families about organ and tissue donation, we try very much to have a consensus view among the family that this is something they are all willing to partake in. It is a journey we are taking the family on as much as the organ donor themself. We have concerns about the negative publicity that might arise were we to enforce this upon a family that was not willing to partake in the organ donation process. Whilst it has been entered into our submission, I think there needs to be some clarity about the laws, but I think it is also, I would like to say, not a totally unanimous viewpoint among all of us.[61]

One of Dr Philpot's colleagues in Alfred Health's organ donation unit, Assoc. Prof. David Pilcher, also believes a strict interpretation of the legal requirements on consent would be unnecessary –

> It might also be fair to say that the potential gains of enforcing a donation where a family is going against the consent on the register, are probably not huge. Over

[59] Alfred Health, Submission No. 11, p. 8.
[60] Mr Stephen Taffe, *Transcript of Evidence*, 8 September 2011, p. 99.
[61] Dr Steven Philpot, *Transcript of Evidence*, 8 September 2011, p. 100.

> 90 percent of the time if there is consent on the register, the family agrees and the donation progresses forward. We recognise and are all in support of clarity on the law and ideally having practice reflect the clarity in the law as well, but there are other aspects of this submission that could be focused on which would lead to more successful transplants, which are likely to get greater benefit than looking at one area which we agree needs some clarity. At the moment 90 per cent of the time in Victoria — this is a Victorian figure — if there is consent on the register, the donation actually occurs.[62]

The Committee appreciates the views of Alfred Health's Legal Officer and its medical practitioners who highlight the complexity of this issue.

The 90 percent referred to by Dr Philpot is reflective of the experience of clinicians at Alfred Health. This can be verified by research commissioned by DonateLife and undertaken by Woolcott Research in 2010-2011. The purpose of the research was to 'measure the ongoing effectiveness of [the] National Community Awareness and Education program.'[63] The research found that when families are aware of their loved one's wishes to donate, 90 percent of Australians say they would support those wishes.[64] However, these results contrast with research commissioned by the Commonwealth Department of Health and Ageing and DonateLife which suggests the rate of family consent remains at less that 60 percent[65] (see further detail below). Family support for the deceased's wishes to donate is extremely important in raising organ donation levels. The importance of an awareness campaign in addressing this issue of family consent and consultation is discussed in Chapter 8.

The Committee's evidence illustrates that existing clinical practices in hospitals result in a situation where it is unlikely that organ donation will proceed without consent from the deceased's family. As noted above, in the vast majority of cases, a family will agree with registered consent and the donation can proceed. The practice of consultation is consistent with the message of nationwide DonateLife campaigns which encourages potential donors to discuss their wishes with their family. Dr Helen Opdam noted –

> Most problematic is if the family has never had a discussion, because most people do want to honour the wishes of the person they love after that person has died. If the family knows that the individual had wanted to donate, generally they will agree.[66]

While the legalities of consent are important, it is equally important to take into account the human element in the donation consent process. Dr Opdam noted –

> Sometimes people talk about donation as if it occurs without family being there. I want to remind you that donation occurs in the context of someone having died, usually suddenly, unexpectedly and tragically. There is an acutely bereaved family, and as clinicians caring for that individual we are also caring for that family. We have to raise donation with that family in that situation. Families can have difficulty accepting the poor prognosis of the relative. Sometimes they do not agree or accept that it is necessary to stop treatment, because they are still hopeful that

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[62] Dr Steven Philpot, *Transcript of Evidence*, 8 September 2011, p. 100.
[63] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2010-2011*, 2010, p. 60.
[64] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2010-2011*, 2010, p. 61.
[65] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2010-2011*, 2010, p. 60.
[66] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 48.

> their relative will survive even though there is medical certainty that the outlook for that individual is hopeless. Sometimes their relative has developed death of the brain, but they do not accept or cannot understand that concept. We spend a lot of time communicating with and supporting these families in multiple meetings and conversations to bring them along in their understanding of what has happened to their relative, and it is only after we have spent all that time that we then raise the option of donation with the family.[67]

The family consent rate is the rate in which a request for donation is turned into consent for donation. Consent rates rely on the next of kin or family to know what the deceased's wishes were in relation to organ donation. Despite '91 percent of Australians agreeing that organ and tissue donation has the potential to save and improve lives' less than 60 percent of families give consent to organ donation.[68]

It is unclear to what extent the number of people that are on the Australian Organ Donor Register who are suitable to be donors at the time of death and are prevented from donating as a result of family objection to consent. The Committee believes there needs to be a greater understanding on the issue of family consent and the extent to which families actually object to organ donation proceeding regardless of organ donation registration. This reinforces the need for early discussion with families about organ donation wishes, as evidence suggests families proceed with donation if they know the wishes of their loved one. Research commissioned by DonateLife suggests that the majority of Australians would support their loved one's wishes.[69]

Mr Allan Turner from Zaidee's Rainbow Foundation explained the importance of an early discussion about organ donation from his family's personal experience.

> Why did Zaidee say yes [to organ donation]? When she was 6½—you would think they do not think much about it. When Zaidee was registered [as an organ donor] in 2000 she was only three, and our son was five. At the age of 6½ Zaidee said, 'Mum, if anything happens to me I want to be a donor to another kid.' Kim wrote that down in her memory book. We can only say with our hand on our heart literally is that when Zaidee died her wishes would probably be, 'Yes, I want to be a donor.' She was brain dead, she could not have made the decision herself, but we as a family discussed it way beforehand. All our promotion, our campaign in the market is, have that discussion now, not at the end of life on the deathbed, as people say.

There is substantial literature which covers why families refuse to consent to organ donation. Recent studies in the United Kingdom and Australia suggest that there are significant contributing factors. Some include:

- the misunderstanding of brain death
- cultural beliefs
- the specific timing of the request
- the setting in which the request is made
- the approach and skill of the individual making the request
- characteristics of the deceased

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[67] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 44.
[68] DonateLife, *Facts and Statistics*, <http://www.donatelife.gov.au/index.php?option=com_content&view=article&id=672&Itemid=159>, accessed 3 October 2011.
[69] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2010-2011*, 2010, p.61.

- perceived quality of care of the donor.[70]

It is clear that families play an important role in the organ donation process. Providing families with support and information at a tragic and difficult time is therefore paramount. The continued focus of the national awareness campaign for families to engage in an early discussion about organ donation is a key strategy to increase organ donation rates. (Refer to Chapter 8 for a further discussion on community awareness). The Committee believes there needs to be a continued focus on the way in which consent is raised with families of potential donors

Finding 7

The Committee notes that seeking consent to organ donation often occurs at a difficult and tragic time for families. It requires those seeking consent to have an understanding of differing cultural and religious beliefs. Recognising this, it is important that undue pressure is not placed on the family of the recently deceased.

Finding 8

The Committee believes medical practitioners should continue to consult with families of potential donors when seeking consent. In particular, it is important that adequate support and information is provided to all families during the time of seeking consent for donation and after the donation process has concluded.

Finding 9

It is unclear to what extent the number of people that are on the Australian Organ Donor Register who are suitable to be donors at the time of death and are prevented from donating as a result of family objection to consent. The Committee believes there needs to be a greater understanding on the issue of family consent and the extent to which families actually object to organ donation proceeding regardless of organ donation registration.

Finding 10

It is important that families have early discussions about their organ donation wishes. Research suggests that families that know the donation wishes of their loved one support those wishes when consent is requested.

Recommendation 2

That existing medical practice be maintained and no change be made to the way in which consent is legislated in the *Human Tissue Act 1982*.

Recommendation 3

That authorities investigate ways to collect data that may provide a greater understanding on the number of suitable registered organ donors that do not donate their organs as a result of family objection. This information would assist in understanding more clearly the family consent rate and could assist in targeted community awareness campaigns.

[70] A Simpkin, L Robertson, V Barber and D Young, 'Modifiable factors influencing relatives' decision to offer organ donation: systematic review', *British Medical Journal*, 2009, 339,p. 991 and R West, 'Why families deny consent to organ donation', *Australian Critical Care*, Vol 15, No 1, Feb 2002, pp. 27-32.

3.2 Defining death and organ donation

The *Human Tissue Act 1982* defines death as:

(a) irreversible cessation of circulation of blood in the body of the person; or
(b) irreversible cessation of all function of the brain of the person.[71]

The removal of organs or tissues for donation can only legally proceed in accordance with this definition. However, the likelihood of death occurring in these two ways is actually infrequent. It was put to the Committee that only 1 to 2 percent of people who end up dying in hospital can actually donate.[72]

3.2.1 Brain death

The irreversible cessation of all function of the brain of the person is often referred to as 'brain death'. Brain death can occur in a number of ways. More commonly, it occurs after a patient has experienced road or other trauma, stroke, infections or a long period of time without oxygen.[73]

Prior to organ donation occurring, the determination of death must be diagnosed independently by two experienced doctors who must ascertain that the patient has lost all brain function. After brain death has been declared, donation of organs may be considered.

The leading professional body for intensivists, the Australian and New Zealand Intensive Care Society (ANZICS) defines brain death in their clinical guidelines in the following way –

> Determination of brain death requires that there is unresponsive coma, the absence of brain-stem reflexes and the absence of respiratory centre function, in the clinical setting in which these findings are irreversible. In particular, there must be definite clinical or neuro-imaging evidence of acute brain pathology … consistent with the irreversible loss of neurological function.[74]

ANZICS also specifies the following process should be followed in the determination of brain death –

> The determination of brain death should be carried out by two medical practitioners regardless of whether or not donation is to occur. The two medical practitioners who determine brain death should have the requisite knowledge and skills, or should be supervised by a medical practitioner with those skills. This expertise should be a core part of intensive care training. At least one of the medical practitioners should be employed as a specialist. The person authorising removal of tissues and the person removing tissues must not be responsible for determining brain death.[75]

To complement the requirements of the ANZICS Statement on Death and Organ Donation, the National Health and Medical Research Council (NHMRC) have a set of guidelines for health professionals with respect to organ and tissue donation after death.

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[71] *Human Tissue Act 1982*, s. 41.
[72] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 43.
[73] National Health and Medical Research Council, *Making a decision about organ and tissue donation after death*, 2007, p. 5.
[74] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation* (Edition 3.1), 2010, p. 15.
[75] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation* (Edition 3.1), 2010, p.40.

The guidelines acknowledge that the unity of body and mind (also referred to as integration) is well accepted by religious and secular groups. It refers to the union of body and mind in the living human being.[76] This means that the death of a human being is a result of the 'irreversible loss of the integrated coordinated life of the person as a single living organism'.[77] This view is well supported by religious organisations. In his article, *Religious and Secular Death: A Parting of the Ways*, Nicholas Tonti-Filippini confirms the views held by religious groups that the important aspect of brain death is the 'link between the medical determination that there is loss of all brain function and the belief that death involves the separation of soul and body'.[78]

Assoc. Prof. Tonti-Filippini discusses a recent development by the US President's Council on Bioethics, which has 'rejected the loss of integration explanation for death by the brain criterion'.[79] The Council has called for a new view – the 'mode of being' view. This allows the diagnosis of death to occur on the basis of permanent loss of consciousness and spontaneous breathing. In effect, this allows death to be determined while there is a possibility of some function of the brain to remain, a diversion from the current requirement for all loss of function. This is an important development as it changes the circumstances and base criteria for determining death. It should be noted that this view has not been adopted in Australia and the criteria for brain death still stands as the irreversible cessation of all brain function.

Evidence received from religious groups supported the existing definition of death and would strongly oppose any changes to the definition as outlined in s.41 of the *Human Tissue Act 1982*.

3.2.2 Donation after cardiac death

The irreversible cessation of circulation of blood in the body is generally referred to as 'donation after cardiac death'. Dr Helen Opdam described the ways in which cardiac death can occur –

> Basically these are individuals who have had perhaps a severe injury to the brain, but they have not lost all brain function or they have some other severe condition and it is determined by medical staff that this is a non-survivable illness and agreed by medical staff and the family that treatment should be withdrawn. If there is consensus that that should be done, and it is felt that upon withdrawal of treatment ... they are going to die very quickly, it is possible that soon after death the person's body will be taken to the operating theatre and the organs will be removed. If the process is very short, the organs may still be in a condition where they could work in someone who requires a transplant.
>
> If the person dies very quickly – and generally we talk about within 60 to 90 minutes – then after the organ donation operation and the removal of organs, the organs will be in a condition where they can help other people. In that situation there are fewer organs that can be used – for example, you cannot use the heart, and often the liver does not work well when donation occurs through this pathway. That is another pathway to donation which is becoming more common, particularly

[76] National Health and Medical Research Council, *Organ and tissue donation after death, for transplantation: Guidelines for ethical practice for health professionals*, 2007, p. 16.
[77] National Health and Medical Research Council, *Organ and tissue donation after death* p. 16.
[78] N Tonti-Filippini, 'Religious and secular death: a parting of the ways', *Bioethics*, 2011, 25: no. doi: 10.1111/j.1467-8519.2011.01882.x.
[79] N Tonti-Filippini, 'Religious and secular death: a parting of the ways', *Bioethics*, 2011, 25: no. doi: 10.1111/j.1467-8519.2011.01882.x.

> for kidney and lung donation, but it can only be achieved in certain situations, and it is also complex.[80]

Donation after cardiac death was previously known as non-heart beating donation. Before the brain death definition was brought into practice, most organs were removed upon circulatory arrest. Donation after cardiac death is ethically and clinically accepted when the necessary guidelines are followed.[81] The important factor to consider with donation after cardiac death, is that the decision to discontinue life support must be made independently of the donation process. At all times the patient's best interests is the priority.

Donation after cardiac death is becoming more common as a second pathway to organ donation. In Victoria, donation after cardiac death programs have been implemented in three major hospitals (The Austin, Alfred Health and The Royal Melbourne) and deaths by this pathway have increased substantially (refer to Chapter 6 for a further discussion on the implementation of donation after cardiac death).

Recommendation 4

The definition of death within the *Human Tissue Act* 1982 is appropriate and should not be changed.

3.3 Ethical frameworks

The NHMRC is the overarching body which deals with the ethics of organ donation. An NHMRC document, *Making a decision about organ and tissue donation after death*, is available to the general public to assist in making decisions about organ donation.[82] NHMRC also publish guidelines for health professionals, *Organ and tissue donation after death, for transplantation – Guidelines for ethical practice for health professionals*.[83] This is the ethical framework underpinning organ and tissue donation and transplantation in Australia.

The purpose of the NHMRC guidelines are to provide the ethical landscape for anyone involved in organ and tissue donation and transplantation in Australia. The overarching principles contained in the guidelines, are –

> Donation of organs and tissues is an act of altruism and human solidarity that potentially benefits those in medical need and society as a whole.
>
> Organs and tissues for transplantation should be obtained in ways that:
>
> - demonstrate the respect for all aspects of human dignity, including worth, welfare, rights, beliefs, perceptions, customs and cultural heritage of all involved
> - respect the wishes, where known, of the deceased
> - give precedence to the needs of the potential donor and the family over the interests of organ procurement

[80] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 44.
[81] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation* 2010, p. 45.
[82] National Health and Medical Research Council, *Making a decision about organ and tissue donation after death, 2007.*
[83] National Health and Medical Research Council, *Organ and tissue donation after death, Guidelines*, 2007.

- as far as possible, protect recipients from harm
- recognise the needs of all those directly involved, including the donor, recipient, families, carers, friends and health professionals.

Organs and tissues should be allocated according to just and transparent processes.

The choice not to donate should be respected and the family shown understanding for the decision.[84]

As outlined in the ethical guidelines, 'ethical practice in donation involves respecting the needs of the bereaved family and carers.'[85] This is achieved by –

- being sensitive to cultural and spiritual differences that may affect decision-making
- providing information relevant to the particular situation
- offering bereavement counselling both at the time of death and later
- maintaining the confidentiality of both donor and recipient.[86]

This ethical framework ensures that the community can have faith and confidence in the organ donation and transplantation sector. It is essential that all of those involved uphold the integrity of these guidelines to ensure ongoing community support for this altruistic act.

3.4 Clinical guidelines

To support the legislative and ethical frameworks, clinical guidelines exist to provide advice on clinical processes. There are a number of clinical guidelines for organ and tissue donation and transplantation.

The Australian and New Zealand Intensive Care Society (ANZICS) publish *The ANZICS statement on death and organ donation*.[87] The purpose of this statement is to outline: the processes for the determination of death; both brain and cardiac death; the responsibilities of intensive care clinicians; and to provide guidelines for the donation after cardiac death pathway to organ donation.

The ANZICS statement on death and organ donation recommends the process for the determination of brain death as –

> Determination of brain death requires that there is unresponsive coma, the absence of brain-stem reflexes and the absence of respiratory centre function, in the clinical setting in which these findings are irreversible.[88]

The statement specifies that 'brain death is determined by: clinical testing if preconditions are met; or imaging that demonstrates the absence of intracranial blood flow.'[89]

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[84] National Health and Medical Research Council, *Organ and tissue donation after death, Guidelines*, 2007, p. 5.
[85] National Health and Medical Research Council, *Organ and tissue donation after death, Guidelines*, 2007, p. 13.
[86] National Health and Medical Research Council, *Organ and tissue donation after death, Guidelines*, 2007, p. 13.
[87] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation*, 2010.
[88] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation*, 2010, p. 15.
[89] Australian and New Zealand Intensive Care Society, *The ANZICS Statement on Death and Organ Donation*, 2010, p. 15.

The statement also provides guidance and outlines the key responsibilities of intensive care unit staff. The main areas of responsibility are focused around:

- responsibilities of intensivists in organ and tissue donation
- care of the dying patient
- care of the family
- recognising the possibility of organ and tissue donation
- determination of death
- liaison with donor coordinators
- discussing the option of organ and tissue donation with the family
- donor registries and other prior expressions of the potential donor
- confidentiality
- ongoing support of the family
- care and support of hospital staff.[90]

The statement outlines the principles for donation after cardiac death as well as how and when to raise donation after cardiac death with the family, the process for withdrawing treatment and finally the determination of death. (Refer to Chapter 6 for a further discussion on the donation after cardiac death pathway.)

The Transplantation Society of Australia and New Zealand (TSANZ) are responsible for providing protocols on the eligibility and allocation criteria of organs for transplantation. TSANZ has been developing these criteria for a number of years.

TSANZ received funding to develop a consensus statement on eligibility and allocation criteria as part of the national reform agenda. The main purpose was to develop 'nationally uniform eligibility criteria to ensure there are equitable and transparent criteria for listing patients for organ transplantation; and nationally uniform allocation protocols to ensure consistency across Australia in the criteria by which donated organs and tissues are allocated.'[91] Central to these protocols are the principles contained in the NHMRC ethical guidelines referred to earlier in this section. The statement outlines that –

> Organs will be allocated justly, following specific processes for each type of organ or tissue as well as criteria for matching the donation to the recipient.[92]

The overarching ethical framework of the TSANZ clinical guideline is to ensure people waiting for an organ transplant are in no way discriminated against. In addition, there are certain medical and clinical factors which may be taken into account to ensure the fair, equitable and transparent process of the allocation of organs for transplantation.[93]

These factors include:

- relative urgency of need
- medical factor which affect likelihood of success (e.g. tissue matching)
- relative severity of illness and disability

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[90] Australian and New Zealand Intensive Care Society. *The ANZICS Statement on Death and Organ Donation*, 2010, p. 25-36.
[91] Transplantation Society of Australia and New Zealand, *Consensus statement on eligibility criteria and allocation protocols*, 2011.
[92] Transplantation Society of Australia and New Zealand, *Consensus statement on eligibility criteria and allocation protocols*, 2011, p. vii.
[93] Transplantation Society of Australia and New Zealand, *Consensus statement on eligibility criteria and allocation protocols*, 2011, p. vii.

- relative length of time on the waiting list
- likelihood that the recipient will (be able to) comply with the necessary ongoing treatment after transplantation.[94]

The Australasian Transplant Coordinators Association produce national guidelines for organ and tissue donation which outline a number of areas of responsibility of transplant coordinators.[95] Some of these areas include: the definition of death; how to approach and support families of potential donors; provision of donor management guidelines; information on the logistics of coordinating organ donation; and tissue and corneal donation.

The National Protocol for Donation after Cardiac Death was published in July 2010 and outlines a number of ethical and clinical processes for the determination of donation after cardiac death. The protocol is based upon the aforementioned ethical principles provided by the NHMRC. Some of the key aspects of the protocol cover the prerequisites for donation after cardiac death which include:

- withdrawal of cardio-respiratory support
- consent for donation after cardiac death
- ante-mortem interventions
- timeframe for donation after cardiac death.[96]

The main ethical issues of donation after cardiac death which include:

- the end of life care
- respecting patient autonomy
- consent
- ante-mortem interventions
- determination of death.[97]

The protocol is discussed in more detail in Section 6.3.

[94] Transplantation Society of Australia and New Zealand, *Consensus statement on eligibility criteria and allocation protocols*, 2011, p. vii.
[95] Australasian Transplant Coordinators Association, *National guidelines for organ and tissue donation*, 2008, 4th Edition.
[96] Organ Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 9.
[97] Organ Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 41- 42.

Finding 11

Existing ethical and clinical guidelines for organ donation and transplantation are appropriate and should be maintained to ensure the continued operation of a fair, transparent and safe sector.

Finding 12

National Health and Medical Research Council ethical guidelines ensure that the community can have faith and confidence in the organ donation and transplantation sector. It is essential that the integrity of these guidelines are maintained to ensure the ongoing community support for organ donation.

Recommendation 5

That the relevant bodies including Australia and New Zealand Intensive Care Society, Transplantation Society of Australia and New Zealand, Australasian Transplant Coordinators Association and the National Health and Medical Research Council continue to maintain clinical and ethical guidelines and periodically review as required.

4. Consent models

An investigation into methods to increase organ donation rates will inevitably be required to consider various consent models, including the concept of presumed consent. Previous parliamentary reviews in other states have considered the merits of presumed consent, as have other jurisdictions overseas. The Committee received a significant volume of evidence on this issue of presumed consent. As this chapter outlines, the majority of evidence, particularly from key stakeholders, did not support a move to presumed consent in Victoria.

As discussed in Section 3.1, Australia and Victoria operate an informed consent model to organ and tissue donation. This means that individuals must explicitly provide their consent during their lifetime to donate organs and tissues upon their death. In other words, they must 'opt-in' to the organ donation system. Informed consent is governed in Australia by state and territory legislation. The contrasting model, as seen in countries such as Spain and Singapore is presumed consent, where every citizen is presumed to have given consent unless they have registered to 'opt-out' of the system.

The role of families differs among countries and consent models. Some consent systems place a greater emphasis on the views or consent of families (called 'soft' systems); others do not take family concerns into account at all (called 'hard' systems). Informed consent models in Australia, the United Kingdom and the United States all adopt a 'soft' approach in seeking the consent of the deceased's family for organ donation.

