Factors Contributing to the Decline in Living Organ Donations

Final Report
December 2013
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<tr>
<td>ABO</td>
<td>ABO blood group</td>
</tr>
<tr>
<td>ABOi</td>
<td>ABO-incompatible</td>
</tr>
<tr>
<td>AKX</td>
<td>Australian Paired Kidney eXchange</td>
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<tr>
<td>ANDD</td>
<td>Altruistic Non-Directed Donation</td>
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<tr>
<td>ANZDATA</td>
<td>Australia and New Zealand Dialysis And Transplant Registry</td>
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<tr>
<td>ANZOD</td>
<td>Australia and New Zealand Organ Donation Registry</td>
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<td>ARCBS</td>
<td>Australian Red Cross Blood Service</td>
</tr>
<tr>
<td>ATSI</td>
<td>Aboriginal and Torres Strait Islander</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>CARI</td>
<td>Caring for Australasians with Renal Impairment</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
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<tr>
<td>DDKTx</td>
<td>Deceased donor kidney transplantation</td>
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<td>ESCKD</td>
<td>End Stage Chronic Kidney Disease</td>
</tr>
<tr>
<td>ESRF</td>
<td>End Stage Renal Failure</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HLAi</td>
<td>Human Leukocyte Antigen Antibody Incompatible</td>
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<td>KHA</td>
<td>Kidney Health Australia</td>
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<tr>
<td>LDKTx</td>
<td>Living Donor Kidney Transplantation</td>
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<tr>
<td>LOTE</td>
<td>Languages Other Than English</td>
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<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<td>OTA</td>
<td>(Australian) Organ and Tissue Authority</td>
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<tr>
<td>PKD</td>
<td>Polycystic Kidney Disease</td>
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<td>Pre-emptive transplantation</td>
<td>Transplantation occurring prior to a patient commencing dialysis.</td>
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<td>SES</td>
<td>Socioeconomic status</td>
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<td>TSANZ</td>
<td>Transplant Society of Australia and New Zealand</td>
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<tr>
<td>Tx</td>
<td>Transplant</td>
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1 Executive Summary

1.1 Background
Since 2008 there has been a determined effort in Australia to lift rates of organ donation for transplantation through a national reform package, ‘A World’s Best Practice Approach to Organ and Tissue Donation for Transplantation’. These reforms have led to improvements in rates of deceased organ donation and transplantation rates. However, over the same period, the rates of organ donation from living donors (predominantly kidney donation) have declined. Living donor kidney transplantation (LDKTx) provides an important treatment option for some patients with end-stage chronic kidney disease (ESCKD), and in the context of a limited supply of deceased kidneys for donation, this decline has been a cause for concern.

This report describes the findings of a review commissioned by the Department of Health to identify possible reasons for the decline in rates of living organ donation in Australia since 2008.

1.2 Methods
This project involved two key activities:

- **A literature review** of the key Australian and international literature was undertaken to identify and describe key barriers to living organ donation and effective strategies for increasing living organ donation rates. This included a focus on understanding the context and issues relating to living organ donation in countries with high-performing deceased donation programs and comparing these with the Australian situation.

- **Consultations** with a range of stakeholders were conducted to obtain perspectives on living organ donation, views about the reasons for the recent decline in rates and suggestions for improving the process for living organ donation and transplantation. Stakeholders included:
  - Representatives from government bodies and departments
  - Nephrologists, transplant coordinators and other health professionals
  - Representatives from support and awareness organisations and clinical organisations
  - International experts in living organ donation
  - Kidney donors and recipients of LDKTx
  - People on the deceased donor waiting list.

Data from the stakeholder consultations was thematically analysed to develop key findings in relation to the factors impacting on rates of living organ donation in Australia. The findings from the stakeholder consultations and the literature review were then synthesised to develop this report.

1.3 Summary of findings
While there was no conclusive explanation for the decline in rates of living organ donation in Australia, two key hypotheses emerged:

- There was a temporary ‘spike’ in rates of LDKTx around 2008 due to:
  - More widespread use of ABO-incompatible (ABOi) transplantation
1 Executive Summary

- Overcoming resource limitations in some centres which cleared a backlog of patients
- Introduction of donor/transplant coordinators in some centres which increased capacity for LDKTx.
  - An increased rate of deceased donation had led to a decrease in the waiting list for a deceased donor kidney transplantation (DDKTx), which ‘took the pressure off’ the need to go ahead with living donation, in the minds of some nephrologists, potential donors and recipients.