4.1 Informed consent

Informed consent models operate in most of Asia (except Singapore), the United Kingdom, the United States and Australia. As noted in Chapter 2, Australia's organ donation rate remains lower than other countries with an informed consent model.

4.1.2 United Kingdom

Organ donation and informed consent is governed by the relevant legislation. In 2006 the Organ Donation Taskforce (UK Taskforce) was established to review organ donation in the United Kingdom, including consideration of the merits of presumed consent.

The UK Taskforce reviewed the evidence of presumed consent (opt-out) and its possible introduction into the United Kingdom. They received evidence from a number of interested parties, those that supported an opt-out approach and those that supported a strengthened opt-in approach. The UK Taskforce made the following conclusion on opt-out systems –

> The Taskforce's members came to this review of presumed consent with an open mind, with many sympathetic to the view that presumed consent seems an obvious step forward. However, the more the Taskforce examined the evidence, the less obvious the benefit, and the more multifaceted and multidimensional the issue of increasing donor numbers was revealed to be. It became clear that what appears to be a simple idea to increase numbers may not in fact generate additional donors in sufficient numbers to justify the significant investment needed to put a new system in place. Moreover, there are risks in going down the opt-out route which could impact negatively on organ donation. The Taskforce reached a

> clear consensus in their recommendation that an opt-out system should not be introduced in the United Kingdom at the present time.[98]

Despite rejecting the introduction of presumed consent, the UK Taskforce made a series of recommendations beginning with the establishment of a United Kingdom-wide organ donation organisation. The remaining recommendations focused on the following areas:

- legal and ethical issues
- the role of the national health system
- organisation of co-ordination and retrieval
- training
- public recognition and public promotion of donation.[99]

Since the review in 2006 and adopting a more coordinated approach, organ donation rates in the United Kingdom have increased from 12.9 donors per million of population (dpmp) to 16.4 dpmp in 2010.[100]

4.1.2 United States

The United States' informed consent model to organ donation is enshrined within its *National Organ Transplant Act 1984*. The Act established the national network called the Organ Procurement and Transplantation Network and a third party organisation to administer the network: the United Network for Organ Sharing.

There are 59 Organ Procurement Organisations in the United States which are members of the Organ Procurement and Transplantation Network, 'that provide deceased donor organs for 287 transplant centres.'[101]

In 2003, the United States launched the Organ Donation Breakthrough Collaborative with the aim to 'dramatically increase access to transplantable organs'.[102] This was achieved by changing the way in which hospital staff and Organ Procurement Organisation staff worked together, effectively forming organ donation teams.

Following the implementation of the Collaborative, there was a clear improvement in organ donation rates in the United States. This increase can mainly be attributed to changes in clinical practice where Organ Procurement Organisations and hospitals collectively worked together to increase the conversion rate.[103] In 2003, the United States recorded a donor per million of population rate of 21.3 and by 2010 the dpmp rate had increased to 25.6.[104] This is 10.7 dpmp higher than the 2011 Australian rate of 14.9 dpmp.

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[98] UK Department of Health, *The potential impact of an opt-out system for organ donation in the UK – an independent report from the Organ Donation Taskforce*, 2008, p. 34.
[99] UK Department of Health, *Organs for Transplants, A report from the Organ Donation Taskforce*, 2008, p. 5.
[100] International Registry of Organ Donation and Transplantation, <http://www.tpm.org/>, accessed 12 December 2011.
[101] H Nathan, S Conrad, P J Held, K P McCullough, R E Pietroski, L A Siminoff and A O Ojo, 'Organ donation in the United States', *American Journal of Transplantation*, 2003, p. 3 (supplement 4) 28-40.
[102] T J Shafer, D Wagner, J Chessare, F A Zampiello, V McBride and J Perdue, 'Organ donation breakthrough collaborative: Increasing organ donation through system redesign', *Critical Care Nurse*, April 2006, Vol 26, No. 2, pp. 33-49.
[103] Australian Health Care Associates,*Mid-point Review Report*, 2011, p. 14 of Appendix 4.
[104] International Registry of Organ Donation and Transplantation, <http://www.tpm.org/>, accessed 12 October 2011.

4.2 Presumed consent models overseas

4.2.1 Spain

Spain is recognised as the world leader in organ donation rates. It enacted legislation in 1979 which introduced the presumed consent model of organ donation. In previous practice the medical profession always adopted the 'soft' approach to presumed consent, where consent is sought from families. If the family objects to donation, it does not proceed. After the introduction of the presumed consent legislation, there was little change in the organ donation rate in Spain. It was not until the late eighties that Spain saw a dramatic increase in the number of organs available for transplantation. Spain's success in organ donation is often attributed to the 'reorganisation of the Spanish organ procurement and donation system in 1989, [which led to] an increase in donation rates of more than 130 percent over the initial ten years of its operations.'[105]

In September 1989, Spain established the Organizacion Nacional de Trasplantes (ONT) within the government's health department. The ONT's role was to establish and develop a central point of responsibility within each hospital for organ donation. Elements of what is now referred to as the 'Spanish Model' includes:

- organ donor coordinators who report directly to the hospital medical director (not the transplant unit)
- carefully designed educational programs for medical staff
- carefully managed media relations
- close relationships with patient associations, judges, coroners and other social groups indirectly related to organ donation.[106]

There has been some suggestion that Spain's system of presumed consent is the major contributing factor to its high organ donor rates. The Committee's evidence indicates there is no direct link between Spain's presumed consent model and its donor rates.

The Victorian Minister for Health, the Hon. David Davis, referred to the Spanish model in his evidence to the Committee, noting the importance of family consent –

> For those who have opt-out presumed consent systems, there are a variety of legislative arrangements in place. Spain has been referred to, I know, a number of times with a very high organ donation rate of 34 per million in 2009. It is often cited as a success of presumed consent. I am not sure that is clear cut as some might imagine. Presumed consent operates with a family, of course, having practically a final consent; not as dissimilar as operates in Australia in any event. It is thought that the introduction of a national system in Spain may well have had the greatest impact on increased donor numbers.[107]

Kidney Health Australia also questioned the connection between presumed consent and Spain's donor rates –

> Spain introduced presumed consent legislation for organ donation in 1979, and the Spanish system is therefore universally described as an 'opt-out' system. The appeal of presumed consent legislation is based on the belief that if consent is a problem, presuming it will solve the problem. The misconception underlying this belief is that presumed consent equates with organ donation. 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 family. In Spain, the

[105] Australian Health Care Associates, *Mid-point Review Report*, 2011, p. 24 of Appendix 4.
[106] B Miranda, M Fernandez Lucas, C de Felipe, M Naya, M Gonzalez-Posada and R Matesanz, 'Organ donation in Spain', *Nephrology Dialysis Transplantation*, 1999, p. 14 (Suppl 3).
[107] Hon. David Davis, Minister for Health, *Transcript of Evidence*, 8 February 2012, p. 205

> family consent rate is 85 percent. 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).[108]

The Centre for Eye Research Australia further noted that –

> Eight of the top ten countries (for organ donor rates), including Spain, always seek consent or lack of objection to donation. This suggests there are many other factors besides legislation that affect donor rates and does not support the notion of introducing presumed consent laws to increase donation.[109]

4.2.2 Singapore

In Singapore, a 'hard' system of presumed consent is legislated in the *Human Organ Transplant Act 1987* (HOTA). Under this system, families are not consulted for consent and individuals must register their objection to HOTA if they do not wish to donate their organs.

In addition, Singapore provides incentives to those who donate organs. Article 12 of HOTA allows those who have not objected to receive priority access to organs for transplantation over those who have objected. Persons who have objected can obtain the same priority two years after they have withdrawn their objection. In addition to this priority system, the government has 'pledged to subsidise 50 percent of all medical expenses incurred at government hospitals for the immediate family members of organ donors.[110] This is effective for five years following a donation.

4.3 The presumed consent debate in Australia

A legislative framework which supports presumed consent allows organs to be removed from individuals upon death if they have not registered an objection. This model places an onus on individuals to register their objection to organ donation, often referred to as 'opting-out'. The issue of adopting an informed or presumed consent model has been debated for many years and is the subject of extensive literature.

A key issue in the Inquiry's terms of reference was to consider consent arrangements such as presumed consent. The Committee considered this to be an important issue to deliberate, however, as stated earlier almost all evidence received opposed the introduction of a presumed consent model in Victoria. It was also emphasised that individual states adopting a presumed consent model in isolation would be in contrast to the national approach.

The National Health and Medical Research Council (NHMRC), which sets the ethical framework for organ donation, raised concern over the concept of presumed consent –

> I would, on behalf of NHMRC, be respectfully urging caution about a presumed consent or opt-out type of model as a means for increasing the availability of organ donation. I see this as contradicting important ethical principles that the NHMRC has contained in its national statement and other documents — principles to do with the dignity of the person and respect for their body; principles of justice and

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[108] Kidney Health Australia, Submission No. 31, p. 11.
[109] Centre for Eye Research Australia, Submission No. 10, p. 2.
[110] B Teo, 'Organs for transplantation: the Singapore experience', *The Hastings Centre Report*, Vol 21, No. 6, p.10.

> beneficence; and most importantly the concept of informed consent and the idea of voluntary choice being an important underpinning ethical principle.[111]

Further to the discussion on the Spanish model, the Australian Medical Association, Victoria, noted that presumed consent models alone cannot be attributed to variations in organ donation rates and that other issues such as the availability of potential donors, infrastructure for transplantation services and public attitudes all play an important role in donation rates.[112]

The Victorian Minister for Health also observed that –

> Key opponents against opt-out would argue that health professionals would be reluctant to override family wishes in any event and that the introduction of the opt-out system may have a negative effect on donation rates; in one respect, if it is introduced without public support. There are the ethical considerations about individual autonomy, and some may not feel that it is a gift in the way that I think many people genuinely do feel with respect to organ donation.
>
> …
>
> There are a lot of different factors at work and I know you have become familiar with many of these: the need to increase community awareness of donation through education; reinforcing donor consent through family discussion; improved registration of the consent process; the strengthening of education of health professionals to assist them with family discussions—sometimes it is about guiding people and asking the questions that enable them as a family or as a group to frame discussions—and also the need to ensure that national organ and tissue donation systems operate in a coordinated way and a systemised way. I indicate quite strongly the state government does support the national arrangements. We see that there are opportunities for states to innovate within that and to show leadership roles and position, and we certainly would very much seek to do that. [113]

Parliamentary inquiries undertaken in Tasmania and Queensland in 2008 found that moving to a presumed consent model would not necessarily increase organ donor levels.[114] The Tasmanian Committee's report recommended the retention of the 'opt-in' system but with improved methods for registration including on-line registration and consultation with families. The Queensland Inquiry noted that 'a change in the consent system in one Australian jurisdiction at a time of substantial reform in organ and tissue donation and transplantation would risk creating community confusion about organ and tissue donation.'[115]

Other evidence highlighted that a presumed consent model would be a fundamental shift away from the notion of volunteerism or donation, to that of compulsion.[116]

The Committee received evidence from a number of religious groups who all supported the retention of the existing informed consent model to organ donation and strongly opposed a presumed consent model.

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[111] Professor Margaret Otlowski, National Health and Medical Research Council, *Transcript of Evidence*, 8 September 2011, p. 68.
[112] Australian Medical Association and Kidney Health Australia, Submissions Nos. 30 and 31, pp. 2-3.
[113] Hon. David Davis, Minister for Health, *Transcript of Evidence*, 8 February 2012, p. 205
[114] Parliament of Tasmania, Legislative Council Select Committee, *Organ Donation,* 2008.
[115] Legislative Assembly of Queensland, *Organ and Tissue Donation: Report of the Review of Organ and Tissue Donation Procedures Select Committee,* 2008, p. 11.
[116] Australian Medical Association, Victoria, Submission No. 30, p. 2.

The Catholic Church of Melbourne advised that it –

> … strongly opposes presumed consent or contracting out and seeks the removal of those provisions in the *Human Tissue Act 1982* (the Act) that allows a designated officer to give consent in the absence of being able to contact the family of the dying patient.[117]

The Catholic Archbishop of Melbourne does not 'consider that opting out or presumed consent is a factor in improving donation rates, and strongly support retaining contracting in and explicit consent requirement which are essential to preserving respect for the person who has died.'[118]

The Rabbinical Council of Victoria and the Jewish Community Council of Victoria both oppose the 'concept of presumed consent in the context of cadaveric organ donation.'[119]

Other Christian based churches and organisations outlined that the ethical integrity of the organ donation system is paramount to continued support from the community. The Catholic Church pointed out in their submission that 'the concepts of giving and receiving organs are humanly central to this issue which should never be just a matter of taking and getting organs.'[120] They go on to say that –

> Catholic teaching views the human body as sacred during life. Hence, the Church is concerned that the body which conveyed the intellect, heart, dignity, personality and spirituality of the human person during earthly life is not treated with disrespect in death. The body which is treated with respect and honour during life warrants the same respect and honour in death.[121]

Evidence from Prof. Fawcett, representing the Royal Australasian College of Surgeons provided a practical perspective of the impact adopting a presumed consent model may have on the transplant sector –

> There has been a question of whether there should be some system of presumed consent. In other words, unless one has specifically said in life and declared in an appropriate place, 'I do not want to be an organ donor', that one should be able to say we can always get those organs. In practice it would be very hard to go ahead and procure organs from a donor where they have said they are going to say yes and the family are all saying no. It would be devastating to the transplant community. You can imagine how that would go down. I think presumed consent is never going to run.[122]

Dr Graeme Pollock, Director of the Lions Eye Bank advised that 'donation needs to occur in a cooperative environment'[123] –

> [You] may formulate legislation that specifies the circumstances in which a donation is consented but you can't formulate legislation that dictates a donation must be accepted.[124]

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[117] Catholic Church, Submission No. 9, p. 8.
[118] Catholic Church, Submission No. 9, p. 6.
[119] Rabbinical Council of Victoria, Submission No. 27, p. 1. Jewish Community Council of Victoria, Submission No. 34, p. 1
[120] Catholic Church, Submission No. 9, p. 7.
[121] Catholic Church, Submission No. 9, p. 7.
[122] Professor Fawcett, Royal Australasian College of Surgeons, *Transcript of Evidence*, 21 September 2011, p. 126.
[123] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 80.
[124] Lions Eye Bank, presentation at 8 September 2011 public hearing, slide 8.

Organ transplant awareness and fundraising groups such as Transplant Australia and Zaidee's Rainbow Foundation did not completely dismiss the concept of presumed consent but believed the existing reforms should be given time to have an impact on donation rates and the public should be better educated on the merits of donation before considering such a significant legislative and policy shift.

With respect to presumed consent, Mr Chris Thomas, CEO Transplant Australia, concluded –

> … let's give the reform package the opportunities to succeed without imposing this quite radical shift; secondly, if at some stage in the future presumed consent is deemed to have a place in our donation system – and we would be supportive of that – let's make it a national model.[125]

Mr Allan Turner, CEO Zaidee's Rainbow Foundation stated -

> I do not swing either way when it comes to opt-out, opt-in. In a harsh sense I do not think at the moment we are ready for an opt-out.[126]

Mr Turner stressed the importance of registering to donate an organ and believed the community should not 'be told by the government what you should do at the time of death.'[127]

While government, medical and community organisations do not support the introduction of presumed consent at this stage, the Committee received evidence from some individuals who supported presumed consent. Most of these individuals have had a personal experience with organ donation, including some who are organ transplant recipients.

Ms Chloe Britton, a liver transplant recipient, recommended that 'governments should introduce a system of presumed consent, where it is assumed an individual wishes to be a donor unless he or she has 'opted-out' by registering their objection.'[128] Mr Peter Morey lost a relative who was on a transplant waiting list. Mr Morey's submission highlighted the costs associated with kidney dialysis treatment and believed the 'principle of assumed consent should apply in the community, and relevant legislation enacted to ensure this occurs throughout Australia.'[129] A submission from Ms Eleanor Morey noted that presumed consent for adults over the age of 35 could be considered.[130]

During the course of the Committee's Inquiry, Melbourne broadcaster Mr Derryn Hinch underwent a well publicised liver transplant after being on a transplant waiting list for some time. The Committee received correspondence from Ms Annette Philpott on behalf of Mr Hinch, outlining his strong support for the introduction of an 'opt-out' model. Mr Hinch believes the concept of opt-out should not be immediately dismissed by governments and authorities.

Significantly in 2008, the National Taskforce on Organ and Tissue Donation, recommended –

> … against the introduction of a presumed consent (opt-out) approach by any Australian state or territory. It is not expected that legislative change in isolation

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[125] Mr Chris Thomas, Transplant Australia, *Transcript of Evidence*, 25 August 2011, p. 21.
[126] Mr Allan Turner, Zaidee's Rainbow Foundation, *Transcript of Evidence*, 25 August 2011, p. 40.
[127] Mr Allan Turner, Zaidee's Rainbow Foundation, *Transcript of Evidence*, 25 August 2011, p. 38.
[128] Ms Chloe Britton and Ms Anne Rea, Submission No. 15, p. 1.
[129] Mr Peter Morey, Submission No. 7, p. 1.
[130] Ms Eleanor Morey, Submission No. 12, p. 1.

> can bring about a substantial increase in donation rates, as there are other relevant factors that can 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 decision and variations in mortality rates (such as road accident fatalities and stroke), 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 within the Australian community, which in relation to organ, eye and tissue donation needs to be countered through education and awareness campaigns (Eureka Strategic Research 2007). The Taskforce considers that a presumed consent system may feed these fears and most likely lead to an increase in the proportion of registrations of objections to donation. It might also lead to clinicians being less likely to proceed with initiating the donation process.[131]

The Western Australian Parliamentary Inquiry in 2000 proposed strong support for the introduction of a presumed consent approach, in view of the fact that statistics indicated up to 90 percent of Australians support organ donation.[132] The Committee recommended the Western Australian Minister for Health pursue the presumed consent model at a national level. The Western Australian Government did not proceed with the recommendation to pursue presumed consent.

More recently in Western Australia, a discussion paper was released in February 2011 which considered the adoption of a soft presumed consent approach. The paper does not actually recommend that the Western Australian government proceed with implementing a presumed consent model. It recommends that 'implementing an opting out policy for registration on the [Australian Organ Donor Register] AODR in Western Australia is a challenging but feasible project.'[133]

The paper suggests that 'if the opting out system is judged by the Executive and the Parliament to be a strategy whose time has not come or whose impact is too uncertain or small compared to the resource and political investment required, the current system of opting in should be pushed to its full potential by the use of community awareness raising.'[134]

In summary, the overwhelming evidence put to the committee rejected the introduction of a presumed consent system in Australia. The Committee formed the view that such a system lacks community support, may be counter-productive in a diverse multi-cultural community and is contrary to the notion of donating an organ as a 'gift of life'.

Finding 13

High donor rates in countries with presumed consent models can be attributed to a range of factors including: reforms to the hospital sector, improvements to transplantation services and increase community awareness.

[131] National Clinical Taskforce on Organ and Tissue Donation National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally, 2008, p.157.
[132] Parliament of Western Australia, Standing Committee on Uniform Legislation and Intergovernmental Agreements, *Inquiry into Organ Donation and Transplantation*.
[133] Prof. L Delriviere, Head of Liver & Kidney Surgical Tranpslant (SCGH), H Boronovskis, Manager DonateLife WA, February 2011, *Adopting an opt-out registration system for organ and tissue donation in Western Australia, a Discussion Paper,* p. 27.
[134] Prof. L Delriviere and H Boronovskis, *Adopting an opt-out registration system for organ and tissue donation in Western Australia, a Discussion Paper,* p. 27.

Finding 14

There is a lack of clear evidence internationally and within Australia to suggest that the introduction of presumed consent would directly lead to an increase in organ donation rates.

Finding 15

There is some community support for a move to presumed consent, most notably from individuals who have had a first-hand experience with transplant waiting lists, organ donation and transplantation.

Finding 16

The overwhelming evidence, including from government, medical and community groups, oppose the introduction of a presumed consent model in Victoria at this stage.

Recommendation 6

That the current system of informed consent (opt-in model) be maintained in Victoria.

5. Tissue donation in Victoria

While the Committee's terms of reference relate to organ donation, the Committee was of the view that it was equally important and relevant to include consideration of tissue and eye donation. The Organ and Tissue Authority and the DonateLife Network provide leadership to the organ and tissue sector and have a responsibility to increase donation rates and awareness for both organs and tissues. However, much of the discussion on donation rates has been limited to organs.

The following evidence from the Donor Tissue Bank of Victoria illustrates the lack of focus on tissue donation, despite the enormous benefits such donations and procedures can achieve. Prof. Stephen Cordner, Director of Victorian Institute of Forensic Medicine (VIFM) and Medical Director of the Donor Tissue Bank, said –

> Organs, of course, have got the space and have got the attention, because of their historical association with brain death, and that has occupied – and still does – the community interest intensely. We tend to be involved with those people who are traditionally dead, but we also get donated tissues from people who also donate organs. As you will hear, we also receive tissue from living people. Tissues can be life saving but are usually life enhancing. They can make a huge enhancement to life: skin for burns patients, and bone, which can stop you having an amputation. We have supplied bones that have replaced half of people's hips, the pelvis, a huge part of somebody's cranium for a disease they had – but that is not the usual thing; they are the headline sorts of uses of bone – and also, of course, heart valves. So we have supplied skin, bone and heart valves, and we help the Lions Eye Bank on occasion to obtain corneas. Over the years that we have been operating, about 15,000 patients, mainly in Victoria, have received human tissue.[135]

5.1 Donor Tissue Bank of Victoria

In Victoria, tissue donation is undertaken by the Donor Tissue Bank of Victoria (DTBV) which is established under the *Victorian Institute of Forensic Medicine Act 1985*, section 64(2)(i). The Institute's functions include: receiving tissue from living persons; removing and receiving tissue from deceased persons; removing or receiving tissue from another state or territory and receiving tissue in accordance with corresponding law of another country, all for the purpose of processing, storing or supplying tissue for transplantation. In addition the Donor Tissue Bank of Victoria is licensed by the *Therapeutic Goods Act (Cwth)*, as the manufacture of donated tissue into transplantable grafts is highly.

The DTBV is the only multi-tissue banking facility in Australia. 'DTBV manufactures transplantable grafts from donated bone, cardiac and skin tissue'.[136] Most other tissue banks in Australia are single tissue banks, that is, they only store and process a single tissue, for example heart valve banks or bone banks. In addition, the DTBV is the only operational skin bank in Australia.[137] So far in 2011, the DTBV has distributed over 800 tissue grafts for transplantation here in Victoria and other parts of Australia.