This review uncovered a broad diversity of views and attitudes towards living donation in Australia. While some stakeholders were passionate about the need to lift rates of living donation, others were more circumspect, cautioning that efforts to improve rates of living donation or overcome ‘barriers’ may risk the unintended effect of lowering the safeguards for donors. Despite these differences, there was general consensus among those interviewed that opportunities do exist to improve the living organ donation and transplantation process. There was broad agreement that if the living donation experience is positive, streamlined and rewarding, and that the donor is given due respect for the gift they are giving, then people may be more inclined to donate, but that optimising outcomes for the donors and recipients should be the primary goal.

1.4 Opportunities

The general view is that Australia’s performance in relation to LDKTx is strong, in terms of quality of care, outcomes and rates of LDKTx (particularly when considered in relation to the population prevalence of ESCKD). However, stakeholders made a number of suggestions for improving policy and practice in relation to living organ donation, which were largely consistent with approaches discussed in the Australian and international literature. These included:

- Continuing to support and develop the Australian Paired Kidney Exchange (AKX) program
- Supporting clinical innovation to expand options and improve outcomes for donors and recipients (including those considered more marginal)
- Ensuring that living donors are not financially penalised by their decision to donate, by expanding financial reimbursement and support (the Supporting Leave for Living Organ Donors Scheme was viewed as a positive first step in this regard)
- Developing and ensuring consistent delivery of education and awareness-raising strategies around living donation, targeting:
  - the general public
  - potential donors and recipients (including having access to ‘mentors’ who are past kidney donors or recipients)
  - health professionals (including nephrologists, GPs and dialysis nurses)
- Increasing health system capacity to undertake LDKTx by addressing funding, staffing and theatre access issues where they exist
- At a national level, improving governance and leadership in relation to living organ donation. This includes:
  - Developing standardised clinical protocols and guidelines
  - Improving communication and collaboration between transplant units
  - Standardising funding arrangements (including reimbursement schemes)
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- Improving capacity for data collection through the Australia and New Zealand Dialysis And Transplant Registry (ANZDATA), including ongoing follow-up of all living donors to establish long-term outcomes
- Ensuring more timely reporting of data and establishment of minimum performance criteria
- Facilitating a consistent national approach to education about living organ donation.

In addition, a number of opportunities for further research arose from this project. These include:

- Conducting a more granular analysis of LDKTx at the level of jurisdictions/transplant centres to identify variations in funding, policies and clinical practice that may impact on rates of living organ donation
- Supporting the ANZDATA live donor registry in order to build the evidence base around long term outcomes (particularly for donors who are considered marginal)
- Sociological and social biology research into the reasons why people consider living kidney donation (from both the donor and recipient perspectives), and the short- and longer-term psychosocial impacts of these choices
- Developing a better understanding of the characteristics of the potential donor pool, including the numbers who present for donation and the attrition rate during the workup process
- Understanding local public opinion regarding altruistic non-directed donation (ANDD), which may be useful in determining whether consideration of strategies to increase this potential donor pool is warranted
- Further investigating variations in access to and rates of LDKTx between population subgroups (particularly Aboriginal and Torres Strait Islander people and socioeconomically disadvantaged groups).

In addition, the planned review of the Supporting Leave for Living Organ Donors Scheme may provide some insight to the extent to which financial factors act as a barrier to living donation in the Australian context.

A key theme emerging from this review is that while opportunities exist to improve the practice of living organ donation in Australia, these efforts should be considered as one aspect of the broader goal of improving outcomes for Australians with ESCKD.
2 Introduction and Background

2 INTRODUCTION AND BACKGROUND

2.1 Organ Donation in Australia

Organ transplantation is the most cost-effective treatment for end-stage chronic kidney disease (ESCKD) and the only available life-saving treatment for end-stage failure of organs such as liver, lung and heart. Australia has seen an ever-increasing number of patients with organ failure on waiting lists for transplantation over past decades. As Australia’s population ages and the prevalence of chronic diseases such as diabetes increases, these waiting lists are likely to continue to grow. There are currently around 1,600 Australians on organ transplant waiting lists.\(^{1}\)

2.1.1 National Reform Agenda: ‘A World’s Best Practice Approach to Organ and Tissue Donation for transplantation

Australia has historically had low rates of organ donation and transplantation, despite being a world leader for successful transplant outcomes. In 2008, the Australian Government, with state and territory governments, implemented a national reform package, ‘A World’s Best Practice Approach to Organ and Tissue Donation for Transplantation’ (the National Reform Agenda) in an effort to lift donation rates.