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[135] Professor Stephen Cordner, Victorian Institute of Forensic Medicine and Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 110.
[136] Donor Tissue Bank of Victoria, Submission No. 36, p. 1.
[137] Professor Stephen Cordner, Victorian Institute of Forensic Medicine and Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 111.

Tissue donation in Victoria is governed by the *Human Tissue Act 1982* and also interacts with the *Coroners Act 2008* when reportable deaths are made to the Victorian State Coroner.

5.2 Tissue donation facts and statistics

Evidence indicates there is an undersupply of tissues for transplantation. Moreover, the real demand for tissues is difficult to determine as many surgeons presently do not request tissues when needed as they are aware the supplies are too low.

Unlike organ donation, where an individual must be declared brain dead or cardiac dead, anyone can become a tissue donor. Tissues do not need to be transplanted within short time frames after being donated like solid organs. In fact, tissues can be collected up to 24 hours after death and stored for up to five years. A number of tissues can be donated and stored for future transplantation. These include:

- musculo-skeletal (bone, tendons, cartilage or ligaments)
- skin (the outermost layers only)
- cardiac tissue (pulmonary and aortic valves and pericardium).[138]

All of these tissues are collected from deceased donors.

Individuals can also be living donors and donate bone, (the femoral head) when undergoing hip replacement surgery. The living bone banking program at the Donor Tissue Bank of Victoria is very successful with on average, over 500 living bone donations per annum.[139]

Tissue donation can be identified in a number of ways. The donor can come from the hospital where both organ and tissue donation has been given under the circumstances of brain death or cardiac death. They can also occur from other deaths within the hospital or they can come from reportable deaths to the Coroner of Victoria.

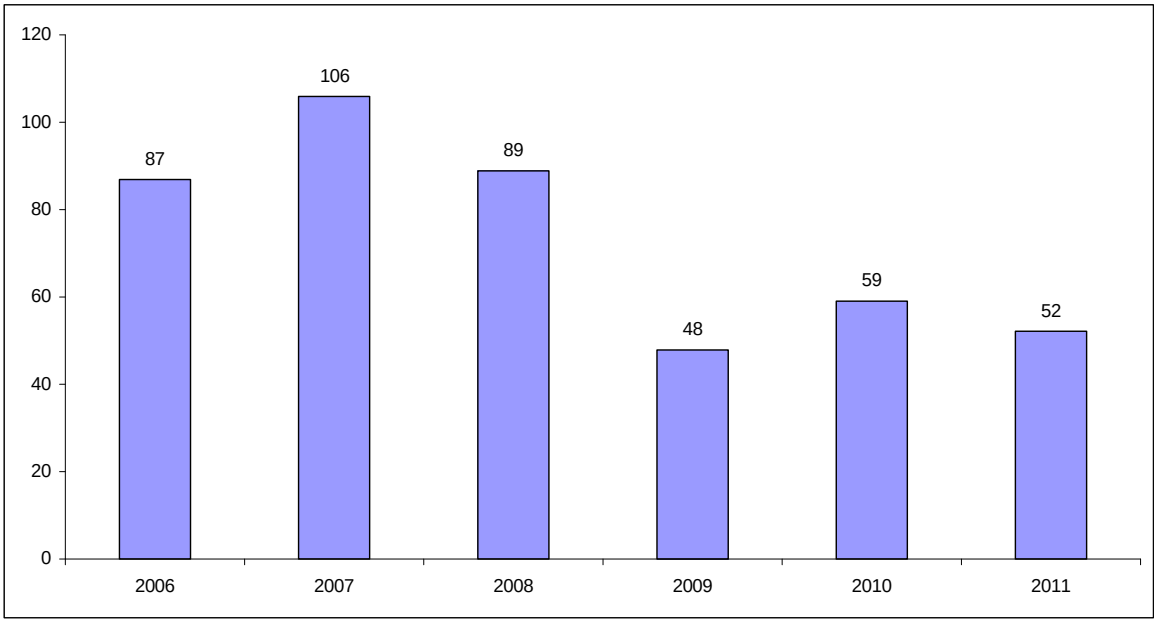
Data provided by the Donor Tissue Bank of Victoria shows that over the last five years the number of deceased donors has declined substantially. Figure 9 shows that in 2010 there were only 52 deceased donors.

Mr Stefan Poniatowski, Acting Head of the DTBV outlined the reasons for the decline over the last five years.

> Primarily what we saw with the instigation of the new Coroners Act was that there were changes as a result to us getting access to potential donors through the coroner system and whilst that system is bedded in. We also saw a suspension of some of our activities as a result of the Victorian bushfires where there was a limited capacity on what the Victorian Institute of Forensic Medicine could handle in terms of additional resources in order to maintain a tissue donation program. We saw a slight drop there, and both of those issues together saw a little bit of a drop-off in referral patterns as tissue donation particularly is not something you cannot turn on and off as to when the tissue bank can handle the cases. Because we are so reliant on so many agencies actually reporting potential cases to us and deaths to us, we really need to maintain a 24/7, 365-day service to ensure that basically those opportunities are followed up and those opportunities are not missed.[140]

[138] Donor Tissue Bank of Victoria, Submission No. 36, p. 2.
[139] Donor Tissue Bank of Victoria, presentation at 21 September 2011 public hearing, slide 13.
[140] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 113.

Figure 9. Total cadaveric tissue donors 2006 to 2011[141]



This dramatically contrasts with eye donation, where in 2010 there were 206 donors that provided 386 corneal transplants and 154 other operations.[142] In terms of donors per million of population, Australia fairs considerably well for corneal donations, ranking fifth amongst developed nations based on 2008 international data.[143]

Finding 17

Tissue donation plays an important role in saving and improving the lives of Victorians. The location of the Donation Tissue Bank of Victoria and the Lions Eye Donation Service in Victoria creates significant advantages for the state.

Finding 18

Recent years have seen a decline in cadaveric tissue donors which is in contrast to the recent increases in organ donors.

5.3 Issues for the tissue donation sector

In evidence to the Committee, the DTBV highlighted a number of issues that presents barriers to tissue donation including lack of focus on tissue donation in the implementation of the national reform agenda, legislative barriers, lack of public awareness of tissue donation and inadequate regional capacity for tissue donation.

5.3.1 Implementation of the national reform agenda

The DTBV stated that the implementation of the current national reform agenda for organ and tissue donation has had limited impact on increasing the tissue donation rate. They cite that –

> Tissue donation too often falls into the 'too hard basket' and is left as a second choice due to several factors:

[141] Donor Tissue Bank of Victoria, *presentation at* 21 September 2011, slide 12 and updated information in personal communication 13 March 2012.
[142] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 78.
[143] Lions Eye Bank, presentation at 8 September 2011 public hearing, slide 6.

- lack of awareness of donor families, ('we did not know that tissues could be donated – only organs')
- misinformation ('If I had known that it is not the whole skin, rather a very thin layer, I would have consented')
- professional awareness focus on organs rather than tissues (tissue donation is not highlighted in educational materials and sessions currently provided)
- fears of 'asking too much' ('the family had already consented to so many organs that to ask for tissues was too much')
- undervaluing the gift of tissue ('sorry, xxx cannot donate organs to save others lives … but can still donate bone…')
- the need to transfer the body to the IFM for tissue recovery; (in coronial cases this happens as a matter of course; in non-coronial, the transfer is an extra step)
- the need for an autopsy as a part of donor screening for bone and heart valve donation. (This requirement is under review by the DTBV's Medical Board).[144]

Even though the awareness campaign and work of the Organ and Tissue Authority is focussed on both organs and tissues, it is clear from the evidence received that the tissue donation sector is not experiencing similar increases in donation rates as is the case with organ donation.

It is however, a positive sign that the Chief Executive Officer of the Organ and Tissue Authority recognises that more work needs to be done in the promotion of tissue donation and that they have actively recognised this as a strategic priority for 2011-2012.[145] Ms Yael Cass, CEO of the Organ and Tissue Authority advised the Committee that 'integrat[ing] eye and tissue donation into our national organ donation system … is an area for significant additional work.'[146]

A significant barrier to tissue donation is community and industry awareness. Mr Stefan Poniatowski, Acting Head of the Donor Tissue Bank advised that –

> … there are other issues which are barriers to tissue donation. One of the main ones is increasing professional and public awareness about tissue donation. We still regularly go into hospitals and talk about tissue donation to health-care professionals who may use tissue within their practice but may not realise where it comes from or realise that this activity happens.
>
> There is also public expectation as to what happens after death and whether or not tissue donation is a potential option or not. For us it would be useful for tissue donation as well as organ donation to become the normalised process as part of the after-death care of both the deceased and the next of kin who are looking after the deceased. It would certainly help us if tissue donation, the approach to tissue donation and how tissue donation occurs was all understood within the community. That would make our process much easier in establishing consent and being able to undertake the procedure in the times that we require.[147]

[144] Donor Tissue Bank of Victoria, Submission No. 36, pp. 7-8.
[145] Ms Yael Cass, Organ and Tissue Authority, *Transcript of Evidence*, 25 August 2011, p. 4.
[146] Ms Yael Cass, Organ and Tissue Authority, *Transcript of Evidence*, 25 August 2011, p. 3.
[147] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 115.

Finding 19

Tissue donation has not benefited from the implementation of the national reform agenda in relation to public awareness to the same extent as organ donation. The importance of tissue donation should be included in all public awareness campaigns.

Recommendation 7

That DonateLife Victoria continue to work with the Donor Tissue Bank of Victoria to increase community awareness and the importance of tissue donation.

5.3.2 The Coroners Act and tissue donation

As with organ donation, tissue donation interacts with the *Coroners Act 2008 (Vic),* when reportable deaths are made to the Coroner's Office. Evidence from the DTBV highlighted the support the Victorian Coroner has for tissue donation, but indicated there are some procedural and timing issues which prohibit or make it difficult for tissue donation to occur.

Mr Stefan Poniatowski, Acting Head of the DTBV stated –

> The coroner undoubtedly supports donation, but there are conflicts with timing in particular. The coroner has a direct provision or requirement under the Coroners Act to establish the identity of the deceased and the cause and circumstances of death of the deceased, whereas we are looking for potential tissue donors, which has to be done in a timely manner. The time criticality of those two processes does not necessarily run hand-in-hand; there is a bit of a conflict with regard to how urgently the coroner needs to follow up or release a potential case to us and for us to be able to get tissue retrieval done within 24 hours of death. I suppose the key point is that although the coroner supports donation and certainly releases many cases to us, there is a timing issue, and under the Coroners Act there is no requirement for her or her team to actually refer us donors. As there is no requirement, there remains a conflicting priority.[148]

The Committee received further evidence from Dr Graeme Pollock, Director, Lions Eye Donation Service Melbourne outlining processes within the coronial system that makes it difficult for the retrieval of tissues for donation. Dr Pollock called for the amendment of the *Coroners Act 2008* to explicitly support organ and tissue donation, he stated –

> Just quickly regarding some simple things to increase donation, one of the things we could do with here is amending of the Coroners Act 2008 to explicitly support organ and tissue donation. There are some processes and things within the act that actually delay the donation process. We are especially feeling this in tissue donation at the moment. You do have a certain amount of time after the death of the patient whereby you have to undertake the donation. In the case of tissues, it is usually 24 hours. In our case, ideally, it is less than 18 hours. We are certainly now being pushed beyond this. There are donors who are not looked at in proceeding because we know that the coroner's process will take them outside of that framework in order to retrieve. The coroner has certain responsibilities that are dictated, but perhaps some amendment in the procedures, regulations, act or whatever could actually assist the coroner and us in streamlining the process so that we can actually accept donations.[149]

[148] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 113.
[149] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 80.

The Victorian State Coroner, Judge Jennifer Coate outlined the role the Coroner's Court in fulfilling its statutory requirements and the support it provides for organ and tissue donation –

> What I would like to convey in opening is I suppose what can be described as the balancing situation that we are in when people are brought into our jurisdiction. On the one hand we are acutely aware that there are some families who are strongly supportive of assisting in the donation of tissue and organs from their loved ones, who they have lost in reportable circumstances, because they know that has been consistent with their family member's wish during life or that it is something that the family have considered an appropriate thing to do in the wake of their loss. That will sometimes be conveyed to us.
>
> The other part of our balancing operation is that we as the independent investigators in the coronial jurisdiction are also charged with the statutory responsibility to independently investigate the cause of death, meaning the medical cause of death, and the circumstances in which the death occurred. We have to be sure that in the context of being asked to consent to tissue and organ donation we are not compromising our own statutory role and our own investigative role, and also to be very sure that the family do not assume that by engaging in tissue or organ donation they are complying with the wishes of the coroner and putting us into some potential conflict situation … In other words, we have to be scrupulously careful to stay away from conveying any such message.[150]

In response to the issue of the timeliness of tissue retrieval, the State Coroner advised –

> … I am well aware of some of the issues about timeliness. They have been brought to our attention, and we have met from time to time with the various agencies and sometimes some of the hospitals and individual medical practitioners involved in the donations. Indeed the formal written process that we have created has been in response to some of those concerns about timeliness. We have come to the view that some of the concerns about timeliness that have been expressed to us have been in the context of those involved in organ and tissue donation not really being fully aware of what it is that we are trying to do behind the scenes in our part of the process.
>
> …
>
> We are acutely aware of the time pressures. We have had lots of engagement with these agencies and we know there is a lot of time, people and money involved and they are very time crucial. But for us too that first 24 hours is understood as the golden period in terms of an investigation as well. What we lose in that first 24 hours we can never get back in terms of getting answers back to the families and the community in terms of our investigation. We are all engaged in a very delicate dance with each other at that time.[151]

To address concerns over timeliness raised by the DTBV, the Coroner highlighted that over the last 12 months a concerted effort has been made to both educate and raise the awareness of the requirements of the Coroner in investigating a reportable death. To address this the Coroner's Office has introduced a 'formalised, step-by-step process for all of those coming into [the Coroner's] jurisdiction.'[152] Judge Coate informed the Committee that this new process was developed in collaboration with the main agencies involved in organ and tissue donation and in their view has contributed significantly to the number of

[150] Judge. J. Coate, Coroners Court of Victoria, *Transcript of Evidence*, 2 December 2011, p. 184.
[151] Judge. J. Coate, Coroners Court of Victoria, *Transcript of Evidence*, 2 December 2011, p. 185.
[152] Judge. J. Coate, Coroners Court of Victoria, *Transcript of Evidence*, 2 December 2011, p. 184.

consent applications that has come before the Coroner up to the 2 December 2011 public hearing.

The DTBV called upon the Committee to amend the *Coroners Act 2008* to support organ and tissue donation. The DTBV stated in their written submission that –

> There is no clear mention of the important contribution of the Coroner in the consent process for organ and tissue donation – one that can influence the donation outcomes and support the wishes of the deceased and next of kin.[153]

The Donor Tissue Bank of Victoria proposed that –

> … a statement in the Coroners Act about the role of coroners in supporting the organ and tissue donation choice and following processes could assist Coroners in their ability to facilitate timely donations – making it clear that the public benefit of organ and tissue donation, and the wishes of the donation wishes of the deceased and their next of kin should be taken into account in balancing competing interests in the context of coronial death investigation, which may otherwise delay or preclude access to the organs and tissues.[154]

The Donor Tissue Bank of Victoria also believes that a conflict exists between the *Coroners Act 2008* and the *Human Tissue Act 1982*, with regard to who should be contacted for the identification of the deceased and who should be approached for consent to donation. In the *Coroners Act 2008*, the Coroner is required to contact the senior next of kin to establish the identity of the deceased. If the senior next of kin is unavailable the process of identification may be delayed. This delay may conflict with the DTBV which is required to contact the senior available next of kin in order to seek consent to donation.

The word 'available' in the *Human Tissue Act 1982* creates flexibility in the consent process. This flexibility is required to enable donation to occur within the required timelines The Committee's evidence suggests that the existing processes within the *Coroners Act 2008* are inflexible and can potentially delay the donation process.

The *Coroners Act 2008* does not specifically deal with the issues of availability of the senior next of kin. As a result interpretation of senior next of kin could potentially be disadvantageous to organ and tissue donation.

Dr Stefan Poniatowski, Acting Head of the DTBV stated –

> The main issue is in establishing contact with the senior next of kin. Both acts require contact with the senior next of kin available. For us, clearly who we can get hold of within a timely manner – within 24 hours of death – might mean that we not go for the senior next of kin to progress with donation, whereas for the people from the coroner's office, clearly under their requirements in the act to establish identity and cause of death they may be looking for the senior next of kin. The way the system is set up currently is that we cannot approach the next of kin until they have made initial contact, so whilst they are finding the senior next of kin we effectively cannot progress with tissue donation.[155]

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[153] Donor Tissue Bank of Victoria, Submission No. 36, p. 6.
[154] Donor Tissue Bank of Victoria, Submission No. 36, p. 6.
[155] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 114.

Finding 20

A potential impediment exists where the statutory requirements within the Victorian Coroner's Office may create time delays in facilitating tissue donation.

Recommendation 8

That key stakeholders including the Department of Health, Donor Tissue Bank of Victoria and the Victorian Coroner meet to clarify their respective roles, legislative requirements and processes in order to further facilitate timely tissue donations.

5.3.3 The Human Tissue Act and tissue donation

In order to facilitate tissue donation in Victoria, the DTBV employs tissue donor coordinators who are responsible for all aspects of the tissue donation process. These donor coordinators rely on DonateLife to assist in identifying potential donors in the hospital system and in making first contact with the potential donor's family. In other instances, the Donor Tissue Bank of Victoria donor coordinator liaises closely with the Coroner of Victoria to seek permission to approach potential donors of reportable deaths.

The Donor Tissue Bank of Victoria's submission highlighted that –

> With respect to hospital deaths, there is currently no formal pathway for routine identification and referral of potential tissue donors. Such formal pathways and mechanisms to coordinate the roles of DTBV, Lions Eye Bank and DonateLife and to raise the profile of tissue donation are necessary to increase the number of tissue donations emanating from hospital deaths.[156]

The Donor Tissue Bank of Victoria suggests that whilst the *Human Tissue Act 1982* enables DTBV to access information and perform the function of tissue donation, it does this on an entirely voluntary capacity; there is no requirement for deaths to be reported to the tissue bank. This makes the identification of potential tissue donors very difficult.

Mr Poniatowski noted –

> The tissue bank essentially relies entirely on voluntary notification, so although the Human Tissue Act is very good in that it actually allows us to access information, unless we know that somebody has died in order to request that information we are not in a position to progress with potential donor opportunities. I suppose it would be useful for us to have some kind of required notification to the tissue bank, as currently we require hospitals to make the choice to notify us or to set up independent programs out of hospitals. Essentially if they do not choose to do that or they do not have time to do that, there is no requirement for them to do that, and hence we lose potential opportunity.[157]

The Donor Tissue Bank of Victoria suggested the *Human Tissue Act* should be amended to mandate reporting of all hospital deaths to a central repository to facilitate identification of potential tissue donors.[158] Under the current system, if hospitals do not notify the Donor Tissue Bank of a death and the tissue bank does not have a strong relationship with the hospital, then there is potential for lost opportunity for tissue donation.

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[156] Donor Tissue Bank of Victoria, Submission No. 36, p. 3.
[157] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 114.
[158] Donor Tissue Bank of Victoria, Submission No. 36, p. 6.

The Committee sought further information from the Donor Tissue Bank on the possible costs or resources required to implement a direct reporting of deaths system. The Donor Tissue Bank of Victoria advised that –

> This is very difficult [to estimate], and is likely to vary from hospital to hospital. As mentioned, DTBV is shortly to sign an agreement with The Austin and The Alfred hospitals whereby they agree to implement a procedure to try and identify such deaths. In parallel, we have put in place a much less formal arrangement with St Vincent's hospital to try and achieve the same outcome. Time will tell if these approaches work. We do know in the United States that places with required report regimes do have higher tissue donation rates. A starting point for such a mechanism, would be easiest to implement, would be that only deaths in the emergency department and the Intensive Care Unit need to be reported. This is where most of the deaths occur and would reduce considerably the number of people to be apprised of the necessary arrangements.[159]

The Committee heard evidence from Dr Graeme Pollock, Director of the Lions Eye Bank on this same issue. Dr Pollock commented on the system in some hospitals within the United States which requires automatic notification of death. This system was implemented in the United States in 1998 by the Department of Health and requires hospitals to report all deaths to a donation service in a timely manner; if they do not, they can be fined.[160]

Dr Pollock noted that –

> When the US introduced that [rule] it got a small increase in organ donor numbers. I say 'small' but, in relative terms across the international community, it was rather significant. The US then came up to actually be, on a per million population basis, the second highest donating country in the world. There was a huge increase in tissue and eye donors … However, it is terribly inefficient and costly to do this. It needs a very large expansion of donation services and infrastructure to accommodate it.[161]

Dr Pollock provided an example of the size of resourcing this may require to be implemented in Victoria –

> … in Victoria we have about 25,000 deaths per year. Even if you had 17,500 reported, you are looking ultimately at two referrals every hour, every day. Those two referrals every hour, every day, have then got to be looked at by the donations services infrastructure as well. So not only do you need a call centre but you also need to expand your donation services infrastructure to do that. The trade-off of course is that it can result in many donors.[162]

Tissue and organ donation retrieval occurs at a difficult time for families, within very tight timeframes and relies heavily on key individuals and stakeholders having strong and collegial relationships to enable donation to occur. With this in mind, and in view of the strong reliance on relationships with hospitals and the Coroner's office, it is clear that for tissue donation rates to increase a more coordinated approach needs to be established among these key stakeholders.

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[159] Donor Tissue Bank of Victoria, *Answers to Questions on Notice*, 21 September 2011.
[160] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 80.
[161] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 80.
[162] Dr Graeme Pollock, Lions Eye Bank, *Transcript of Evidence*, 8 September 2011, p. 80.

Finding 21

With respect to the identification and retrieval of tissues for donation, the lack of a legal requirement or process for the notification of deaths to the Donor Tissue Bank or Lions Eye Donation Service may in fact delay the opportunity for tissue donation to occur.

5.3.4 Regional capacity for tissue donation

The Donor Tissue Bank has identified limitations in the regional capacity to collect tissues. Currently there is only one facility in Geelong at the Barwon Hospital which collects femoral heads from living donors, which are in most cases distributed locally.[163] Aside from Barwon Health, tissue collection is mainly an activity of metropolitan Melbourne. There are no deceased tissue collection programs in regional Victoria, despite the tissue bank presently suppling tissues to all regions of Victoria.

In their written submission, the DTBV suggested that with 'appropriate planning and resources a program could be developed to establish a regional collection and centralized multi-tissue processing model.'[164] In establishing this type of model, regional donors that are closer to Melbourne would be referred to the DTBV, other more remote donors would be referred to a local or mobile centre. This proposal would have the potential to significantly increase the number of tissue donors in Victoria.[165]

The Donor Tissue Bank also highlighted transportation costs of living tissue donations as an additional barrier to tissue collection.

> We are limited by transport infrastructure arrangements to enable us to get that tissue back to the institute in time for us to do the testing and so the blood is kept in a suitable condition and also so the microbiology testing and storing of the femoral head takes place within the time frames required.
>
> We currently use the rail system, which uses Green Star, which is operated by VLine, which I understand has, or has had, significant government subsidies to ensure that that continues to run. I understand that subsidy is being withdrawn, and as a result of that essentially that transport infrastructure using rail is not going to exist anymore. Therefore our only opportunity will be to ship that tissue – one single piece of bone – from regional Victoria to the tissue bank on the road. That incurs huge transit costs by using road couriers, and as a result it is likely that, again under a cost-recovery structure the cost of actually moving the tissue from outer Victoria into Melbourne makes it prohibitive to provide that service.[166]

[163] Donor Tissue Bank of Victoria, Submission No. 36, p. 8.
[164] Donor Tissue Bank of Victoria, Submission No. 36, p. 8.
[165] Donor Tissue Bank of Victoria, Submission No. 36, p. 8.
[166] Mr Stefan Poniatowski, Donor Tissue Bank of Victoria, *Transcript of Evidence*, 21 September 2011, p. 114.

Regional areas are faced with a number of constraints that limit their capacity to support the collection of tissues for transplantation. This is an important issue for regional Victoria and the Committee suggests work be undertaken to address these constraints.

Finding 22

There exists a number of constraints on tissue donation in regional areas, including the collection of tissue, transportation costs and lack of facilities to collect and process tissues in regional Victoria.

Recommendation 9

That the Victorian Government examine ways to improve access to the collected tissues for donation throughout regional Victoria, including the need to process tissues more efficiently and minimise transportation costs associated with tissue donation.

6. The clinical setting

6.1 Becoming an organ donor

As noted in Chapter 2, in 2011 there was a total of 337 organ donors in Australia; this illustrates that organ donation does not occur often. In addition to registering as an organ donor on the Australian Organ Donor Register, certain medical steps need to be fulfilled in order for donation to be possible. The act of registering does not guarantee that individuals will become donors upon their death. Evidence received from some of the medical professionals indicated that only one to two percent of deaths in a hospital can proceed to organ donation.

Dr Helen Opdam, State Medical Director for Organ and Tissue Donation, outlined the process of becoming an organ donor –

> A lot of people think because they put their hand up and say they are prepared to be a donor that they will be. In fact in order to donate after death you have to die under very specific circumstances for donation to be feasible. Only 1 percent to 2 percent of people who end up dying in hospital can technically donate. Were I to die in front of you now I could not donate organs because the blood would stop in my body, it would congeal in the organs and the organs would be unsuitable for people to receive as a transplant; they would not work.
>
> Who can be a donor? You have to be healthy enough so that your organs are of use to other people. If you have cancer, if you have a major untreated infection or if you are at risk of transmitting infections like HIV or hepatitis, you would be unsuitable. If you were in very poor health and your kidneys, your liver or your lungs did not work, they would be unsuitable as well. You basically have to have survived to have ended up on a mechanical ventilator with a breathing tube — that is, you are intubated, in hospital, in an emergency department or more commonly in an intensive care unit. And you have to have either developed a condition called 'brain death' or you have to be suitable for donating organs through this other pathway, the donation after cardiac death pathway.[167]

Given that the opportunity to become an organ donor is so infrequent, it is important that a number of measures are taken to enhance opportunities for donors within the clinical setting. This chapter will consider ways to increase the donor pool including opportunities in donation after cardiac death and living donation programs. Consideration is also given to matters such as organ retrieval processes, regional issues and the need for improved data collection.

Chapter 3 discussed the process of seeking consent from families for organ and tissue donation. It highlighted that in most instances donation will not proceed without the consent of the deceased's family. This is the accepted medical practice in Australia.

[167] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 43.

6.2 Increasing the donor pool

Dr Helen Opdam outlined some strategies that can assist in increasing the donor pool:

Expanding medical suitability criteria

The donor pool could be increased by expanding the medical suitability criteria in order to become an organ donor. The medical suitability criteria outlines the broad parameters in which organ donation can be considered. In recent years this has meant increasing the number of marginal and higher risk donors. Marginal donors can include older donors up to the age of 80 and people who may have 'more borderline health' issues.[168] Ten years ago, the upper age limit would have been around 70 years of age and more complicated health issues would have meant a person would not have been considered suitable.

Identifying all potential donors

Another way to increase the donor pool is to ensure all potential donors are identified. As part of the implementation of the national reform agenda, the process of 'clinical triggers' was established. This system reminds clinicians to consider organ donation when dealing with end of life care decisions with patients. Following the identification of a potential donor, it is important that the option for organ donation is raised with the family.

An area of development has been the introduction on a national level of hospital death audits. This initiative commenced in Victoria and was expanded during the National Organ Donation Collaborative.[169] It has recently been formally introduced as part of the implementation of the national reform agenda.

Hospital audits are important as they provide an opportunity to determine if there have been any missed donation opportunities. The conduct of audits also enables the hospital to determine rates of request for donation and rates of consent of donation. These results can help to determine why the opportunity was missed, if there are any barriers to donation within the hospital and what strategies can be implemented in the hospital to remove those barriers to donation.[170]

Dr Opdam provided the Committee with a case study as an example of the sort of cases that are identified as part of the audit process. These cases are used in training and raising awareness among hospital staff with the view to removing barriers to donation within the hospital system. [171] Dr Opdam advised the Committee that these are the sort of cases clinicians will be required to investigate in order to further increase the organ donation rate. These cases are extremely complex and require highly skilled clinicians to manage.

Obtaining higher consent rates is the final way in which the organ donation rate can be increased. Dr Opdam explained that from the hospital death audit process they have found the consent rate to be 57 percent, meaning that only one in two families consent to organ donation.[172]

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[168] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 46.
[169] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 47.
[170] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 47.
[171] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, pp. 47-48.
[172] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 48.

Dr Opdam advised that –

> This is much lower than if you survey the public or when you ask someone, 'Are you willing to be a donor or consent to your relative donating?', and the answer is 'Yes, sure'. Ask the same question of an acutely bereaved family within hours or days of them having to come to terms with the loss of someone they dearly love, and then explain the additional time frames and the detailed aspects of what is required of them for them to agree to donate, it is a different story.[173]

A critical aspect of consent relates to whether the family has discussed organ donation before. Dr Opdam explained most families 'want to honour the wishes of the person they love … if the family knows that the individual … wanted to donate, generally they will agree.'[174]

Evidence indicated that the consent rate would be higher when the request for donation conversation was initiated by a senior, more experienced clinician. This is just one of many factors that can influence the decision a family makes when asked to consent to donation. A detailed discussion of family consent rates and factors influencing their decision is contained in Section 3.1.

Australia is addressing the issue of consent rates through a national awareness campaign managed by DonateLife to raise awareness about having discussions with family about organ donation and an individual's wishes. This is discussed in more detail in Chapter 8.

6.3 Donation after cardiac death

Donation after cardiac death is a relatively new pathway which has been implemented in Victorian hospitals as an alternative method for increasing organ donation. Donation after cardiac death is defined in the *Human Tissue Act 1982* as 'the irreversible cessation of circulation of blood in the body of the person.'[175] In the past it was often referred to as non-heart beating donation.

Before the brain death definition was brought into practice, most organs were removed upon circulatory arrest. Donation after cardiac death is ethically and clinically accepted when the necessary guidelines are followed.[176] The important factor to consider with donation after cardiac death is that the decision to discontinue life support must be made independently of the donation process. At all times the patient's best interest is the priority.

6.3.1 Donation after cardiac death policy framework

As part of the national reform agenda, the Organ and Tissue Authority released a National Protocol for Donation after Cardiac Death in July 2010.[177] This protocol was developed in conjunction with the National Health and Medical Research Council's National Institute of Clinical Studies and leading clinicians in organ and tissue donation, transplantation and acute care sectors.[178] The protocol has been informed by the ANZICS Statement on Death and Organ Donation, the New South Wales Department of Health Organ Donation after

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[173] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 48.
[174] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 48.
[175] *Human Tissue Act 1982,* s. 41.
[176] Australian and New Zealand Intensive Care Society. *The ANZICS Statement on Death and Organ Donation,* 2010, p. 45.
[177] Organ and Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 9.
[178] Organ and Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 5.

Cardiac Death guideline and the NHMRC ethical guidelines.[179] The purpose of the protocol 'is to outline an ethical process that respects the rights of the patient and ensures clinical consistency, effectiveness and safety for both donors and recipients. This protocol provides a detailed framework for practice, which has a strong emphasis on communication and consistency and aspires to avoid any potential harm to patients, their families, recipients and the healthcare team.'[180]

As described in the protocol, donation after cardiac death is 'complex and raises significant ethical and logistical concerns.'[181] The ethical principles underpinning the guidelines are:

> Donation of organs and tissues is an act of altruism and human solidarity that potentially benefits those in medical need and society as a whole.
>
> Organs and tissues for transplantation should be obtained in ways that:
>
> - demonstrate the respect for all aspects of human dignity, including worth, welfare, rights, beliefs, perceptions, customs and cultural heritage of all involved;
> - respect the wishes, where known, of the deceased;
> - give precedence to the needs of the potential donor and the family over the interests of organ procurement;
> - as far as possible, protect recipients from harm; and
> - recognise the needs of all those directly involved, including the donor, recipient, families, carers, friends and health professionals.
>
> Organs and tissues should be allocated according to just and transparent processes.
>
> The choice not to donate should be respected and the family shown understanding for the decision.[182]

The protocol also outlines key requirements to facilitate donation after cardiac death. In the first instance, the withdrawal of cardio-respiratory support may only occur if the continuation of treatment will not lead to the patient's health improving, or continuing with treatment is not in the patient's interest. The decision must always reflect the best interest of the patient.

Once cardio-respiratory support is withdrawn, consent to organ donation can be sought from the patient's family. This can only occur once the decision to cease cardio-respiratory support has been made. If donation after cardiac death is to proceed, a number of additional medical processes are required. Ante-mortem interventions are performed for the benefit of potential recipients rather than the donor patient.

Finally, donation after cardiac death will only proceed if the patient dies within a specified timeframe (up to 90 minutes) to enable successful donation. Donation after cardiac death can only proceed if all of the above criteria are met.

6.3.2 Implementation of donation after cardiac death in Victoria

The Committee's evidence indicates that the implementation of donation after cardiac death pathway programs are contributing significantly to the organ donation rate in

[179] Organ and Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 4.
[180] Organ and Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 5.
[181] Organ and Tissue Authority, *National Protocol for Donation after Cardiac Death*, 2010, p. 8.
[182] National Health and Medical Research Council, *Organ and tissue donation: Guidelines*, 2007, p. 5.

Victoria and that organ donation rates should increase further as donation after cardiac death programs are implemented more broadly across the Victorian hospital network.[183] Figure 10 illustrates the increase in donations after cardiac death in Victoria. Since 2007 there has been a marked increase in donations through this pathway. The Committee notes that the hospitals which have implemented donation after cardiac death programs have made significant progress.

Figure 10. Donors following cardiac death in Victoria – 2006 to 2011[184]

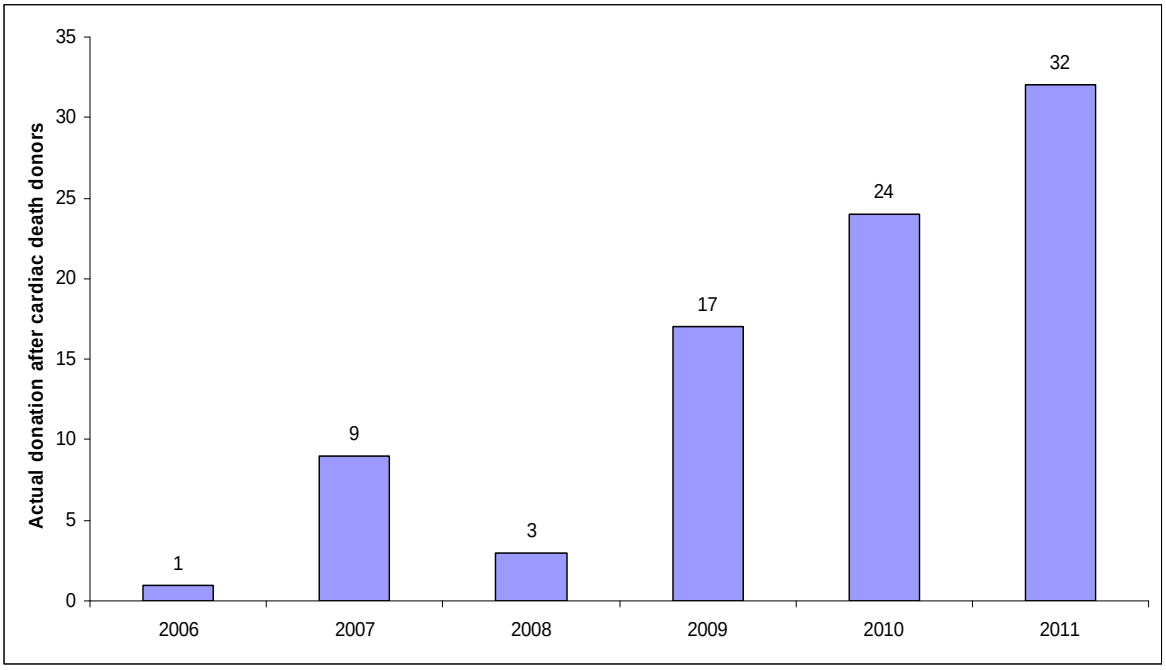
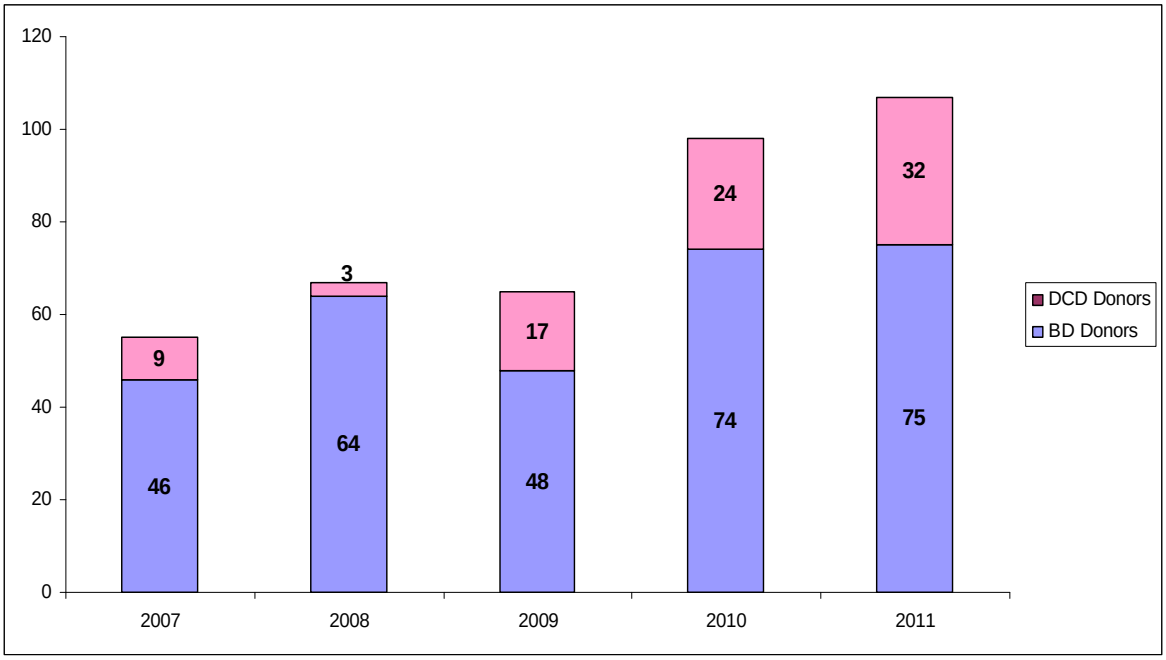


Figure 11 clearly demonstrates the significant impact and proportion that the donation after cardiac death programs are having on the total number of deceased donors in Victoria. The introduction and focus on donation after cardiac death as an alternative pathway to donation is welcomed in increasing the overall donation rate in Victoria. The Committee acknowledges there are inherent complexities in the donation after cardiac death process and there may be some sensitivities and misunderstanding within the community on these issues. Given that donation after cardiac death is now more commonplace, the Committee considers it is important and a valuable exercise for the community to be better informed of the processes involved in donation after cardiac death as it differs significantly from the better understood processes of brain death donation.

[183] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 46.
[184] L Excell, L Hee, and G Russ, *ANZOD Registry Reports 2008 – 2011* and *ANZOD monthly updates for 2011*, Australia and New Zealand Organ Donation Registry, (Data compiled from Annual Reports 2007 to 2011 and monthly updates in 2011).

Figure 11. Brain death and donation after cardiac death donors in Victoria – 2007 to 2011[185]



Finding 23

Historically the main pathway to donation was through the brain death criteria. More recently the donation after cardiac death pathway has been introduced. This pathway is inherently more complex and differs significantly from the well understood processes of brain death donation. The community would benefit from further education on the different processes involved in donation after cardiac death.

Finding 24

The introduction of donation after cardiac death programs have substantially contributed to the recent increase in the organ donation rate in Victoria.

Recommendation 10

That the donation after cardiac death program continue to be implemented across appropriate Victorian hospitals to further improve the opportunity for deceased organ donation in Victoria.

6.4 Living donation

6.4.1 Living donation: facts and statistics

The Committee's evidence indicates that an increasing opportunity exists in the area of living donation, notwithstanding the need to maintain strict eligibility criteria. However, evidence suggests greater incentives are required in order to further enhance the number of living donors.

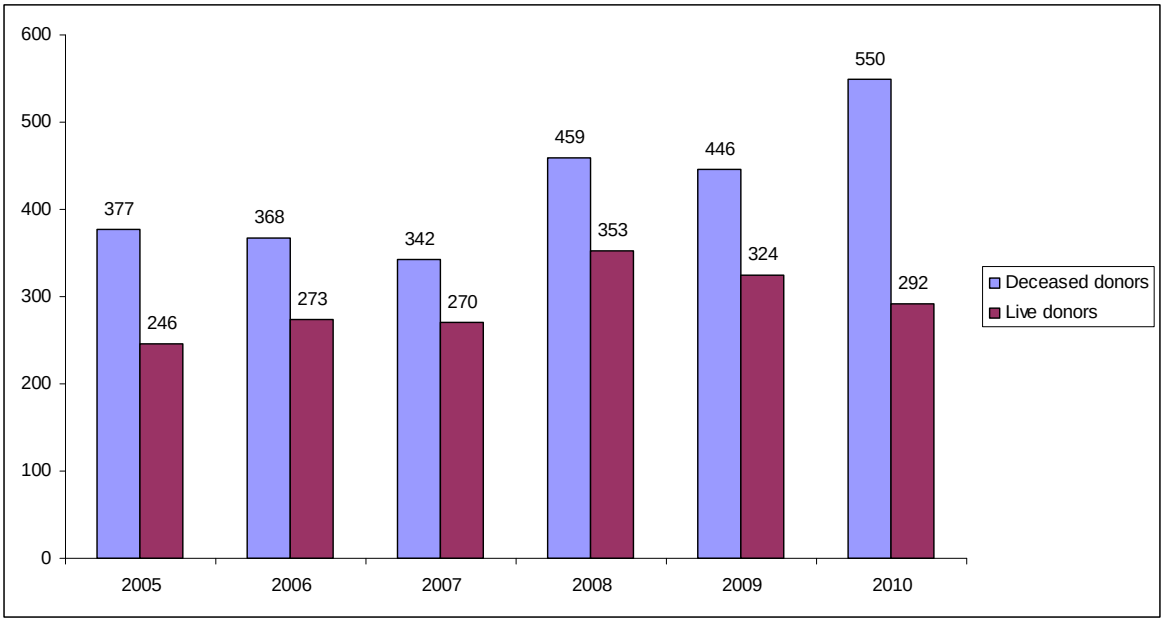
The National Health and Medical Research Council (NHMRC) have established ethical guidelines governing living organ and tissue donation. The guidelines state that living

[185] L Excell, L Hee, and G Russ, *ANZOD Registry Reports 2008 – 2011* and *ANZOD monthly updates for 2011*, Australia and New Zealand Organ Donation Registry, (Data compiled from Annual Reports 2007 to 2011 and monthly updates in 2011).

donation is only possible if the donor can still live healthily without that organ or tissue. The NHMRC note that many types of living donation are of regenerative tissue. This type of tissue grows back naturally after some of it is removed. Kidney donation is the most common form of this type of donation. It is also possible to transplant a part of the liver. Living donation can only proceed after a number of medical and legal criteria are satisfied. Criteria and practices dealing with living donors are dealt with later in this chapter.

In 2011, there were approximately 370 people in Victoria waiting for a kidney transplant and over 1200 throughout Australia. Despite an increase in deceased organ donors, these large waiting lists have lead to an increasing number of living donors, particularly living kidney donors. Data released in 2010 by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) confirm this trend. Figure 12 shows the number of living kidney donors compared with the number of deceased kidney donors from 2005 to 2009 in Australia. It is clear from Figure 12 that living donations are generally increasing every year, except for in 2007 and 2009 where there was a minor dip. In 2010, living donors accounted for 42 percent of total kidney donors.

Figure 12. Number of living and deceased kidney donors 2005 – 2010 in Australia[186]



Data from Kidney Health Australia showed that in 2009, the average age of a living donor was 54.50 years, with the youngest donor at 30.35 years and the oldest at 76.91 years.[187]

Kidney Health Australia advised that live donor recipients 'have an increased life expectancy by [more] than 12 years over deceased donors.'[188] Other benefits of receiving a living donor transplant include:

- Reduced rate of death
- Longer duration of functioning of the transplanted kidney
- Avoidance of the psychosocial and economic impact of dialysis.[189]

[186] L Excell, L Hee, and G Russ, *ANZOD Registry Reports 2008 – 2011* and *ANZOD monthly updates for 2011*, Australia and New Zealand Organ Donation Registry, 2011 (Data compiled from ANZOD Annual Reports 2006 to 2011 and monthly updates in 2011, note this data is based on information from the living kidney donor registry as cited in ANZOD reports).
[187] Kidney Health Australia, *Answers to Questions on Notice*, 21 September 2011.
[188] Kidney Health Australia, presentation at public hearing on 21 September 2011, slide 5.
[189] Kidney Health Australia, presentation at public hearing on 21 September 2011, slide 5.