The National Reform Agenda included funding of $151 million over four years and comprised nine measures that aimed to establish Australia as a world leader in best practice organ and tissue donation for transplantation.\(^{2}\) These were:

Measure 1: A new national approach and system - a national authority and network of organ and tissue donation agencies (the Organ and Tissue Authority)

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

Measure 3: New funding for hospitals

Measure 4: National professional education and awareness

Measure 5: Coordinated, ongoing community awareness and education

Measure 6: Support for donor families

Measure 7: Safe, equitable and transparent national transplantation process

Measure 8: National eye and tissue donation and transplantation network

Measure 9: Additional national initiatives, including living donation programs

The Organ and Tissue Authority (OTA) was established on 1 January 2009 as an independent statutory agency within the Australian Government Health and Ageing Portfolio to implement the following aspects of the National Reform Agenda:

- A nationally coordinated approach and system for organ and tissue donation, known as the DonateLife Network. At the end of December 2010, the DonateLife Network comprised 234 staff, including 162 clinical specialists in organ and tissue donation in 77 hospitals across Australia. In addition, there were 72 staff in eight specialist organ and tissue donation coordination agencies (across each state and territory)

- Additional funding for hospitals to remove clinical barriers to organ and tissue donation

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2 Introduction and Background

- Enhanced and tailored national professional education programs for clinical staff on organ and tissue donation practice
- Delivery of a national public communication campaign to raise community awareness of, and action to, increase donation rates
- Delivery of nationally consistent support for donor families
- Maintenance and continual development of safe, equitable and transparent national transplantation processes
- A national eye and tissue donation and transplantation network as part of the broader DonateLife Network
- Development and implementation of the Australian Paired Kidney Exchange and Donation after Cardiac Death programs.

The reform package appears to be having a positive impact on organ donation and transplant rates. In 2012, 354 donors donated organs to 1,052 Australians. This is the highest number of organ donors and transplant recipients since national records began. However, despite these improvements in overall donations, the rates of living organ donation have declined since 2008. Considerations relating to the practice of living organ donation and the possible reasons for this decline are the focus of this report.

2.2 Living Organ Donation

Most transplanted organs and tissues come from deceased donors. Living donation offers an alternative to deceased donor transplantation for patients who are suitable candidates for transplantation. It increases the existing donor organ and tissue supply and provides a source of some tissues that cannot be retrieved from deceased donors. Living organ donation usually involves the donation of a kidney. Donation of a partial liver, pancreas or lung are also possible but very uncommon (the latter two have not been performed in Australia). The first living donor kidney transplant was performed over fifty years ago and the procedure has now become an important treatment option for those with ESCKD.

Australia’s clinical guidelines for living donor kidney transplantation state that the ‘potential benefit of live donor transplantation needs to be weighed up against the likely outcome with the alternative options. For the individual recipient, factors to consider include the eventual or continuing need for dialysis, the suitability and possible outcome of deceased donor transplantation, as well as the likely waiting time for a deceased donor organ.’

In addition, there are also important ethical standards that must be met in order to safeguard the wellbeing of potential donors. These include:

- Donors must understand and accept the risk to themselves

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6 National Health and Medical Research Council. Organ and Tissue Donation by Living Donors: Guidelines for Ethical Practice for Health Professionals. NHMRC, Canberra, 2007.
2 Introduction and Background

- There must be a very low chance of harm to the donor’s physical or mental health, at the time of the transplant or in the future
- There must be a very high chance that the transplant will be successful.

Further, 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. ⁹

Throughout this report, unless otherwise specified, the term ‘living organ donation’ and ‘living kidney donation’ will be used interchangeably, since living kidney donation accounts for the vast majority of living organ donation in Australia.

2.3 Rates of living organ donation

The most pertinent information regarding rates of living organ donation in Australia is provided by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA Registry) and the Australia and New Zealand Organ Donation Registry (ANZOD Registry). The ANZDATA Registry records the incidence, prevalence and outcome of dialysis and transplant treatment for patients with ESCKD. In addition, ANZDATA has also established a Living Kidney Donor Registry which aims to record and clarify long-term donor outcomes in Australia and New Zealand.