Finding 25

As organ transplant waiting lists remain high, living kidney and liver donation has become more common. Evidence suggests that living organ transplants are likely to have improved success outcomes.

6.4.2 Principles and practices

The Committee believes there are benefits in increasing the number of living donors but is mindful that there should be a continued effort to increase deceased donation where possible.

The Committee received a written submission from Mr Kevin Stubbs who outlined his experience as a living liver donor in Canada several years ago. Mr Stubbs raised several concerns and questions over the existing living liver donation practice in Victoria including possible hospital restrictions on certain living donors and reluctance to accept donations from non-relatives. No further evidence was received with respect to any real or perceived limitations on living organ donors, however it is worth pointing out the relevant principles and practices operating within Australian hospitals.

As noted above, living donation is possible from both related and non-related donors, however an operation will not proceed until strict medical and legal criteria have been met. There must be no evidence of coercion, monetary payment or reward and the donor must have full knowledge of the risks and benefits of the donation.[190]

Each hospital transplant unit develops policies regarding the application of living donors with the underlying principle that any risk to the donor is justified by the expectation of an acceptable outcome for the recipient.

The NHMRC guidelines stipulate that important ethical standards must be met before living donation can proceed. These include:

- donors must understand and accept the risk to themselves
- there must be a very low chance of harm to the donor's physical or mental health, straight away or in the future
- there must be a very high chance that the transplant will be successful.[191]

Hospital transplant units will always consider the wellbeing of a potential donor above the health of the person who needs the transplant. Potential living donors will undergo mental health and social assessments together with a comprehensive medical assessment to determine organ matching suitability and potential physical health problems after the donation.

The Committee is mindful that the above guidelines and internal hospital practices and policies are an important safeguard with respect to the living donor processes. The Committee does not believe these guidelines and policies should be eased in order to increase the number of living organ donors.

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[190] DonateLife, 2011, *Your questions answered*, <http://www.donatelife.gov.au/index.php?option=com_content&view=article&id=770&Itemid=165>, accessed 19 January 2012.

[191] National Health and Medical Research Council, *Making a decision about organ and tissue donation after death*, 2007, p. 4.

Finding 26

It is important that guidelines and hospital practices and processes that pertain to living donation contain safeguards for the potential living donor. The health and safety of the living donor is paramount. These guidelines and practices should not be eased in order to increase the number of living organ donors.

6.4.3 Paired Kidney Exchange Program

In order to further support living donation in Australia, the Organ and Tissue Authority have established a program called the Paired Kidney Exchange (APX) Program. This program is designed to 'increase live kidney donor transplants by identifying matches for incompatible donor/recipient pairs.'[192]

This national program and database matches otherwise incompatible potential living donors with a compatible potential recipient. It requires 'pairs' of potential donors and organ recipients to register together with the hope that a compatible 'pair' can be found. By registering as an incompatible potential living donor and recipient pair, the computer database will search for matches of both the living donor and potential donor recipient pair. If no match is found, the 'pair' will remain on the database until a potential match is found in the future.

The DonateLife website states that even if a person is identified as a possible donor/recipient match, the transplant may not proceed, as there are a number of physical and psychological issues to that need to be taken into account, including the complex nature of this exchange.[193] If however, a match is found for the living donor and recipient pair, further testing is undertaken to ensure the recipient and potential donor are compatible. Consultation is held with both recipient and living donor and once consent to the operation is agreed only then will the transplant occur.

6.4.4 Living donor reimbursement scheme

Evidence from witnesses including Kidney Health Australia and Transplant Australia highlighted that there are considerable financial barriers which prevent more people becoming living donors. Kidney Health Australia noted the benefits of pre-emptive transplantation, that is, 'transplantation shortly prior to reaching end-stage kidney disease,[194] but noted existing financial barriers create limitations –

> Overseas research has found that 45 percent of donors experience some financial hardship. 24 percent of potential living donors chose not to donate because of anticipated financial hardship. We receive calls regularly from people who want to donate a kidney to a loved one but cannot do so because of financial reasons.[195]

Kidney Health suggested 'the Victorian government … consider introducing organ donation leave for public servants.'[196] It was pointed out that 'the ACT government is the only jurisdiction in Australia that provides up to three months [paid] leave for employees who donate an organ.'[197]

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[192] DonateLife, 2011, *The Australian Paired Kidney Exchange Program*, <http://www.donatelife.gov.au/the-authority/the-australian-paired-kidney-exchange-program/information-for-patients-and-willing-living-donors>, accessed 19 January 2012.
[193] DonateLife, 2011, *The Australian Paired Kidney Exchange Program.*
[194] Ms K. Johnson, Kidney Health Australia, *Transcript of Evidence*, 21 September 2011, p. 147.
[195] Ms K. Johnson, Kidney Health Australia, *Transcript of Evidence*, 21 September 2011 p. 148.
[196] Ms K. Johnson, Kidney Health Australia, *Transcript of Evidence*, 21 September 2011 p. 148.
[197] Ms K. Johnson, Kidney Health Australia, *Transcript of Evidence*, 21 September 2011 p. 148.

Kidney Health believes one of the reasons Australia's organ donation rates are low on an international comparison is because Australia does not have a 'government funded expense reimbursement program for live donors',[198] as exists in many other countries.

The United States introduced a living donor reimbursement program in 2007 with a cap of $6,000. Similar schemes in Canada are capped at $5,500. In New Zealand, a financial assistance program was introduced in 2005 and provides assistance for loss of income and child care costs associated with being a living donor. The New Zealand program consists of payments over a 12 week period. Since the New Zealand program began, there has been a 25 percent increase in the use of the program.

In Australia, the only state with a reimbursement scheme is Western Australia. The program Western Australia Country Health Service was introduced in 2006 and covers accommodation, meals and travel costs for those going to Perth to donate as a living donor.

The Committee notes the existence of the Victorian Patient Transport Assistance Scheme (VPTAS) which offers travel and accommodation support for eligible rural Victorians travelling more than 100 kilometres one way or 500 kilometres on average for a minimum of five weeks in order receive medical treatment which satisfies the medical criteria of the VTPAS.[199] Rural Victorians required to travel to participate in an organ transplant are eligible for VTPAS assistance.[200]

Kidney Health highlighted that this reimbursement is insufficient and does not adequately cover the cost of accommodation, leaving significant out-of-pocket costs for donors.[201] Kidney Health suggested this Victorian program be reviewed and more assistance be provided to donors. Witnesses pointed out that a reimbursement scheme of up to $10,000 would be a small expense for the government when compared to the significant costs of ongoing dialysis treatment.[202]

Transplant Australia noted that –

> In Australia we have had reports of discrimination where employers refuse to allow someone sick leave to donate their kidney to a family friend, their daughter or their son, and they have refused to allow them to take sick leave because, 'you're not sick'. If we take the overseas experience, it is possible that we could transplant another 70 patients a year in Australia or 25 in Victoria, simply by promising to cover out-of-pocket expenses and loss of wages. That should not be confused with financial incentives in organ and tissue donation. It is accepted in many countries across the world.[203]

Alfred Health commented that –

> There should be resources available to facilitate removal of organs from living donors. Currently donors may face hardship and costs (travel, time off work,

[198] Ms K. Johnson, Kidney Health Australia, *Transcript of Evidence*, 21 September 2011 p. 148.
[199] Department of Health, *Victorian patient transport assistance scheme (VPTAS) guidelines*, 2009, p. 2.
[200] Department of Health, *Victorian patient transport assistance scheme (VPTAS) guidelines*, 2009 p.7.
[201] Department of Health, *Victorian patient transport assistance scheme (VPTAS) guidelines*, 2009, p. 4.
[202] Mr C. Thomas, Transplant Australia, *Transcript of Evidence*, 25 August 2011, p. 23.
[203] Mr C. Thomas, Transplant Australia, *Transcript of Evidence*, 25 August 2011, p. 21.

medical costs) in assisting in a lifesaving transplant, particularly donors who are not Australian citizens.[204]

Finding 27

Personal expenses associated with living donation, including cost of travel, meals, accommodation, loss of income and childcare, are limiting factors to people becoming living donors.

Recommendation 11

That the Victorian Government consider, in consultation with DonateLife Victoria, the introduction of a reimbursement scheme for living donors which would cover reasonable associated expenses such as, accommodation, transport, meals, loss of income from time off work and childcare.

6.5 State-wide organ retrieval service

Prof. Bob Jones, Head of Liver Transplant Unit at the Austin Hospital, suggested that Victoria needs a centralised organ retrieval team to coordinate and undertake organ retrieval operations. He stated that currently The Austin and Royal Children's Hospital undertakes 80 percent of all organ retrieval in Victoria and Tasmania.[205] As part of this role, these teams travel interstate and to New Zealand sometimes to retrieve organs. Prof. Jones identified that trying to provide this service under the current funding arrangements and with the growth in organ donor numbers is proving difficult. Most of the staff undertaking these procedures do so voluntarily and in addition to their normal duties. This places further resourcing constraints on the hospitals they come from as their absence from normal duties needs to be filled.

Prof. Jones recommended to the Committee that Victoria should have a state-wide organ retrieval service. This service would have designated staff, a separate budget and would be sitting outside the general operations of the hospital. This would enable surgeons from other hospitals to be involved. It would however, require a hospital to host the service.[206]

Finding 28

Evidence presented to the Committee proposed that Victoria would benefit from a centralised organ retrieval service.

Recommendation 12

That the Victorian Government consider the proposal to establish a coordinated organ retrieval service in Victoria.

6.6 Regional issues

The Committee's evidence has highlighted some barriers which restrict the ability of regional hospitals to deliver organ donation programs. The State Medical Director of Organ and Tissue Donation stated that one area which is difficult for regional hospitals, is the provision of Donation after Cardiac Death (DCD) programs. There are a small number of cases for donation after cardiac death in regional hospitals and the implementation of

[204] Alfred Health, Submission No. 11, p. 10.
[205] Prof. Bob Jones, Austin Hospital, *Transcript of Evidence*, 8 September 2011, p. 89.
[206] Prof. Bob Jones, Austin Hospital, *Transcript of Evidence*, 8 September 2011, p. 90.

DCD programs can be costly and resource intensive. As a consequence DCD programs are not being encouraged within regional hospitals.[207]

Dr Opdam recommended that given there are constraints on the use of surgical retrieval teams, potential donors could be transferred to a metropolitan hospital to undertake the donation process. However, in this instance the regional hospital would be required to pay the ambulance transport costs, which for example can be in the order of $10,000 to $15,000 from Mildura to Melbourne.

Dr Opdam explained that regional transportation is costly for a small hospital that may already be experiencing budget constraints, and could create a barrier to proceeding with donation. Dr Opdam advised that 'if we could come up with some way of removing that cost barrier, I think we would give more regional people and their families the opportunity to donate, and that of course would benefit people who require transplantation.'[208]

Prof. Bob Jones suggested that transferring potential regional donors to metropolitan hospitals may not be appropriate. Instead effort should be made to ensure hospitals have the capability for organ donation, with support from limited external teams. This way local operating services, nurses, staff and anaesthetists can be involved.[209]

More work needs to be done in collaboration with regional and metropolitan hospitals to establish a system which both supports organ donation across the hospital network in Victoria and is financially viable for smaller regional hospitals.

Finding 29

There are a number of barriers which impact on the ability of regional areas to support organ donation programs including lack of expertise in organ retrieval and resources to implement organ donation programs in hospitals as well as transportation costs.

Recommendation 13

That the Victorian Government work with hospitals and DonateLife Victoria to establish an effective and sustainable organ donation programs in regional Victoria.

6.7 Data collection

The Organ and Tissue Authority presented to the Committee two initiatives on data collection. The first initiative is the hospital audits (discussed in Section 6.2) which, as part of the national reform agenda has been rebranded as the DonateLife Audit. As outlined in Section 6.3, this audit process provides an opportunity to determine if there are any barriers to organ donation in individual hospitals, which allows for the review of hospital procedures. The other key components of the audit are to establish the number of requests for donation, consent rates and conversion rates.

Ms Yael Cass, Chief Executive Officer of the Organ and Tissue Authority, outlined a new initiative under development,. the Electronic Donor Record (EDR) program. Ms Cass informed the Committee that this database 'will give hospital based staff a tool to better collate data on prospective donors and then to make the offer and allocation process to recipient hospitals'.[210] It is expected that this tool will make the donation process more

[207] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 51.
[208] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 51.
[209] Prof. Bob Jones, Austin Hospital, *Transcript of Evidence*, 8 September 2011, p. 93.
[210] Ms Yael Cass, Organ and Tissue Authority, *Transcript of Evidence*, 25 August 2011, p. 5.

efficient and provide some safety and quality controls around collection of information for the donation process.

It is also important to note that the Organ and Tissue Authority regularly provides updates on progress and performance against the nine reform measures. This information is readily available in their annual reports.

Alfred Health believes there is a need for a more coordinated approach to the collection and use of patient data. There presently exists a number of separate databases recording patient (both donors and recipients) details and outcomes which are utilised by transplant teams. There are also time constraint issues in accessing this data, often due to privacy laws.[211]

Alfred Health recommends the establishment of a national donation and transplantation database/registry. The database should cover all stages of process, from identification of the potential donor to outcomes in transplant recipients. Alfred Health advised that –

> The potential benefits to the community significantly outweigh the potential risks to individuals through collection and use of identified patient data. Collection and use of identified patient data is vital to enable linkage between clinical databases and registries throughout Australia and can be performed in a secure manner. Support for legislative change to facilitate linkages should be considered.[212]

Finding 30

The Committee recognises the importance of data collection for organ and tissue donation and transplantation and notes the future implementation of the Electronic Donor Record by the Organ and Tissue Authority.

Recommendation 14

That the Victorian Government monitor the implementation of the Electronic Donor Record in Victoria to ensure future effectiveness in improving the processes of organ and tissue donation.

[211] Alfred Health, Submission No. 11, p. 4.
[212] Alfred Health, Submission No. 11, p. 5.

7. Hospital funding and resourcing

One of the key issues that arose from evidence to the Committee is the need for further resources for hospital transplantation units. As noted earlier in this report, the success of the national reform agenda and the establishment of the DonateLife network has led to increased donation rates, which in turn has resulted in an increase in transplantation activity. Evidence suggests this increased workload has not been met with a commensurate increase in hospital funding and staff resources.

A number of submissions and witnesses, including DonateLife Victoria, Alfred Health, the Transplantation Society of Australia and New Zealand and the Royal Australasian College of Surgeons raised concerns over a lack of resources dedicated towards organ retrieval and transplantation. The need for greater resources includes appropriate levels of funding, together with additional specialist staff and non-medical support staff.

The national reforms to organ donation and the work of DonateLife Victoria are aimed at increasing donation rates. The purpose of this Parliamentary Inquiry is to examine ways to increase Victoria's organ donation rates. It is therefore obvious that as organ donation rates continue to increase and the number of transplants continue to rise, that hospitals be provided with the appropriate levels of funding and resourcing to meet this increased workload.

During the course of the Committee's Inquiry, the resourcing and workload capacity issue came to a head when Alfred Health temporarily suspended its adult lung transplant program for one week in September 2011. This specific issue is dealt with later in this chapter.

7.1 Existing funding arrangements

Funding for organ donation and transplantation is provided by both State and Commonwealth Governments. The national reform agenda announced by the Commonwealth Government provided a funding package of $151 million, including new funding of $136.4 million over four years.[213]

The majority of funds available over 2008-2012 were allocated to state and territory governments for resourcing the state-based DonateLife Network, including hospital-based donation specialists and state DonateLife Agency staff, and activity-based hospital funding for organ donation activity under the Organ Donation Hospital Support Funding (ODHSF) program.

As outlined in Chapter 2, the funding included:

- $67 million to fund dedicated organ donation specialist doctors and other staff in public and private hospitals
- $46 million to establish a new independent national authority to coordinate national organ donation initiatives
- $17 million in new funding for hospitals to meet additional staffing, bed and infrastructure costs associated with organ donation
- $13.4 million to continue national public awareness and education

[213] Department of Health (Victoria), *Organ and Tissue Donation*, <http://www.health.vic.gov.au/organdonation/>, accessed 20 December 2011.

- $1.9 million for counselling for potential donor families

As part of these funding arrangements, new clinical positions were created within the Victorian hospital network to promote and coordinate organ and tissue donation in Victoria's hospitals. The new funding created 25 organ and tissue donation hospital medical directors (8.4 FTE positions) across 13 Victorian hospitals.[214] In addition, 33 organ and tissue donation hospital-based senior nurses (15.1 FTE positions) were appointed across 24 Victorian hospitals.[215]

The Organ and Tissue Authority budget allocation for Victoria over 2008-2012 was $26.7 million. In Victoria this funding is paid under a Commonwealth/State Funding Agreement based on occupancy of the agreed DonateLife Network staff positions and under hospital-specific ODHSF Funding Agreements based on organ donation activity.

The Committee notes that the initial four year funding agreement ends in June 2012. The Organ and Tissue Authority has advised that 'the Australian Government has committed recurrent funding for continued implementation of the organ and tissue donation – national plan to increase organ donation and save lives. This includes funding for State and Territory DonateLife Agency and hospital-based staff and continued activity-based hospital funding. Negotiations are underway for the 2012-2014 Funding Agreements and are intended to be finalised before June 2012.'

The Victorian Department of Health provides funding to Victorian hospitals to deliver organ donation and transplantation services. Specifically, the Victorian Government provides 'Activity Based Funding' to address additional costs associated with delivering organ donation programs.[216] This funding is available to all Victorian hospitals involved in organ donation.

The Department of Health outlined its funding arrangement as follows. In 2010-2011; Victoria received the following funding from the Australian Organ and Tissue Donation Authority:

- DonateLife Victoria – $2.1 million
- Victorian Hospital based full time or fractional time staff – $4.18 million
- Hospitals receive life preserving funding directly from AOTDA – Q2 2010-11 hospital claims = $0.4 million.

The Victorian Government additionally funds:

- DonateLife in Victoria – $0.98 million
- Victorian Transplantation and Immunogenetics Service (VTIS) – $1.8 million
- Hospital transplant costs.

7.2 Planning for future organ transplant activity

As noted earlier, Victoria is leading the nation in terms of organ donations over the past few years. Victoria's total number of organ donations increased significantly in 2010 and is now in excess of 100 per year. The recent trends and excellent work of DonateLife Victoria suggests the total number of organ donors should continue to rise, however it is unclear to what extent. The increase in organ donors has had a corresponding impact upon hospital transplant activity.

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[214] Department of Health (Victoria), *Organ and Tissue Donation,* <http://www.health.vic.gov.au/organdonation/>, accessed 20 December 2011.
[215] Department of Health (Victoria), *Organ and Tissue Donation,* <http://www.health.vic.gov.au/organdonation/>, accessed 20 December 2011.
[216] Department of Health (Victoria), *Organ and Tissue Donation,* <http://www.health.vic.gov.au/organdonation/>, accessed 20 December 2011.

At this stage, there appears to be no planning done within Victoria in terms of projecting future organ donation rates. This in turn makes it difficult for hospitals to determine anticipated transplant workloads. The Alfred Health case, as an example of the impact of unpredicted growth, is discussed later in this chapter.

In his evidence to the Committee, the Minister for Health highlighted the challenge of keeping donor rates at sufficient levels and the activity required to deliver outcomes. The Minister sought input from the Committee in terms of setting targets and goals for future donation rates. The Committee is not in a position to advise of possible organ donation targets given that this would require very specific skills and significant resources. The Committee believes the Department of Health and DonateLife is best equipped to develop such targets and strategies. Further, it believes such work is essential to ensure adequate resources are available to fund retrieval, transplantation and post-operative support.

The evidence below highlights the existing gap between donation rates and transplant resources. The Royal Australasian College of Surgeons noted that while there has been provision of funds for the donation side, there has not been funding allocated to the recipient side of transplantation.[217] Additional funding for donation has led to an increase in the number of organs available for transplantation and a commensurate demand on the transplantation programs. During this time resourcing levels have remained static for transplantation.

Dr Helen Opdam discussed the issue of the lack of funding for the 'downstream aspects of transplantation' in her evidence to the Committee –

> We need to ensure that there is no loss of a donor due to the inability to facilitate donation. I say that because although this national funding has been very effective – we have doubled our rate in Victoria over four years – the funding is all at the donation end. The national funding is not funding any of the downstream aspects of transplantation. It does not fund the surgical retrieval service. There is a team of surgeons who has to come to where the person has died, whether it be the hospital in Shepparton or Mildura or the Alfred or the Austin, and they undertake the organ donation operation. The organs then need to be transplanted into the recipient by surgeons. There is tissue typing that needs to be done, so there is a lag, to check carefully that there is going to be a suitable match. That often means calling people into the lab out of hours, and it takes many hours to do that tissue typing cross-matching. Then you need the team of doctors and nurses and other staff who care for the recipients who have received the transplant.[218]

The Committee sought a response from Dr Opdam on the capacity of hospitals to deal with the current increase in donation rates. In Dr Opdam's view, existing resources are inadequate particularly if donation and transplant activity continues to increase –

> In answer to your first question about the additional resourcing, I do not have the figures. I know from my direct communications with the staff who work in those areas that everyone is very stressed and working very hard. This is obviously not sustainable, particularly if activity increases further. Those groups are communicating with the Department of Health and putting forth arguments and business cases to obtain additional resources, and I hope that the Victorian government is responsive enough to be able to deliver on some of those requests for additional resourcing. With respect to additional resources for further staff,

[217] Royal Australasian College of Surgeons, Submission No. 23, p. 2.
[218] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 50.

> there is a real lead time because you need to train staff, which, depending on the area in which they work, is variable; it might be six months; it might be a year; for surgeons it might be quite a long time.
>
> There has been no new funding, nationally, for those activities, yet they are dealing with a doubling in the activity as a result of the success of the donation program.'[219]

The Transplantation Society of Australia and New Zealand also raised concerns over hospital capacity to meet an increase in transplants –

> A specific area that needs urgent attention is hospital infrastructure/capacity. The increase in transplant activity has already placed a strain on existing transplant programs and the hospitals in which they operate particularly utilisation of operating facilities and intensive care beds. Increased demand for these acute hospital services to enable increased organ transplants impacts on major elective and emergency surgery and other hospital programs that rely on these services. We regard an expansion of hospital staffing and infrastructure to meet the increased organ transplant activity without negatively impacting on other acute hospital services as a major priority.[220]

The Royal Australasian College of Surgeons noted that resourcing constraints are impacting upon the direct organ transplant services as well as ancillary and downstream services –

> … there should be recognition within funding models that many donation-related medical activities occur out of standard operating hours. This has a wide impact on the availability of appropriate staff. This includes non-medical staff, including ancillary services including social work, translator services and pastoral services for example. Additionally, any increased level of donations will include a higher demand placed on procedural diagnostic services to assess suitability for donation.[221]

A number of the written submissions to the Inquiry were from individuals who reported their personal experiences with organ donation and transplantation. Mr Peter Morey outlined his personal experiences with organ failure and made a 'plea for more funding for organ transplants in public hospitals'. He referred to the high costs associated with ongoing kidney dialysis treatment and noted there are 'both tangible humanitarian and economic benefits to increasing funding of kidney transplants'.[222]

Dr Opdam informed the Committee that –

> At the Australian Health Ministers Conference on 18 February [2011] it was explained that donation rates had increased, and members at that meeting committed to proactively doing what was necessary to ensure that the downstream effects were adequately resourced. Whether that has actually translated into additional resourcing or not is unclear to me, but it has been put up.[223]

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[219] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 50.
[220] Transplantation Society of Australia and New Zealand, Submission No. 28, p. 2.
[221] Royal Australasian College of Surgeons, Submission No. 23, p. 2.
[222] Mr Peter Morey, Submission No. 7, p. 1-2.
[223] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 52.