As shown in Figure 1, between 1991 and 2009, the annual number of kidney transplants performed in Australia increased by 65% (from 470 to 772 transplants). This was largely due to the rise in donations from living donors, which increased more than four times during this period (from 78 to 326 transplants). This rise can be attributed in part to changes in the surgical techniques used in removing kidneys from living donors over that time. Currently almost all surgeries use the less invasive laparoscopic technique and the length of hospital stay for donors has decreased. ¹⁰

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Figure 1: Number of kidney transplants from deceased and living donors, 1991 - 2009\textsuperscript{11}.

However, in recent years, this previously upward trend in living donation has reversed. In 2012, 843 kidney transplants were performed in Australia, with live kidney donations comprising 28% of this total\textsuperscript{12}. This represents a reduction in both absolute numbers and proportion of total donations from a peak in 2008, as shown in Figure 2.


2 Introduction and Background

**Figure 2: Australian kidney transplants, deceased and living, 2007 - 2012**

In 2012 there were four live liver donations in Australia, and two in 2011.
Data Source: Australian New Zealand Organ Donor Registry.

2.3.1 International comparisons

The International Registry of Organ Donation and Transplantation has published data comparing the rates of living donor kidney and liver transplants around the world (see Figure 3). Identifying countries in which living donations are more frequently used and exploring the potential reasons for this provides some insight into the recent decline in Australia’s living donation rates.

Of the countries with high-performing deceased donation rates, the United States is a leader in terms of LDKTx. However, the proportion of living donor to deceased donor kidney transplantations is similar to that of Australia.14

In contrast, while the rates of LDKTx in European countries with world-leading deceased organ donation rates (including Spain, Belgium and France) are increasing, they remain comparatively low.15 Although it could be argued that a shorter organ transplant waiting list and a higher deceased donor kidney transplantation rate may lessen the need for LDKTx, the authors of a recent international analysis found no relationship between these factors. They concluded that the factors influencing deceased donation are entirely different to those influencing living kidney donation and argued that efforts to increase kidney transplantation rates should consider living donation and deceased donation as completely separate and distinct entities. Further, they argued that ‘because the factors associated with increased

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2 Introduction and Background

LD KTx appear complex and, not readily amenable to simple policy changes, more study is needed to better understand how donor and recipient outcomes in LDKTx can be improved.16

While rates of organ donation and transplantation are often expressed in relation to ‘per million population’ (pmp), it is recognised by most experts that for kidney disease, it is more appropriate to use the population of interest as the denominator – in this case, the number of treated patients with end-stage renal failure (ESRF). When this is taken into account (as shown in Table 1), it can be seen that Australia’s rates of kidney donation are high by world standards.

Table 1: Comparative Kidney Transplant statistics 2010

<table>
<thead>
<tr>
<th>Country</th>
<th>TKTx pmp*</th>
<th>LDKTx pmp*</th>
<th>DDKTx pmp*</th>
<th>TKTx ptpESRF#∞</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>35.7</td>
<td>13.2</td>
<td>22.5</td>
<td>42.7</td>
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<tr>
<td>USA</td>
<td>54.4</td>
<td>20.2</td>
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<td>39.1</td>
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</tr>
<tr>
<td>Spain</td>
<td>46.8</td>
<td>5.1</td>
<td>41.7</td>
<td>45.7</td>
</tr>
<tr>
<td>Japan</td>
<td>9.4</td>
<td>7.9</td>
<td>1.5</td>
<td>4.1</td>
</tr>
<tr>
<td>Norway</td>
<td>53.8</td>
<td>16.9</td>
<td>36.9</td>
<td>62.7</td>
</tr>
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</table>

Notes:
TKTx pmp = Total kidney transplant per million population
LDKTx pmp = Live donor kidney transplant per million population
DDKTx pmp = Deceased donor kidney transplant per million population.
TKTx ptpESRF = Total kidney transplant per thousand patients with ESRF
2010 data has been used as this is the most recent year for which a full set of data is available

2 Introduction and Background

Figure 3: Kidney Transplants per country and per million population

Source: Global Observatory on Donation and Transplantation Organ Donation and Transplantation Activities 2011 (updated 10/7/2013).
2 Introduction and Background