The Minister for Health, at a hearing on 8 February 2012, referred to additional Victorian Government funding in 2011-12 in response to increased transplantation activity:

> This year, 2011-12, in recognition of the increased transplantation required with the growth of organ donation rate of 2009 and 2010, we have provided an additional tagged investment of $2.7 million to support the growth in these services and also additional general funding, but we acknowledge that there is still more that will need to be done.[224]

7.3 Training and education

Limited resources have also affected staffing levels and the training of future medical professionals in the organ donation and transplantation specialities.

Training of medical professionals in organ donation is important and a mandatory component for any intensive care specialist. The Australasian Donor Awareness Program is conducted by DonateLife and other intensivists to provide those involved in organ donation with training about 'brain death, about donation, about how to communicate sensitively with acutely bereaved families and about how to raise donation levels.'[225] To further complement this training program, the Organ and Tissue Authority is developing other national training programs for organ donation.

Dr Steve Philpott, intensivist and Medical Director at the Alfred advised that –

> … more resources should be directed towards strategies aimed at improving the success of organ retrieval and transplantation and developing and maintaining an appropriately trained and supported workforce in the fields of not only organ donation but also organ transplantation, including transplant surgeons and physicians, transplant nurses and allied health professionals and intensive care staff.[226]

Training medical staff involved in organ donation and transplantation is a lengthy process. It can be many years before a medical professional has reached the required level of training to undertake work within the organ donation and transplantation speciality. A further issue is that it is often difficult to attract, young doctors into this field simply because it is fairly demanding and requires them to be available at any time of the day to undertake organ retrieval and transplantation surgery. Prof. Greg Snell, physician at the Alfred Hospital, identified a need for succession planning, making time for recruitment and training and managing the demanding hours and stress within donation and transplantation units.[227]

Finding 31

Existing hospital funding and staff levels are inadequate to effectively meet current demands required within transplantation units in Victoria.

[224] Hon. David Davis, Minister for Health *Transcript of* evidence, 8 February 2012, p. 2.
[225] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 48.
[226] Dr Steve Philpott, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 98.
[227] Prof. Greg Snell, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 102.

Finding 32

National and Victorian initiatives to increase organ donation rates must be supported with additional resourcing. There is potential for negative outcomes or a withdrawal of community support for organ donation, if organ donation or transplantation does not occur as a result of funding or resourcing constraints. This will be worsened by the prospect of willing donors not being utilised due to a lack of resources.

Finding 33

The establishment of future organ donation targets will assist the Government in determining appropriate levels of funding to meet transplant outcomes and this needs to be prepared by the Department of Health as a priority planning issue.

7.4 Alfred Health resourcing issues and temporary closure of the Alfred lung transplant program

In its April 2011 written submission to the Inquiry, Alfred Health requested 'an increase in the funding provided for transplantation to meet the increase in demand that it is experiencing'.[228] The hospital's submission noted 'the major problem for Victorian hospitals carrying out transplants has become the lack of resources required to utilise the increased number of organs donated for transplantation'.[229] Alfred Health suggested the Victorian Government consider undertaking an analysis of how resources are currently utilised to translate organ donation into organ transplantation, and what additional resources are required to ensure optimum safe, quality and cost efficient outcomes.[230]

Alfred Health provided further evidence when it was represented by a number of witnesses at a public hearing on 8 September 2011. In a hearing which covered a wide range of issues, Alfred Health further highlighted the need for additional resources –

> As a result of the success of that national campaign there has been an increase in the volume of organ transplantation cases recently, and whilst there has been a significant injection of resources into the organ donation aspect, there has been a much smaller focus on supporting transplantation activities. We feel that more resources should be directed towards strategies aimed at improving the success of organ retrieval and transplantation and developing and maintaining an appropriately trained and supported workforce in the fields of not only organ donation but also organ transplantation, including transplant surgeons and physicians, transplant nurses and allied health professionals and intensive care staff.
>
> We think there should be consideration of an activity-based funding model for organ transplantation similar to that which is in place for organ donation.[231]

Two weeks after this public hearing appearance, on Friday, 23 September 2011, Alfred Health announced it was cutting back on adult lung transplants until 10 October 2011 due to an exceptionally high workload. Alfred Health subsequently advised on 29 September that the workload had eased sufficiently to incrementally resume normal operations on 3 October 2011.

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[228] Alfred Health, Submission No. 11, p. 3.
[229] Alfred Health, Submission No. 11, p. 2.
[230] Alfred Health, Submission No. 11, p. 3.
[231] Dr Steve Philpott, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 98.

Following this announcement, the Commonwealth Parliamentary Secretary for Health and Ageing commented that Victoria was not committed to meeting the increasing cost of organ transplantation, as agreed at a Health Ministers Council Meeting earlier in 2011.[232] The Victorian Government stated that the problem at the Alfred was not funding related but rather a workforce capacity issue.[233] The Victorian Government reiterated that Alfred Health would receive growth funding of $24 million which includes increased funding specifically for lung transplants. The Victorian Government further commented that increased funding to the hospital system by $2.7 million for organ transplants as part of the 2011-12 Budget, in recognition of the increasing demand.[234]

The announcement by Alfred Health to temporarily close its adult lung transplant program received considerable negative media coverage. A number of key organ donation and transplant stakeholder groups raised concerns over the implications of the closure, including the possible damage to community perception towards organ donation.

Despite having recently taken evidence from Alfred Health, the Committee decided to invite Alfred Health to a further public hearing to discuss hospital transplant unit resourcing and Alfred Health's decision to temporarily suspend its adult lung transplant program. Mr Andrew Way, Chief Executive Officer of Alfred Health, gave evidence on 2 December 2011.

At the hearing, Mr Way did not reiterate Alfred Health's previous evidence seeking additional resources for organ transplant activity. Rather, Mr Way provided a detailed analysis of how Alfred Health is funded through grants and activity-based funding and how the hospital manages these funds and workloads within its transplant programs. With respect to workloads, Mr Way advised –

> Within the Alfred what we do is the day-to-day management decisions about who to transplant and how many to transplant. What capacity the organisation has sits with the clinical team, so every day they will make decisions about whether an organ is usable.
>
> ...
>
> We review annually the anticipated workload for the next year, and then we provide the department with expenditure budgets based on that expected activity. Then we negotiate the overall volume of funding with the Department of Health.[235]

Mr Way advised the Committee that within Alfred Health there had been some confusion over available funds for the current year and what would be required in terms of workloads and appropriate staffing levels.

> What became apparent at the end of August was that there was now a $5 million gap between what we had assumed we were going to be able to achieve in the way of income from the department and what was actually available. It was no-one's fault, but we had misjudged the level of funding that would be available for health services this year – that is, after we had made a $22 million saving program. On $800 million we were already taking out $22 million of savings and reinvesting them or using them to cope with the efficiency savings expected by the department. In addition to that we had tried to suggest that we might see further funding for more activity from the department, particularly as we had seen two or

[232] Julia Medew, 'Alfred closes door on transplants',*The Saturday Age*, 24 September 2011, p. 1.
[233] Julia Medew, 'Alfred closes door on transplants',*The Saturday Age*, 24 September 2011, p. 1.
[234] Julia Medew, 'Alfred closes door on transplants',*The Saturday Age*, 24 September 2011, p. 1.
[235] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 176.

> three areas of considerable growth – like lung transplant, like trauma, like our surgical program – and broadly speaking we did not see a growth in activity in WIES[236] that funded those, so we had to make a readjustment at the end of August in our internal budgets to meet what were the stated priorities of government.[237]

Turning to the decision to temporarily close the adult lung transplant program, Mr Way advised –

> … the clinical staff advised me that the workload in the department had reached a level where they could not actually continue to admit people. So we have got all of this stuff going on about how much money and the level of growth, and then separately – because we have not put, I guess, the amount of growth in that people were expecting – the clinicians said, 'We just need to stop doing transplants for a couple of weeks so that the six or seven very, very, very sick patients we have got in the system at the moment have a chance to recover and be managed with full attention, so that those transplants that we have transplanted have the maximum opportunity to succeed and benefit their patients, rather than continue to transplant more people who probably would not be able to benefit from the full attention of our staff because they are so diverted by these.[238]

Mr Way indicated this decision was not unusual in terms of how the hospital and its clinicians manage the workload of the transplant program. However, in this instance the decision became public and, according to Mr Way, appeared to be inaccurately reported publicly as a decision caused by funding cuts.

> Normally – and I refer to the way in which the department works – that would have just happened. The clinical team would have done that, no-one would have known about it other than the clinical team and they would have just managed the overall workload in the department, but because we were in this rather public space of what level of activity to fund and how to fund it, it became very public. What you see in the report is a little hint of the confusion – was this cuts? was this something else? – but actually the program was stopped on the advice of the clinical department saying, 'We don't have the right number of staff for what we're doing at the moment'.[239]

Despite the national reforms to improve organ donation rates and the trend since 2008 of increasing donation rates and organ transplants, it would appear that insufficient investment and planning has occurred to ensure sufficient staffing levels existed to effectively operate transplant programs. Mr Way advised –

> You could argue that if we had made an investment a year ago and put more staff in, then of course that would not have happened, but the perfect view of hindsight is not easy sometimes to agree at the time.[240]

Referring to ongoing trends of increased transplant numbers, Mr Way advised –

> If we get to 120 or 130, we have to then say, 'Are we going to have to create effectively a second transplant program in order to cope with that step from 130 to 150, if we get to that place, and if so, how do we do that, or would it be better that another centre creates another program, so we have the resilience of two programs, two sets of hospital capacities and so on?'. There are some quite big questions if the program continues to grow at the rate it is going.

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[236] WIES is a cost weight (W) that is adjusted for time spent in hospital (IES), and represents a relative measure of resource use for each episode of care in a Diagnoses Related Group.
[237] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, pp. 176-177.
[238] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 177.
[239] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 177.
[240] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 177.

> The current view is that it will probably stop growing at around 120 to 130, so it is probably reasonable to contain it in one, within the state, but once you go to a step increase outside, you have got — absolutely right — a very difficult problem of not only the surgeons but particularly the transplant physicians. These are the people who deal with the physiology, who manage the patient over a much longer period of time and who are incredibly difficult to support and to find.[241]

The shortages in appropriate staffing levels within transplant units was highlighted in previous evidence from Alfred Health and other key bodies such as DonateLife and is referred to earlier in this chapter. Prof. Greg Snell, spoke of staff shortages during the hospital's earlier evidence on 8 September. When asked about the actual number of surgeons required to facilitate the increase in organs, Prof. Snell advised –

> It is hard to be sure. It is a matter of bringing people in so that you can beef up the current numbers but also so that you have got people to replace those who fall by the wayside. That is a very important aspect, because at the moment it just handles exactly what it was designed to do about three years ago. The increased numbers are yet to be figured into the workforce.[242]

Prof. Snell also told the Committee that transplantation programs need 'some form of activity-based support so that if we do more, there is some curve which responds to the activity. At the moment any increased activity is not matched in any plausible way.'[243]

At the subsequent public hearing on 2 December, the Committee questioned the appropriate level of investment required to ensure the ongoing effective management of Alfred Health's transplant programs. Mr Way responded –

> Broadly speaking we are working about a year behind in our investment. What we had in place in 2009–10 was really sufficient to deal with 2008–09 and in 2011 it is 2010, so we are working about a year behind. We have not done that piece of work because it is very difficult to answer, but the bid from the local unit was for in the order of $1 million. We then had to go through and say, 'Yes, we can afford some of this and some of that'. The additional costs per patient that go on the program are something of the order of $30 000 to $40 000 per year. Some of that is covered by direct costs and some of it by indirect costs. It is quite difficult to say what the net difference would be. This is the problem with it being inside the capped program as opposed to a separate program, so it does not get looked at differently for all of its activity. It would not surprise me if the shortfall overall was something of the order of $1 million now, and then it probably needed to grow at – you have to recognise the total cost per patient – something of the order of $30 000 to $50 000 per patient additional to the program.[244]

In particular, Mr Way believed Alfred Health's transplantation units would benefit from additional nurse coordinators –

> The team tells me that the most important need is nurse coordinators, so the nurses who actually manage the patients over long periods of time, and then after that is a transplant physician, and then after that it is the transplant team services in general, the sort of administrative stuff.[245]

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[241] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 178.
[242] Prof. Greg Snell, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 103.
[243] Prof. Greg Snell, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 105
[244] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 180.
[245] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 178.

Inconsistent Evidence to the Committee

The Committee became aware of a story which aired on Channel 7 News on 7 March 2012. The media report referred to a Freedom of Information (FOI) document from Alfred Health which suggested that money had been diverted from the lung transplant program into other hospital programs. The Committee subsequently wrote to Mr Andrew Way, Chief Executive Officer of Alfred Health, seeking clarification on his evidence to the Committee and the Channel 7 story.

Mr Way wrote to the Committee on 22 March explaining that there was a change in the level of investment for the lung transplant program, however there was no withdrawal of funds. Mr Way commented that –

1. In the last three years at least, no funds have been taken from the lung (or any other) transplant program.
2. In the years prior to 2010/11, the number of organs donated meant that not all funds received were allocated, and as with all programs those funds were used to support other areas of critical need or 'hot spots' in the health service.
3. This use of funds did not cause any constraint on the transplant programs and is entirely consistent with the Department of Health to health service funding allocation model as Alfred Health understands it. Within this model there is no mechanism for moving one year's unused allocations to another.[246]

A copy of Mr Way's letter and the document released to Channel 7 (an internal Alfred Health Board briefing note) provided to the Committee, is attached in Appendix E.

Conclusion on Alfred Health Resourcing Issue

The Committee, and the community more broadly through public comments by third party health organisations and their representatives, has viewed the Alfred Health resourcing issue and temporary closure of its lung transplant program very seriously. The Committee's evidence and events can be summarised as follows –

- 20 April 2011 – Alfred Health's written submission to the Inquiry seeks an increase in funding to meet their growing transplantation activity.
- 8 September 2011 – Alfred Health's public hearing evidence again calls for additional resources for organ retrieval and transplantation.
- 23 September 2011 – Alfred Health temporarily closes its adult lung transplant program due to an 'exceptionally high workload'.
- 2 December 2011 – Alfred Health give further evidence in a public hearing to explain that the temporary closure of the lung transplant program was a result of pressures on staff and workload capacity.
- 7 March 2012 – Channel 7 News report suggests Alfred Health funds set aside for the lung transplant program had been diverted into other programs.
- 22 March 2012 – Alfred Health reaffirm that there was no withdrawal of funding from the lung transplant program in 2011 and that the temporary halt to its transplant program was due to a 'lack of investment' and pressures in workload capacity.

The FOI briefing note to the Alfred Health Board indicates that to date, the constraint on transplantations was due to a lack of donation. However recent increases in donation have not been matched with funding increases. In particular Mr Way advises his board

[246] Mr Andrew Way, Chief Executive, Alfred Health, letter to Committee, 22 March 2012.

that within a 400 WEIS increase,[247] the Department of Health attached spread sheet shows that none has been allocated to transplantation services.

The briefing note continues as follows –

> Once it became clear that the minimal level of investments that we had hoped to provide to the rapidly growing transplant service were not likely to be possible, it became necessary to have a conversation with the clinical staff. This discussion caused the initial stories in the media on Saturday 17 September.[248]

The Committee is concerned that this position, put to the Board by Mr Way on 5 October 2011, is inconsistent with the evidence given to the Committee on 2 December that year. In that evidence Mr Way indicated that the decision to close was based entirely on advice from Clinical Staff that transplantations had to cease due to workload pressure. He did not advise the Committee that he had gone to the staff to advise them of the shortage of funding as is done in the briefing note to the Board.

The Committee's evidence suggests there continues to be confusion and public concern over the reasons and impacts of Alfred Health's decision to temporarily close its adult lung transplant program in September 2011. Early evidence from Alfred Health to the Committee clearly highlighted the need for additional funding to meet increased transplant activity. However, this call for funding was not reiterated by the Alfred Health's Chief Executive Officer, Mr Andrew Way at the 2 December public hearing. Further, the Committee is concerned that Mr Way was not as clear and open in his evidence to the Committee as he was in his explanation to the Alfred Health Board.

As a result of these concerns, the Committee has, by majority decision, determined to undertake two courses of action –

1. To refer the cancellation of Alfred Health's Lung Transplant services and the causes of that cancellation to the Victorian Ombudsman for investigation.
2. To recall Mr Way to clarify his evidence and to examine the perceived inconsistency of his evidence. The Committee will provide a supplementary report to the House at the conclusion of that examination.

Finding 34

Insufficient investment and planning within Alfred Health's transplantation programs created unsustainable workload capacities which lead to the temporary closure of the Alfred Health's adult lung transplant program in September 2011.

Finding 35

A situation exists within Alfred Health where investment levels are a year behind actual donation and transplant numbers is not sustainable and has the potential to undermine efforts to improve donation levels and damage public and patient confidence in organ donation more generally.

Recommendation 15

That the Victorian Government review existing resourcing levels within hospitals to ensure organ transplantation activity can operate to maximum capacity in order to meet current and future increases in organ donation and transplant rates.

[247] WIES is a cost weight (W) that is adjusted for time spent in hospital (IES), and represents a relative measure of resource use for each episode of care in a Diagnoses Related Group.
[248] Refer to 'Appendix E Response from Alfred Health regarding funding', p.106.

8. Community awareness

The importance of organ and tissue donation is widely accepted within the Australian community. DonateLife report that 79 percent of Australians are willing to be organ donors and 76 percent are willing to be tissue donors.[249] However, despite these statistics, as noted elsewhere in this report, Australia's organ and tissue donor rates remain low. Further, Chapter 3 highlights that less than 60 percent of families provide consent to organ donation.

Research conducted for DonateLife indicates that the most important aspect is that families know the wishes of their loved one. It found that 43 percent of Australians do not know or are unsure of their family members' donation wishes. The research also found that of those families that know their loved one's wishes, 93 percent agree and support those wishes.[250] This reinforces the need for families to be aware of each others' donation wishes.

8.1 National reform agenda campaigns

One of the nine COAG-endorsed measures of the national reform agenda is raising community awareness and education campaigns focused on the importance of organ donation.

The Organ and Tissue Authority provides grants to community groups for the promotion of organ and tissue donation. They also are responsible for nationwide marketing campaigns. In addition, the Authority provides support through educational materials, such as their guide for community speakers and training information for medical professionals.

To meet these requirements, the Authority has developed and implemented two main campaigns: 'DonateLife, discuss it today. OK?' – released in 2010; and 'DonateLife, know their wishes. OK?' – released in 2011.These campaigns focused on promoting the need for families to discuss and know each other's donation wishes. As highlighted on the DonateLife website, the campaigns 'aim to address the prevailing gap between people who believe that their family know their wishes (68%) and awareness of family members' wishes (55%).' [251]

The other key awareness campaign is DonateLife Week, the national awareness week for organ and tissue donation. In 2012, DonateLife Week was held from 19 – 26 February 2012. DonateLife encourages the community to have early discussions about organ and tissue donation. It seeks community involvement by registering events which reflect the theme of DonateLife Week, which was 'Ask and know your loved ones' wishes'. The week also creates a promotion opportunity for the DonateLife Book of Life, which was launched at DonateLife Week 2011 by the Governor-General of the Commonwealth of Australia, Ms Quentin Bryce AC CVO.

The national campaign for 2012 DonateLife Week is largely focused on raising awareness within the community for families to have early discussions on organ and tissue donation and to make their individual wishes for organ and tissue donation known. Chapter 3

[249] DonateLife, 2011, *Facts and Statistics*, <http://www.donatelife.gov.au/discover/facts-a-statistics>, accessed 12 January 2012.
[250] DonateLife, 2011, *Facts and Statistics*.
[251] DonateLife, 2011, *Know their wishes campaign*, <http://www.donatelife.gov.au/resources/donatelife-campaign/know-their-wishes-campaign> accessed 12 January 2012.

identified the importance of raising awareness of donation wishes within the community as it can greatly influence a family's decision to consent to organ donation at the time of death of their loved one. As pointed out in Chapter 3 families play an important role in the consent process for organ donation. Research has found that less than 60 percent of families consent to organ donation.[252]

Mr Chris Thomas from Transplant Australia suggested to the Committee that –

> … our family consent rates are still too low. Transplant Australia believes the sector could transplant another 750 people a year if we could improve the consent rate from around 50 percent to 90 percent to 100 percent. Social marketing plays an important role in addressing issues in the community sector.[253]

This highlights the important role that campaigns have in raising the awareness of organ and tissue donation within the community.

Recommendation 16
The importance of family consent and early discussion within families on organ donation should continue to be a priority focus of national community awareness campaigns.

8.2 State findings

Elsewhere in this report, the Committee refers to recent state parliamentary reviews relating to organ and tissue donation. One of the key themes arising from each of these reviews was the importance of community education to promote organ and tissue donation.

The 2008 Queensland Parliamentary review concluded that 'improved community education is a vital strategy to increase the rate of organ donation.' The report recommended the 'Queensland Government should both undertake community education activities that are consistent with the national framework, and provide funding for community groups to be involved in consistent education about organ and tissue donation.'[254] The 2008 Tasmanian Select Committee inquiry noted the key message that was derived from submissions and evidence was that education and discussion are the most important aspects of increasing the donor rates.[255]

Three years after these reviews in other jurisdictions and the implementation of the national reform agenda, evidence continues to highlight the need for greater community awareness and understanding of the importance of organ donation.

8.3 The role of the not-for-profit sector

The role of various not-for-profit organisations in raising community awareness cannot be underestimated. There are a wide range of not-for-profit organisations who are involved in raising awareness of organ and tissue donation in Australia and Victoria. These include:

- Australian Liver Foundation
- Australian Red Cross Blood Service
- David Hookes Foundation

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[252] Australian Organ and Tissue Donation and Transplantation Authority, *Annual Report 2010-2011*, p. 60.
[253] Chris Thomas Transplant Australia public hearing evidence, p. 20.
[254] Legislative Assembly of Queensland, *Organ and Tissue Donation: Report of the Review of Organ and Tissue Donation Procedures Select Committee,* 2008, p. 21.
[255] Parliament of Tasmania, Legislative Council Select Committee, *Organ Donation,* 2008.

- Kidney Health Australia
- Transplant Australia
- Zaidee's Rainbow Foundation.[256]

Australia also participates in the World's Biggest Walk, a global event to raise awareness for organ donation and transplantation.

The Committee heard evidence from a number of not-for-profit organisations which are involved in raising awareness in the community. Some groups have specific areas that they target, for example, Transplant Australia's focus is on advocacy, awareness and support for the community and their members. Zaidee's Rainbow Foundation works closely with the community to help inform parents and families about the importance of having a conversation about organ donation in case they are confronted with making a decision at the time of losing a child. Kidney Health Australia focuses on improving kidney health in the community, to ensure kidney disease occurs less frequently so the need for transplantation can be reduced.

Transplant Australia's submission states that it is 'the national community stakeholder organisation promoting organ and tissue donation and caring for all of those touched by transplantation.' The mission of Transplant Australia is to be a strong advocate for best practice in the organ and tissue donation sector, to promote its life-saving benefits to governments and the Australian public, and to provide all those touched by transplantation with support, education and guidance to improve their health, quality of life and well-being.[257]

Consistent with other organ awareness community groups, Transplant Australia has a strong emphasis on raising awareness through sporting events. In particular, much of the organisation's promotional work is carried out through the Transplant Games, an event held every two years with participants including transplant recipients, those undergoing dialysis treatment, those awaiting transplantation, living donors, family members of deceased donors and supporters. The Transplant Games are Australia's largest awareness event for organ and tissue donation and demonstrate 'what a life difference' transplantation makes. In its submission to the Inquiry, Transplant Australia suggested Victoria could gain increased organ donation awareness if it were to host the Australian Transplant Games in the future.

Groups such as Zaidee's Rainbow Foundation and the David Hookes Foundation were established following a tragic loss of individuals who generously donated their organs to save other lives.

Zaidee's Rainbow Foundation was established in 2004 soon after the sudden death of Kim and Allan Turner's 7 year-old daughter, Zaidee. Zaidee was a registered organ donor and at the time of her death, her parents honoured her wishes and consented to organ donation. The Foundation promotes the value of organ donation to children and adults. Zaidee's Rainbow Foundation aims to ensure every Australian requiring a transplant will receive one. Zaidee's Rainbow Foundation strives to increase the number of people who honour the wishes of their loved ones to donate their organs and tissues through the implementation of Zaidee's National Awareness Campaign. The Foundation is a partner with DonateLife, and has a number of corporate partners. In particular, the organisation

[256] DonateLife, 2011, *Support and Awareness Organisations*, <http://www.donatelife.gov.au/resources/links/support-and-awareness-organisations>, accessed 1 December 2011.
[257] Transplant Australia, Submission No. 14, p. 1.

has strong links with the sporting industry, Australian Football League and Cricket Australia.

Mr David Hookes, international cricketer and media personality, died tragically in 2004. The David Hookes Foundation website notes:

> David was passionate about organ donation. It was something we had discussed as a family and he made his views clear: if he died he wanted to donate his organs if at all possible. When the worst happened in January 2004 and David was declared brain dead in hospital, that knowledge made it easier for our family to agree for him to become a donor. We were comforted by the fact that we wouldn't let him down.
>
> When the news got out, the story under the headline 'Champion's Gift of Life' went around the world. The reaction was overwhelming. In the weeks after his death, three times as many people as the weekly average put their names on the Organ Donor Register. It was inspirational. How proud we were.
>
> Out of that came the David Hookes Foundation. It was established to inspire more Australians to register as organ donors and to encourage them to discuss their important decision with family and friends, just as David did. The end of this world for one need not be the end of the world for others.[258]

Notwithstanding the excellent work of these organisations undertaking awareness raising campaigns, it was not clear to the Committee that the efforts of all groups was aligned at a strategic level to meet the objectives of a nationally consistent approach.

Finding 36

The Committee acknowledges the positive contribution of the not-for-profit sector and other community organisations in their involvement in raising awareness in the community on organ and tissue donation.

Recommendation 17

That organisations involved in awareness raising campaigns coordinate their efforts to ensure a consistent and collaborative national campaign to the extent that they wish to be involved.

8.4 The need for further education and awareness

The Committee commends the tireless and passionate work of these community organisations and notes that while some of their income is derived from fund raising, they are also dependent on continued support from governments. The Committee believes both State and Commonwealth Governments should continue to support and fund these key community awareness groups.

The Committee's evidence highlights the importance of sporting events and identities in promoting organ donation. Mr Dermot Daley, a registered organ donor, believed an ideal way to increase organ donation would be through sports promotion. By encouraging the support of peak sporting bodies such as the Australian Football League, Victoria Racing

[258] David Hookes Foundation, <http://www.davidhookesfoundation.com/>, accessed 12 January, 2012.

Club and Tennis Australia, high profile sports men and women could sign up on the organ donor register and thereby send a strong message to the community.
Australians, and Victorians in particular, are passionate about their sport. The work of Transplant Australia through the Transplant Games, and groups like Zaidee's Rainbow Foundation and the David Hookes Foundation in promoting awareness through sporting events and identities should be further encouraged.

Mr David Hayne wrote to the Committee with the background of his wife Kaye who underwent a lung transplant in 2006, which proved to be a life-saving operation. Mr Hayne's submission highlighted the importance of a greater awareness and understanding of organ donation by potential donors, families and society as a whole. Mr Hayne recommended 'a continued and aggressive publicity campaign that encourages organ donation and arrives at the point where donation becomes a societal norm.'[259] On balance, Mr Hayne supported the retention of the opt-in system but encouraged 'robust dialogue engaged with the public that explains and encourages organ donation.'[260]

Correspondence received from Ms Penny Mitchell suggested that the Victorian Government consider additional ways to acknowledge and recognise the important 'gift of life' of an organ donor. Ms Mitchell proposed that an organ donor could be acknowledged on the death certificate. The Committee believes this proposal has merit and would provide donor families with additional recognition of the life-saving act their loved one provided for other families, and would also be a way of raising the profile of organ donation within the community.

Education through schools was also highlighted as an important initiative. A young woman who received a liver transplant, Ms Chloe Britton, noted in her submission that 'an education program aimed particularly at students should support the Organ Donation program to ensure that there is full awareness of the changes to the system and its impacts on individuals.'[261]

Submissions from religious/faith-based groups, including the Catholic Archdiocese of Victoria, the Lutheran Church of Australia, and the Ad Hoc Interfaith Committee, all suggested a greater education campaign which explains:

- Conditions under which a registered donor can become an organ donor
- The diagnosis of death by the brain death criterion and of 'beating heart' donation issues involved in donation after loss of circulation
- What happens to the donor when organs are donated and what is involved for families.

Shortly prior to finalising this report, the Committee informally became aware of a potential issue regarding the protocols that might presently exist, or perhaps should exist, between the families of donors and donor recipients to make appropriate contact with each other. The Committee did not receive any detailed evidence in relation to this issue but considers that it warrants further investigation and consideration by the Government, health organisation and donor families.

Finding 37

Promoting the benefits of organ and tissue donation through community awareness and education campaigns is a vital strategy to encourage more people to register as an organ and tissue donor.

[259] Mr David Hayne, Submission No. 3, p. 2.
[260] Mr David Hayne, Submission No. 3, p. 3.
[261] Ms Chloe Britton and Ms Anne Rea, Submission No. 15, p. 1.

Finding 38

The profile of organ and tissue donation in Victoria would be enhanced through further campaigns directed at schools and through sporting organisations. In particular, Victoria would benefit from hosting the Australian Transplant Games.

Recommendation 18

That additional resources be directed to strategic community awareness and education campaigns aimed at demystifying and promoting the benefits of organ and tissue donation.

Recommendation 19

That the Victorian Government meet with Transplant Australia and other relevant stakeholders with a view to Victoria hosting a future Australian Transplant Games.

Recommendation 20

That the Victorian Government consider ways to acknowledge and recognise the altruistic act of organ donation including the possibility of suitable acknowledgement on the donor's death certificate.

Recommendation 21

That the Victorian Government, in association with health organisations and donor families, give consideration to any potential protocol issues in relation to contact between donor recipients and donor families.

Committee Room
28 March 2012

Appendix A: List of Written Submissions Received

1. D Daley
2. S & V Marcus
3. D & K Hayne
4. Lutheran Church of Australia
5. Tasmanian Government
6. Humanist Society of Victoria
7. P Morey
8. L Campbell
9. Catholic Archdiocese of Melbourne
10. Centre for Eye Research Australia
11. Alfred Health
12. E Morey
13. Dr H MacDonald
14. Transplant Australia
15. C Britton & A Rea
16. Assoc Prof Ian Fraser
17. Organ and Tissue Authority
18. Ad Hoc Interfaith Committee
19. Victorian Medical Director of Organ and Tissue Donation
20. National Health and Medical Research Council
21. Hon C King, MP, Parliamentary Secretary for Health and Ageing
22. NSW Department of Health
23. Royal Australasian College of Surgeons
24. Northern Territory Department of Health
25. Assoc Prof Nicholas Tonti-Filippini
26. Victorian Department of Health
27. Rabbinical Council of Victoria
28. Transplantation Society of Australia and New Zealand
29. K Stubbs
30. Australian Medical Association – Victoria
31. Kidney Health Australia
32. Australia Red Cross Blood Service
33. P Farnell

34. Jewish Community Council of Victoria Inc
35. Royal Australasian College of Physicians
36. Donor Tissue Bank of Victoria

Further correspondence received from:

Ms P Mitchell
Mr D Hinch
Sharelife

Appendix B: Schedule of Public Hearings

Thursday, 25 August 2011

Organ and Tissue Authority
- Ms Y Cass, Chief Executive Officer
- Dr J Gillis, National Medical Director

Australian Medical Association Victoria
- Ms J Stephens, Chief Executive Officer
- Ms E Muhlebach, Policy Officer

Transplant Australia
- Mr C Thomas, Chief Executive Officer
- Mr K Green, Chairman, Victorian committee

Zaidee's Rainbow Foundation
- Mr A Turner, Chief Executive Officer
- Mr J Carey, Events and Communications Manager

Thursday, 8 September 2011

Victorian Medical Director of Organ and Tissue Donation
- Dr H Opdam, Victorian Medical Director of Organ and Tissue Donation
- Ms B Dwyer, Clinical Manager, DonateLife

Assoc. Prof. Nicholas Tonti-Filippini

National Health and Medical Research Council
- Prof. M Otlowski, Dean and Head of School, Faculty of Law, University of Tasmania
- Mr M Sammels, Director Health and Research Ethics

Centre for Eye Research Australia
- Dr G Pollock, Director, Lions Eye Donation Service, Centre for Eye Research Australia

Austin Hospital
- Prof. R Jones, Head, Liver Transplant Unit

Alfred Hospital
- Dr S Philpot, Intensivist, Medical Director for Organ Donation
- Mr S Taffe, Legal Counsel
- Assoc. Prof. D Pilcher, Intensivist, Medical Director for Organ Donation
- Prof. G Snell, Lung Transplant Physician

Wednesday, 21 September 2011

Victorian Institute of Forensic Medicine/Donor Tissue Bank of Victoria
- Prof. S Cordner, Director, Victorian Institute of Forensic Medicine, and Medical Director, Donor Tissue Bank of Victoria
- Mr S Poniatowski, Acting Head, Donor Tissue Bank of Victoria
- Ms H McKelvie, Manager, Medico-Legal, Victorian Institute of Forensic Medicine

Royal Australasian College of Surgeons
- Prof. J Fawcett, Chair, Transplant Surgery Section

Rabbinical Council of Victoria
- Rabbi Y Glasman

Ad Hoc Interfaith Committee
- Mr R Ward, Victorian state director
- Rev D Palmer

Kidney Health Australia
- Ms K Johnson, National Manager, Government Relations and Health Policy
- Mr W McGlone, Chairperson, Victorian Consumer Committee

Progressive Judaism Victoria
- Rabbi F Morgan

Catholic Archdiocese
- Msgr A Ireland, Episcopal Vicar, Health and Aged Care
- Mr F Moore, Business Manager, Catholic Archdiocese of Melbourne

Transplantation Society of Australia and New Zealand
- Prof. P Macdonald, President

Friday, 2 December 2011

Alfred Health
- Mr A Way, Chief Executive Officer

Coroners Court of Victoria
- Judge J Coate, State Coroner
- Mr M Botros, Legal Policy Officer

Wednesday, 8 February 2012

- Hon D Davis MLC, Minister for Health
- Ms N Reinders, Acting Director, Integrated Care Branch, Department of Health

Appendix C: Section 26 Authority to remove tissue after death

26 Authority to remove tissue after death

(1) A designated officer for a hospital may, subject to and in accordance with this section, authorize the removal of tissue from the body of a person who has died in the hospital or whose dead body has been brought into the hospital—

(a) for the purpose of the transplantation of the tissue to the body of a living person; or

(b) for use of the tissue for other therapeutic purposes or for medical or scientific purposes—

where—

(c) the deceased person—

(i) had, at any time, in writing; or

(ii) had, during his last illness, orally in the presence of two witnesses— expressed the wish for, or consented to, the removal after his death of tissue from his body for such a purpose or use;

(d) subject to subsection (3), where the senior available next of kin of the deceased person makes it known to the designated officer that he consents to the removal of tissue from the body of the deceased person for such a purpose or use; or

(e) where the designated officer—

(i) after making such inquiries as are reasonable in the circumstances, is unable to ascertain the existence or the whereabouts of the next of kin of the deceased person; and

(ii) has no reason to believe that the deceased person had expressed an objection to the removal after his death of tissue from his body for such a purpose or use.

(2) Where the body of a deceased person is in a place other than a hospital, a registered medical practitioner and a person with an authority given under section 25(b) are authorized, subject to and in accordance with this section, to remove tissue from the body of the deceased person—

(a) for the purpose of the transplantation of the tissue to the body of a living person; or

(b) for use of the tissue for other therapeutic purposes or for medical or scientific purposes—

where—

(c) the deceased person—

(i) had, at any time, in writing; or

(ii) had, during his last illness, orally in the presence of two witnesses— expressed the wish for, or consented to, the removal after his death of tissue from his body for such a purpose or use;

(d) subject to subsection (3), where the senior available next of kin of the deceased person makes it known to the registered medical practitioner or authorized person that he consents to the removal of tissue from the body of the deceased person for such a purpose or use; or

(e) where the registered medical practitioner or authorized person—

(i) after making such inquiries as are reasonable in the circumstances, is unable to ascertain the existence or the whereabouts of the next of kin of the deceased person; and

(ii) has no reason to believe that the deceased person had expressed an objection to the removal after his death of tissue from the body for such a purpose or use.

Appendix D: Outline of the organ, eye and tissue donation sector[262]

Regulation	State and territory Human Tissue Acts and regulations. Therapeutic Goods Act (regulation or eye, tissue and HPC banking)		
	Clinical standards	**Professional Colleges and Societies**	
Processes and protocols	• ANZICS statement on brain death and organ donation • ATCA guidelines • NHMRC ethical guidelines • TSANZ protocols	• ACCCN • ACEM • ACEN • ACORN Inc • ANZCA • ANZICS • ANZSN	• ATCA • JFICM • RACGP • RACP • RSA • TNA • TSANZ
Organ donor coordination	State-based DonateLife agencies[263]		
Eye and tissue banking	• State/territory heart valve banks • State/territory skin banks • State/territory tissue banks • State/territory eye banks • State/territory bone banks • State-based organ donation agencies in some states		• ATBF • EBAANZ • RANZCO
Transplant centres	State/territory transplant centres		
Data collection	• ACGR • ANZLTR • ANZCOTR • ANZDATA	• ANZOD • NOMS • NPTR	
Training and education	Australasian Donor Awareness Programme (ADAPT)		
Community awareness & donor registration	Community Organisations Australians Donate Kidney Health Australia David Hookes Foundation Transplant Australia Zaidee's Rainbow Foundation Donor registers AODR		

[262] 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.33.

[263] This has been updated from the Taskforce Report to take into account the new DonateLife network.

Appendix E: Letter from Alfred Health

22 March 2012

AlfredHealth

55 Commercial Road
PO Box 315 Prahran
Victoria 3181 Australia
Telephone 03 9076 2000
www.alfred.org.au

Office of the Chief Executive
Andrew Way

EA Lisa Vandersluys
t 03 9076 2449
e ceo@alfred.org.au

Mr Matt Viney
Chair
Legal and Social Issues References Committee
Legislative Council - Parliament of Victoria
Parliament House
East Melbourne Victoria 3002

Dear Mr Viney

Inquiry into Organ Donation in Victoria

I write in response to your letter of 15 March 2012.

Please find attached a copy of the document that was provided to Seven Network (Operations) Limited under the *Freedom of Information Act* on 30 January 2012. The network subsequently made the document available to other media outlets.

The story that ran on Seven contained a range of misleading links. While we are aware that Seven had conducted interviews on the topic a week or two earlier, it was only the evening prior to the broadcast that The Alfred was approached to comment. At this point the news angle was set, promos for the story were ready to run, and while we were given a right of reply it was not going to change the tone of the story. Despite attempts to clarify issues with the reporter, the story ran without further consideration. The other media outlets that contacted the health service decided not to run the story once they had received the same clarification that Seven News had received.

I would make three comments in relation to the issue:

1. In the last three years at least, no funds have been taken from the lung (or any other) transplant program.

2. In years prior to 2010/11, the number of organs donated meant that not all funds received were allocated, and as with all programs those funds were used to support other areas of critical need or 'hot spots' in the health service.

3. This use of funds did not cause any constraint on the transplant programs and is entirely consistent with the Department of Health to health service funding allocation model as Alfred Health understands it. Within this model there is no mechanism for moving one year's unused allocations to another.

As I stated in my evidence to your committee, having decided on a level of investment for the lung transplant program and discussed it with clinical staff, it later had to be reduced. In other words the level of increase in investment was not as much as had been hoped, but there was no withdrawal of funds.

Alfred Health incorporates
The Alfred
Caulfield General Medical Centre and
Sandringham & District Memorial Hospital
ABN 27 318 956 319

The use of a child (under 16) in the Channel 7 piece is misleading as the Paediatric Lung Transplant Program is funded under a different arrangement by the Federal Government as a nationally dedicated centre and there has never been any constraint on paediatric lung transplants. My understanding is that this was also clarified with the Seven News reporter.

I hope this information is helpful to the committee.

Yours sincerely

Andrew Way
Chief Executive

Attachment 10

AlfredHealth

For noting **5 October 2011**
Agenda Item 7.3

Lung Transplantation

Introduction

The Board will recall that in a resolution to achieve a balanced budget whilst still attempting to meet key access and performance targets, it accepted a recommendation to reduce the intended investment in a number of areas, including Lung Transplantation. In view of the considerable patient and media interest, I felt the Board would wish for a specific briefing on this matter. In producing this briefing I have discussed matters with, amongst others, Dr Trevor Williams, Clinical Director of the lung transplant program, officers at the DH, and senior operation managers at The Alfred. The situation remains fluid so this briefing will be verbally updated as necessary at the Board meeting.

Background

Lung transplantation has taken place at The Alfred since 1990 as a natural expansion of and collaboration with the longer established heart transplant program. The Alfred is the only centre in Victoria undertaking heart, lung, and heart and lung transplants. Three other lung transplant centres exist in Australia, two of which also transplant hearts. The Alfred had recently been designated as the only paediatric lung transplant centre in Australia. The Alfred, along with five other centres in Victoria also undertakes Kidney transplants.

To date the shortage of organs has been the constraining factor on the scale of the program with approximately 40 lungs (one or both sides) being transplanted each year until 2009. The Federal Government's initiative to increase donations was initially met with considerable scepticism by both individual clinicians and organisations. However the increase in use of Donation after Cardiac Death (DCD) has seen a considerable rise in the availability of organs. Lungs, because of their structure, are more robust than some other organs so are particularly useable following DCD.

Transplant programs at Alfred Health are funded by a mix of block grants and activity based funding. Additionally the DH assumes direct funding contributes 80% of costs to a program, whilst the remaining 20% is covered from other non-specified grants such as 'complexity' and 'training & development'. Separately the DH and The Alfred have reviewed the income and expenditure of the service and reached different conclusions as to the net position. Recently (this week) the DH agreed that we should initiate a review of sources and allocation of funding for our transplant services with a view to agreeing the differences in our understandings. The rate of transplantation has risen from less than one per week (40 pa) to 1 to 2 per week (80 pa) and at the current rate, should no other intervention take place I am advised we would undertake 90+ transplants in 2011/12.

The waiting list for transplantation has been relatively steady at about 50 and over recent months has reduced to 40. Approximately 2 patients a week are assessed for suitability for transplant and most are added to the waiting list (6-8 per month). In addition to removal for transplantation, 1-2 patients per month are removed from the waiting list for clinical or other

reasons e.g. commenced or recommenced smoking, too clinically unstable. Any individual patient's wait is primarily determined by the suitability of donated organs rather than length of time on the waiting list.

The Alfred raised, amongst a range of issues, the additional costs of transplantation at its budget review meeting with the DH in August of this year. At that point, 400 additional WIES were offered for general growth, and in the confirmatory spreadsheet none of these WIES were identified as being for transplantation. The income received per transplant has reduced from $228k (whilst health CPI has risen by 12.58%, which would make the comparator $258k) to $175k between 2007/8 and 2010/11.

Once it became clear that the minimal level of investments that we had hoped to provide to the rapidly growing adult lung transplant service were not likely to be possible, it became necessary to have a conversation with the clinical staff. This discussion caused the initial stories in the media on Saturday 17 September.

Subsequently and separately, the clinical director for the service advised me that the current clinical workload in the unit had reached something of a cross roads, in that in his view, there was such a high volume of clinical workload for the transplant physicians that he felt the possibility of unnecessary adverse clinical events was becoming too high. As part of that discussion I accepted the need to temporarily reduce the level of transplantation undertaken at The Alfred by agreeing that no adult lung transplants should take place other than those where retrieval had included the heart. The heart and paediatric lung programs are unaffected by this position.

Arguably the two are intrinsically linked; an earlier investment may have reduced the necessity to reduce the program. Had the initial investment not had to be reduced the current clinical team may have 'soldiered on' and covered the service. It is impossible to know with certainty.