2.3.2 Implications of the declining rates

Concern has been expressed at the decline in living organ donation rates (since 2008) in Australia for two main reasons. Firstly, compared with deceased-donor kidney transplantation, living-donor kidney transplantation enables earlier transplantation and is associated with superior long-term recipient outcomes\(^\text{17}\), although the relative advantage in outcomes of live donor over deceased donor transplants has reduced over the past decade.\(^\text{18,19}\) Secondly, the wait for a kidney transplant is costly in both human and financial terms. Hospital-based kidney dialysis costs an average of $83,000 per person per annum, while in contrast, a kidney transplant costs approximately $65,000 per recipient for the first year and $11,000 per year thereafter.\(^\text{20}\) Consequently, increasing the pool of living kidney donors is potentially both cost-saving and life-saving, and is viewed by many as an important goal.

2.4 Policy Context

2.4.1 Role of the Organ and Tissue Authority in Living Organ Donation

As outlined in Section 2.1.1, Measure 9 of the National Reform Agenda included ‘Additional national initiatives, including living donation programs’. In relation to living donation, the OTA is responsible for overseeing the Australian Paired Kidney Exchange (AKX) Program, and funded the ‘National Coordination Centre’ based at Fremantle Hospital in Western Australia to coordinate and manage the program. The AKX Program aims to increase living donor kidney transplants by identifying biologically incompatible donor-recipient pairs and matching them with other incompatible donor-recipient pairs. The program commenced enrolling donor-recipient pairs in August 2010, and appears to be a promising approach to increasing rates of living kidney donation.\(^\text{21}\)

The high level objectives of the National Reform Agenda are to increase the capability and capacity within the health system to maximise donation rates and to raise community awareness and stakeholder engagement across Australia to promote organ and tissue donation.\(^\text{22}\) However, with the exception of the introduction of the AKX program, the dominant focus of the OTA has been on deceased donation rather than living donation.

2.4.2 State/Territory governance of living organ donation

There are also jurisdictional and local policies relating to living organ donation. For example, the Reform Agenda prompted specific responses from a number of Australian state governments, such as New South Wales.\(^\text{23}\) In addition, there have been few, but isolated, schemes for compensating living donors such as travel assistance for donors in country areas of Western Australia. Eligibility criteria and processes for accessing such assistance have been inconsistent between jurisdictions. It is hoped that the recent introduction of the Supporting Leave for Living Organ Donors Scheme (Section 2.4.3) may be a step towards reducing this variation.

2 Introduction and Background

2.4.3 Supporting Leave for Living Organ Donors Scheme

A pilot initiative to support living organ donors commenced on 1 July 2013 at an expected cost of $2.6 million. A payment up to the national minimum wage for up to six weeks is available to employed living donors. The payment is made to the employer to cover two scenarios:

a) an employee uses their paid leave entitlements for the donation process; or
b) an employee has no leave entitlements but is provided with an ex gratia payment by their employer in place of income lost due to the donation process.

Depending on the scenario, the payment will then be used either to credit the employee’s paid leave entitlements or to reimburse the employer.

The scheme is managed by the Department of Health and delivered by the Department of Human Services.24

2.4.4 Guidelines and clinical criteria

Key Australian guidelines addressing living donation kidney transplants include those from the National Health and Medical Research Council (NHMRC)25, and the Caring for Australasians with Renal Impairment (CARI) group.26 Other local/jurisdictional guidelines also exist to guide practices in individual hospitals or health services.

The NHMRC and CARI guidelines cover issues such as the evaluation of potential living donors, psychosocial impacts of living donation, care of the donor and discussion of the ethical issues surrounding living donation. International guidelines, including those by the British Transplant Society/British Renal Association27 and recommendations from The Amsterdam Forum cover similar territory.28

In addition, many hospitals have developed centre-specific guidelines and protocols for LDKTx.

2.5 Potential reasons for the decline in living organ donation rates

Living organ donation is a complex process that has been described as ‘both an intimate and interpersonal exchange and, in most developed countries, a highly regulated clinical “exchange”.29 As

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such, rates of donation may be influenced by a range of medical, legal, regulatory, ethical, psychological, sociological and cultural factors.