Role of DH and media management

The DH necessarily has two important roles, one ensuring that patients are appropriately managed by the health service, and secondly the political direction set by the Minister for Health and Ageing is achieved. The briefings that were given to the media were developed in collaboration with the DH media offices. The message tried to separate the two actions, but of course, not unexpectedly, the two became linked.

Unexpectedly, Federal Parliamentary Secretary for Health and Ageing, Catherine King, entered into the debate over the weekend of 24 September, raising a mismatch in intents between governments. At this point, I asked our communications team to ensure that Alfred Health remained outside (above) the political debate.

I have received a little over 40 letters from concerned members of the public, mostly transplant patients or relatives, most of whom have provided a pro-forma letter that appears to have been initiated by Cystic Fibrosis Victoria. Many of these letters were copied to either the Premier or the Minister for Health and Ageing, or both. I have also received representations from the CEO of Cystic Fibrosis Victoria and the Australian Lung Foundation.

Current Position

The program operated at a reduced level between 4.00pm on Thursday 22 September and the evening of 28 September. We initially anticipated a two week reduction in activity, but in dialogue with the clinical staff we believed it reasonable to recommence after a shorter period as the inpatient clinical workload reduced and some key staff returned from leave.

During this period one unsuccessful paediatric transplant retrieval took place and one set of organs was declined. As far as I can ascertain there were no deaths whilst waiting.

All those members of the public and ex-patients who wrote to me objecting to the changes have been notified of the current position, all patients on both the heart and lung transplant waiting list have been written to advising that the program has returned to normal working. I have similarly advised the CEO of CF Victoria, Medical Director of DonateLife and the Chair and CEO of the Australian Lung Foundation. I have also informed staff of the position using the weekly information bulletin.

Financial Considerations

Our financial review of the service indicates the following for lung transplantation (excluding retrieval):

For 2010/11

Item	Income $000's	Expenditure $000's
Inpatients	6386	9200
Outpatients	801	3026
Pharmacy		2400
Specified Grant	5623	
Total	12810	14626
Gap		1810

Based on the DH assertion that direct income should cover 80% of costs (which we currently cannot validate, currently we estimate non-specified grants provide 10% of DH funding) you would expect $11,700,000 of income to be available. In this instance $12,810,000 has been received. At 90% this is a shortfall of $353,000. A similar position exists for heart transplants.

For 2011/12, we have not been able to undertake the same analysis, but the expectation is that with the additional income for transplantation being 142 WIES (valued at full cost at $529,000 – and we had already accounted for this at the margin making the impact on Alfred Health income substantially less) and $500,000 growth in specified grant the additional $1m Alfred Health is investing in the service, being the minimum acceptable to the clinical staff, continues to exacerbate the position.

Our accounting software and account structure, as specified by the DH, makes detailed analysis at the specialty level very difficult. We have had concerns about our abilities in this area for some time and have been working with a UK based team over the last few months on how we might increase our capacity and expertise in this area.

We have reviewed the likely reasons behind the financial position set out above, compared with the year to year budgetary gap experience. It is our belief that in the past, with transplant activity capped by availability of organs, full use of the specified grant has not been necessary, allowing this funding to be used for other clinical 'hot spots'. In effect this process has identified that this program may be adequately funded in 10/11 but is likely to be less so as we move forward without a revision of the block contract and an uplift that reflects both inflation and activity – particularly in the rise in transplant survivors. It also means that some other services are almost certainly less adequately funded.

Looking forward

The key question is, what is the 'normal' level of activity and how will this be managed? In particular, the success of DCD has meant a rapid rise in activity with a very long and very expensive consequence, particularly in drug costs, even after PBS and S100 rebates are taken into account. This issue was highlighted to the Finance Committee at its meeting on 28 September by Prof Michael Dooley, Director of Pharmacy.

As I have already commented, we have opened discussions with the DH to clarify each other's understanding of the financial position, so that at best we will agree on the problem, and at worst agree what it is we are not agreed upon and why. I believe we have jointly agreed to a piece of work reviewing current costs, looking towards the future likely workload. If this goes ahead, it will inform 2012/13.

For this year (2011/12), we have had more detailed discussions with the transplant team as to the scale of service they feel is clinically appropriate to offer. We have particularly raised with them the issues of very expensive abortive retrievals, transplantation for diseases with little or no supportive clinical evidence, and a range of operational issues including out of hours operating. At this time we have not been able to determine the new 'stable' level of donations that could be achieved, but it is likely to be in excess of 120 per annum, three times the volume for which the infrastructure was originally created.

For this year, we have made a number of further financial adjustments to the transplantation budget including taking account of some fortuitous non-recurrent income, the likely delivery of further internal savings, the part year nature of the effect of this year's investments and the potential for the achievement of additional funding in any mid-year review. With the expectation that the program will undertake approximately 90 transplants in this financial year, we believe that the most recently approved budget framework does not need further adjustment, although we will, as described earlier, be making several operational budget changes within that framework.

Andrew Way
Chief Executive
30 September 2011

Extract of proceedings

Legislative Council Standing Order 23.17 requires the Committee to include in its report the divisions which occurred during adoption of the report. The Chairman of the Standing Committee has a deliberative and casting vote in the event there is an equality of votes.

Meeting No. 18 — 27 March 2012

Chapter 7: Hospital funding and resources

Question - That Chapter 7, including findings 31 to 35 and recommendation 15 (excluding Mr Viney's foreshadowed additional paragraphs for insertion at the end of Chapter 7), stand part of the report – put.

Ayes 4	**Noes 4**
Mr Elasmar	Ms Crozier
Ms Hartland	Mr O'Brien
Ms Mikakos	Mr O'Donohue
Mr Viney	Mrs Petrovich

There being an equality of votes, the Chairman gave his casting vote with the Ayes.

Question agreed to.

Meeting No. 19 — 28 March 2012

Chapter 7: Hospital funding and resources

Mr Viney moved – That the following paragraphs be inserted at the end of Chapter 7:

Inconsistent Evidence to the Committee

The Committee became aware of a story which aired on Channel 7 News on 7 March 2012. The media report referred to a Freedom of Information (FOI) document from Alfred Health which suggested that money had been diverted from the lung transplant program into other hospital programs. The Committee subsequently wrote to Mr Andrew Way, Chief Executive Officer of Alfred Health, seeking clarification on his evidence to the Committee and the Channel 7 story.

Mr Way wrote to the Committee on 22 March explaining that there was a change in the level of investment for the lung transplant program, however there was no withdrawal of funds. Mr Way commented that:

1. *In the last three years at least, no funds have been taken from the lung (or any other) transplant program.*
2. *In the years prior to 2010/11, the number of organs donated meant that not all funds received were allocated, and as with all programs those funds were used to support other areas of critical need or 'hot spots' in the health service.*
3. *This use of funds did not cause any constraint on the transplant programs and is entirely consistent with the Department of Health to health service funding allocation*

> *model as Alfred Health understands it. Within this model there is no mechanism for moving one year's unused allocations to another.*[264]

A copy of Mr Way's letter and the document released to Channel 7 (an internal Alfred Health Board briefing note) provided to the Committee, is attached in Appendix E.

Conclusion on Alfred Health Resourcing Issue

The Committee, and the community more broadly through public comments by third party Health Organisations and their representatives, has viewed the Alfred Health resourcing issue and temporary closure of its lung transplant program very seriously. The Committee's evidence and events can be summarised as follows:

- *20 April 2011 - Alfred Health's written submission to the Inquiry seeks an increase in funding to meet their growing transplantation activity.*
- *8 September 2011 – Alfred Health's public hearing evidence again calls for additional resources for organ retrieval and transplantation.*
- *23 September 2011 – Alfred Health temporarily closes its adult lung transplant program due to an 'exceptionally high workload'.*
- *2 December 2011 – Alfred Health give further evidence in a public hearing to explain that the temporary closure of the lung transplant program was a result of pressures on staff and workload capacity.*
- *7 March 2012 – Channel 7 News report suggests Alfred Health funds set aside for the lung transplant program had been diverted into other programs.*
- *22 March 2012 – Alfred Health reaffirm that there was no withdrawal of funding from the lung transplant program in 2011 and that the temporary halt to its transplant program was due to a 'lack of investment' and pressures in workload capacity.*
- *The FOI briefing note to the Alfred Health Board indicates that to date the constraint on transplantations was due to a lack of donation, however recent increases in donation have not been matched with funding increases. In particular Mr Way advises his board that within a 400 WEIS increase, the Department of Health attached spread sheet shows that none has been allocated to transplantation services.*
- *The briefing note continues as follows: "Once it became clear that the minimal level of investments that we had hoped to provide to the rapidly growing transplant service were not likely to be possible, it became necessary to have a conversation with the clinical staff. This discussion caused the initial stories in the media on Saturday 17 September."*
- *The committee is concerned that this position, put to the Board by Mr Way on October 5th 2011, is inconsistent with the evidence given to the committee on December 2nd that year. In that evidence Mr Way indicated that the decision to close was based entirely on advice from Clinical Staff that transplantations had to cease due to workload pressure. He did not advise the committee that he had gone to the staff to advise them of the shortage of funding as is done in the briefing note to the Board.*

The Committee's evidence suggests there continues to be confusion and public concern over the reasons and impacts of Alfred Health's decision to temporarily close its adult lung transplant program in September 2011. Early evidence from Alfred Health to the Committee clearly highlighted the need for additional funding to meet increased transplant activity. However, this call for funding was not reiterated by the Alfred Health's Chief Executive Officer, Mr Andrew Way at the 2 December public hearing. Further, the Committee is concerned that

[264] Mr Andrew Way, Chief Executive, Alfred Health, letter to Committee, 22 March 2012.

Mr Way was not as clear and open in his evidence to the Committee as he was in his explanation to the Alfred Health Board.

As a result of these concerns, the Committee has, by a majority decision, determined to undertake two courses of action:

1. *To refer the cancellation of Alfred Health's Lung Transplant services and the causes of that cancellation to the Victorian Ombudsman for investigation and report.*

and

2. *To recall Mr Way to clarify his evidence and to examine the perceived inconsistency of his evidence. The Committee will provide a supplementary report to the House at the conclusion of that examination.*

Question – that the new paragraphs for insertion in Chapter 7 form part of the report – put.

Ayes 4	**Noes 4**
Mr Elasmar	Ms Crozier
Ms Hartland	Mr O'Brien
Ms Mikakos	Mr O'Donohue
Mr Viney	Mrs Petrovich

There being an equality of votes, the Chairman gave his casting vote with the Ayes.

Question agreed to.

Minority report

(by Mr O'Donohue, Ms Crozier, Mr O'Brien and Ms Petrovich)

CHAPTER 7: HOSPITAL FUNDING AND RESOURCING

Introduction

In Chapter 2 the Committee has detailed the success of the National Reform Agenda initiated by the Howard Government[1] and continued by the Rudd and Gillard Labor Governments. The Committee makes recommendations that this excellent work continue.

The growth in deceased donors in Victoria from 64 in 2009 to 107 in 2011 is significant. We congratulate the hospitals and medical professionals involved in this life saving work.

The majority in addressing hospital funding and resourcing have focused on two key points:

1.) The establishment of growth targets in relation to Commonwealth and State funding;

2.) The six day period of reduced activity in the transplant program between 4pm on 22 September 2011 to the evening of 28 September 2011.

These two issues, together with the alternative proposed by the minority, are dealt with below.

Targets

The majority in Chapter 7 have focused on the need for specific targets on the number of organs transplanted. We believe, however, that the setting of specific targets in relation to organ transplantation is an overly simplistic measure when health services manage their budgets to balance a range of competing and complex priorities. In addition, Victoria plays a significant role in relation to organ transplant services for Tasmania, southern New South Wales, South Australia and New Zealand making the setting of targets unrealistic.

Moreover, there needs to be a better understanding of the impact of continued growth and the relationship between this growth and the need for additional investment in both medical professionals, equipment and physical infrastructure. For example Mr Andrew Way the CEO of Alfred Health advised the Committee-

> *If we get to 120 or 130, we have to then say, 'Are we going to have to create effectively a second transplant program in order to cope with that step from 130 to 150, if we get to that place, and if so, how do we do that, or would it be better that another centre creates another program, so we have the resilience of two programs, two sets of hospital capacities and so on?'. There are some quite big questions if the program continues to grow at the rate it is going.*
>
> *The current view is that it will probably stop growing at around 120 to 130, so it is probably reasonable to contain it in one, within the state, but once you go to a step increase outside, you have got — absolutely right — a very difficult problem of not only the surgeons but particularly the transplant physicians. These are the people who deal*

[1] Media release, Minister for Health and Ageing, Hon Tony Abbott MHR, 19 February 2006

> *with the physiology, who manage the patient over a much longer period of time and who are incredibly difficult to support and to find.*[2]

The minority consider that without clarity regarding these the setting of targets is inappropriate.

Alfred Health

The Alfred Health transplantation program generated significant media interest during the course of this inquiry, particularly when it became known that the transplant unit operated at a reduced level for a six day period from 4pm on 22 September 2011 to the evening of 28 September 2011.

Much of the debate around this matter has raised questions about funding, availability of suitably qualified health professionals and the resource allocation decisions made by Alfred Health.

We note that in May 2011 the Victorian Budget delivered $24 million of growth funding to Alfred Health, including additional resources for transplantation services.[3]

We are concerned that the focus of the majority on this issue has the potential to have negative adverse consequences and detract from the great benefits of the organ donation program.

It is regrettable that the majority have focused a disproportionate amount of the Committee's time and energy on evidence given to the Committee on the reduced level of activity of the Alfred transplant unit.

State funding

Victoria is leading the nation in terms of organ donation.

The recent trends and excellent work of DonateLife Victoria suggests the total number of organ donors (subject to ongoing Commonwealth funding being secured) should continue to rise. The increase in organ donors has had and will continue to have a corresponding impact upon hospital transplant activity.

The Committee received evidence highlighting the downstream resourcing challenges flowing from the increased number of organ donations. Dr Helen Opdam discussed the challenge presented as a result of the demand increase for the 'downstream aspects of transplantation' in her evidence to the Committee-

> *We need to ensure that there is no loss of a donor due to the inability to facilitate donation. I say that because although this national funding has been very effective – we have doubled our rate in Victoria over four years – the funding is all at the donation end. The national funding is not funding any of the downstream aspects of transplantation. It does not fund the surgical retrieval service. There is a team of surgeons who has to come to where the person has died, whether it be the hospital in Shepparton or Mildura or the Alfred or the Austin, and they undertake the organ donation operation. The organs then need to be transplanted into the recipient by surgeons. There is tissue typing that needs to be done, so there is a lag, to check carefully that there is going to be a suitable match. That often means calling people into the lab out of hours, and it takes many hours to do that tissue typing cross-*

[2] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 178.
[3] *The Saturday Age* 24 September 2011, Page 1, Alfred closes door on transplants, Julia Medew

> *matching. Then you need the team of doctors and nurses and other staff who care for the recipients who have received the transplant.*[4]

The Committee sought a response from Dr Opdam on the capacity of hospitals to deal with the current increase in donation rates-

> *There has been no new funding, nationally, for those activities, yet they are dealing with a doubling in the activity as a result of the success of the donation program."*[5]

The Transplantation Society of Australia and New Zealand also raised concerns over hospital capacity to meet an increase in transplants –

> *A specific area that needs urgent attention is hospital infrastructure/capacity. The increase in transplant activity has already placed a strain on existing transplant programs and the hospitals in which they operate particularly utilisation of operating facilities and intensive care beds. Increased demand for these acute hospital services to enable increased organ transplants impacts on major elective and emergency surgery and other hospital programs that rely on these services. We regard an expansion of hospital staffing and infrastructure to meet the increased organ transplant activity without negatively impacting on other acute hospital services as a major priority.*[6]

The Royal Australasian College of Surgeons noted that, resourcing constraints are impacting upon the direct organ transplant services as well as ancillary and downstream services-

> *… there should be recognition within funding models that many donation-related medical activities occur out of standard operating hours. This has a wide impact on the availability of appropriate staff. This includes non-medical staff, including ancillary services including social work, translator services and pastoral services for example. Additionally, any increased level of donations will include a higher demand placed on procedural diagnostic services to assess suitability for donation.*[7]

The Minister for Health, Hon David Davis, at a hearing on 8 February 2012, advised that the Victorian Government has made additional resources available in 2011-12 in response to increased transplantation activity-

> *State Government invests more than $40 million in transplant services in 2010-11…*
>
> *This year, 2011-12, in recognition of the increased transplantation required with the growth of organ donation rate of 2009 and 2010, we have provided an additional tagged investment of $2.7 million to support the growth in these services and also additional general funding, but we acknowledge that there is still more that will need to be done.*[8]

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[4] Dr Helen Opdam, Organ and Tissue Donation in Victoria, *Transcript of Evidence*, 8 September 2011, p. 50.

[5] ibid.

[6] Transplantation Society of Australia and New Zealand, Submission No. 28, p. 2.

[7] Royal Australasian College of Surgeons, Submission No. 23, p. 2.

[8] Minister for Health evidence, 8 February 2012, p.2

Commonwealth funding

The Commonwealth, through the National Reform Agenda, has done much to raise community awareness about organ donation and has provided in-hospital support to promote and coordinate organ and tissue donation in Victoria's hospitals.[9]

The Commonwealth funding for the National Reform Agenda is set to expire on 30 June 2012. The Organ and Tissue Authority has advised the Committee-

> *'The Australian Government has committed recurrent funding for continued implementation of the organ and tissue donation national plan to increase organ donation and save lives…Negotiations are underway for the 2012-2014 funding agreements and are intended to be finalised before 30 June 2012'.*[10]

While we welcome the commitment to ongoing funding, we are concerned that there is no guarantee that funding will be increased and that the proposed funding agreement is for a two year period only.

Centre of excellence

Victoria is fortunate to have a long tradition of being a leader in medical specialisation, research, innovation and patient care. There are many examples of the recent recognition of Victoria's national role in medical collaboration including the Melbourne Brain Centre and the Victorian Comprehensive Cancer Centre.

Discussing Victoria's leading role in the context of the need for Commonwealth collaboration, Minister Davis stated:

> *I think to be fair, the nationally funded program is a significant help in that regard. Over a longer period, Victoria has had some Commonwealth assistance which is welcomed. It is fair to say—and this is not in any way a party political comment, I think it is broader—that Victoria would like a sharper share of funding in health generally, and probably that is actually a comment we would make across a number of portfolio areas. The answer is, I think the clinical base, the research base and the quality education base here is something that suits us very well to building the capacity and the infrastructure that matches the high level of research outcomes that are beneficial to not just Victorians but at a national level as well.*
>
> *We do transplant work effectively for Tasmania and much of the southern part of New South Wales and South Australia and so forth. Indeed, talking to the New Zealand minister recently there is quite a lot of movement across the Tasman as well. There is an argument for greater recognition of that without in any way being*
>
> *churlish about the fact that several Commonwealth governments have recognised the need to put this on a more national footing.*[11]

[9] Department of Health (Victoria), Organ and Tissue Donation, http://www.health.vic.gov.au/organdonation/

[10] Yael Cass, CEO Organ and Tissue Authority, email to the Committee dated 19 March 2012

[11] Minister for Health Evidence, 8 February 2012 p. 11

Professor Bob Jones of the Austin Hospital stated:

> *We operate in all the other states without being licensed, because it has been impossible to license. We travel interstate and operate with no licences, nothing, and then travel back. That is partly because the system is not geared to cope with this sort of interstate-national service; it has been a sort of cottage industry that has grown up outside our regular practices, and it is only recently that some of the regulations and government structures have been able to cope with this. Perhaps this is apropos of what is happening in Victoria, which is starting to look at the structure and make some structural changes.*
>
> *Victoria has made significant changes in ICU, and we have one of the better structures that exist across the states. It has been gradually incorporated into the way intensive care units manage their patients.*

Training medical staff involved in organ donation and transplantation was also a matter raised by a number of health services. It can be many years before a medical professional has reached the required level of training to undertake work within the organ donation and transplantation speciality. A further issue is that it is often difficult to attract new, young doctors into this field simply because it is fairly demanding and requires them to be available at any time of the day to undertake organ retrieval and transplantation surgery. Professor Greg Snell, Physician at the Alfred Hospital identified a need for succession planning, making time for recruitment and training and managing the demanding hours and stress within donation and transplantation units.[12]

Dr Steve Philpott, Intensivist and Medical Director at the Alfred advised that –

> *As a result of the success of that national campaign there has been an increase in the volume of organ transplantation cases recently, and whilst there has been a significant injection of resources into the organ donation aspect, there has been a much smaller focus on supporting transplantation activities. We feel that more resources should be directed towards strategies aimed at improving the success of organ retrieval and transplantation and developing and maintaining an appropriately trained and supported workforce in the fields of not only organ donation but also organ transplantation, including transplant surgeons and physicians, transplant nurses and allied health professionals and intensive care staff.*[13]

Mr Way believed Alfred Health's transplantation units would benefit from additional nurse coordinators-

> *The team tells me that the most important need is nurse coordinators, so the nurses who actually manage the patients over long periods of time, and then after that is a transplant physician, and then after that it is the transplant team services in general, the sort of administrative stuff.*[14]

Subject to appropriate ongoing funding for the National Reform Agenda, it is likely that growth in organ donation will continue. Meeting this growth is multifaceted and has implications for resourcing, training and downstream services.

Given the negotiations to extend current Commonwealth funding for the National Reform Agenda extends only to 30 June 2014, an opportunity for both governments to work together to consider a new way of funding this important and growing area of specialisation. A centre of excellence could, working with the major health services, have the function of projecting

[12] Prof. Greg Snell, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 102.
[13] Dr Steve Philpott, Alfred Health, *Transcript of Evidence*, 8 September 2011, p. 98.
[14] Mr Andrew Way, Alfred Health, *Transcript of evidence,* 2 December 2011, p. 178.

demand, research, infrastructure development, medical and health professional training, resource allocation as well as performing transplant services.

We are pleased to present the report to the Legislative Council together with the transcripts of evidence for the consideration of the Parliament in discharge of the reference given to this Committee.

Finding 1

The growth in demand is placing strain on transplantation services. There has been no new funding, nationally**,** for those activities, yet they are dealing with a doubling in the activity as a result of the success of the donation program.

Finding 2

National and Victorian initiatives to increase organ donation rates must be supported with additional resourcing so that the successes and future skills development in this highly specialised area of medicine and health care delivery can be further developed.

Recommendation 1

Victoria has a leading role in this highly specialised area of medicine and health care delivery. Building on the remarkable work of health services such as The Alfred and The Austin, the Victorian and Federal Governments give consideration to the establishment of a Centre Of Excellence for organ transplantation in Victoria.

Georgie Crozier, MLC

David O'Brien, MLC

Edward O'Donohue, MLC

Donna Petrovich, MLC

28 March 2012