Reasons for the decline in rates of living organ donation in Australia have been considered in a number of inquiries and reports, including the Victorian Legislative Inquiry into Organ Donation (2012)\(^{30}\) and the Increasing Organ Donation in NSW – Government Plan 2012.\(^{31}\) Proposed reasons include:

- Financial barriers to donation – some living donors may be left substantially out of pocket due to required time off work for recovery and other out-of-pocket expenses
- Transplant capacity – the increases in deceased donation and subsequent transplantation, may be impacting prioritisation of living donor programs
- Reduction of living donors – there may have been a bottleneck of living donors, which was cleared in 2008, and the current numbers may represent a stabilisation.\(^{32}\)

However, there has been limited evidence to support these postulated reasons for the observed decline.

2.6 Project Objectives

This project was undertaken in order to identify possible reasons for the decline in living organ donation since 2008. Factors considered include:

- Financial barriers to donation
- Transplant capacity (i.e. that increases in deceased donation and transplantation may be impacting prioritisation of living donor programs)
- Reduction of living donors (i.e. there may have been a bottleneck of living donors that was cleared in 2008, with the subsequent decline in rates representing a stabilisation)
- Health service related constraints (e.g. funding or personnel availability).

In addition, other possible reasons for the decline were also explored.


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3.1 Overview of project process

The following phases have been undertaken to complete this project:

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Project Initiation</td>
<td>Initial Briefing with the Department. Finalisation of project plan and stakeholder list Review of key documents</td>
</tr>
<tr>
<td>2. Preparation for stakeholder consultations</td>
<td>Development of consultation methods and tools Submission of ethics application</td>
</tr>
<tr>
<td>3. Stakeholder consultations and literature review</td>
<td>Completion of stakeholder interviews Literature review</td>
</tr>
<tr>
<td>4. Analysis and interpretation</td>
<td>Analysis of stakeholder consultations Development of key findings</td>
</tr>
<tr>
<td>5. Reporting</td>
<td>Development of draft report Delivery of final report</td>
</tr>
</tbody>
</table>

The project was undertaken between May and September 2013. The following sections describe phases 1 – 4 in more detail.

3.2 Project Initiation

During this phase, the project plan, list of proposed stakeholders, and key background papers were discussed and agreed with DoH. During these discussions, it was decided that a stakeholder workshop, which was specified as a requirement in the RFQ documentation, would not be necessary. It was agreed that the workshop was unlikely to add to the information elicited through the stakeholder interview process as in many cases, the stakeholders who were interviewed would again be represented at the workshop.

3.3 Preparation for stakeholder consultations

An ethics application was submitted to the Department of Health's Departmental Ethics Committee on 31 May 2013 and approval was granted on 1 August 2013.

Consultations targeted two broad categories of stakeholders: representatives from organisations and individual donors/patients.

For representatives from organisations (such as Government health departments, hospitals and transplant awareness/advocacy organisations), the interviews were designed to capture the respondents' views on living organ donation generally and on the reasons for the decline, including the relative importance of the following four proposed causes:

- Financial barriers to donation
- Transplant capacity
- Reduction in living donors
- Health service-related constraints.
3 Methods

For individual donors or patients, questions explored factors and issues relating to organ donation including:

- Opinions on live organ donation
- Effects on life and how decisions have been made
- Opinions of those around them (family and friends)
- Stories (worries, concerns, health).

Interviewees were also invited to comment on possible reasons for the recent decline in rates of living donation, and to make suggestions for improving the process of donation and transplantation.

Donors and patients were recruited with the assistance of health professionals from several hospitals who had offered during their interview to approach donors/patients, explain the project, and provide Plain Language Statement and Consent forms.

3.4 Stakeholder consultations and literature review

3.4.1 Literature review

A comparative literature review was undertaken to provide an analysis of living donor programs in countries with high-performing deceased donation rates and to compare and contrast these programs with the Australian situation. The literature review led to the development of a set of key evidence-based findings.

The details of the search strategy for the literature review, along with a report of the findings, can be found in Appendix A. A summary of the literature review findings is also provided in Chapter 4.

3.4.2 Stakeholder groups and sample sizes

Table 2 outlines the stakeholder consultations undertaken.

Most interviews were conducted by phone, with consent provided verbally or via email. One face to face interview was conducted, with consent provided verbally. Plain Language Statement and Consent forms were supplied to all participants.

Ten stakeholders elected to respond to the interview questions by email due to time constraints. Of those providing email responses, all were organisational stakeholders.

The table shows that the actual sample size for specialist hospital staff (20) was higher than the target (5), while the actual sample size for clinical organisations/associations (4) was lower than the target (10). This is because the membership of clinical organisations/associations is primarily made up of specialist hospital staff. The achieved sample size for specialist hospital staff therefore reflects the total number of consultations with this stakeholder group, while the achieved sample size for clinical organisations/associations reflects the number of organisations/associations whose members participated in the consultations.
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Table 2: Stakeholder consultations

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Target sample size</th>
<th>Achieved sample size</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisational representatives</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organ and Tissue Authority</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Government Health Departments</td>
<td>8</td>
<td>7</td>
<td>Included representatives from SA, NSW, VIC and QLD.</td>
</tr>
<tr>
<td>Specialist hospital staff</td>
<td>5</td>
<td>20</td>
<td>Included nephrologists (from transplanting hospitals and regional hospitals), transplant surgeons, donor coordinators, transplant clinical nurses (covering VIC, NSW, QLD, SA and WA). In addition, one clinical specialist in lung transplantation was interviewed.</td>
</tr>
<tr>
<td>International donation/transplant organisations/specialists</td>
<td>4</td>
<td>3</td>
<td>The Transplantation Society (International)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>NHS Blood and Transplant (UK)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Organizacion Nacional de Transplantes (Spain)</td>
</tr>
<tr>
<td>Clinical organisations/associations</td>
<td>10</td>
<td>4</td>
<td>The following organisations were represented in the interviews conducted with specialist hospital staff:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Transplant Society of Australia and New Zealand</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Australian and New Zealand Society of Nephrology</td>
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<td></td>
<td></td>
<td></td>
<td>Renal Society of Australia</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Transplant Nurses Association</td>
</tr>
<tr>
<td>Support and awareness organisations</td>
<td>5</td>
<td>8</td>
<td>Included representatives from:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Kidney Health Australia</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>ShareLife</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Organ Donation and Transplantation Foundation of WA</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Transplant Australia</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>1</td>
<td>Australian Red Cross Blood Service – Transplant Services</td>
</tr>
<tr>
<td>Individual donors/patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living organ donors</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Living organ donation recipients</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>People currently on the deceased donor waiting list</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

3.5 Analysis and Interpretation

A thematic analysis approach was used to analyse the data collected during the stakeholder consultations. Records from the stakeholder interviews (or emailed responses to the questions) were
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reviewed to identify key themes and common responses to the various issues examined during the process. Emphasis was placed on contextualising the different themes emerging from each of the stakeholder groups, in order to identify the key factors impacting on rates of living organ donation in Australia.

Findings derived from the document review, stakeholder consultation and the Literature Review were collated and synthesised and form the central component of this Report.

3.6 Limitations to methodology

The views expressed in this report are those of the stakeholders who agreed to participate. Due to the relatively small sample size and purposive sampling approach used, caution should be used in generalising these views to the broader Australian context. It was beyond the scope of this review to survey representatives from all relevant hospitals/jurisdictions. As such, barriers or issues identified by staff working at some centres may not necessarily be present within others. There was also considerable variation between the donors, recipients and patients interviewed in relation to age, health status, family situation and other circumstances.

Furthermore, the potential for bias within the sample of participating stakeholders cannot be ruled out because those who agreed to participate may have had stronger views (either positive or negative) in relation to living organ donation, that than those who opted out. For example, it is possible that the donors and recipients who agreed to take part in an interview may have had very positive experiences that they were keen to share, compared with those who preferred not to participate and who may have been more ambivalent.

Despite these limitations, a number of key themes emerged from each stakeholder group interviewed in relation to issues and opportunities for improving Australia’s approach to living organ donation.
4 Findings – Literature Review

4 FINDINGS – LITERATURE REVIEW

4.1 Aims of literature review
A review of the Australian and international literature was undertaken to identify and describe key issues and barriers to living organ donation and effective strategies for increasing living organ donation rates. The review focused on living donor kidney transplantation as this is by far the most common living organ donation procedure. The key findings are outlined in subsequent sections, and the full review (including search strategy) is provided in Appendix A.

4.2 Findings: Barriers to living organ donation
Four key themes emerged in relation to barriers to living organ donation. These are:

- Clinical contraindications in terms of both donor and ESCKD patient suitability to undergo LDKTx.
- Financial barriers, including the need to take unpaid leave and to pay for travel and accommodation.
- Demographic and cultural barriers.
- Societal attitudes, including the views held by:
  - potential donors
  - potential recipients
  - clinicians.

4.3 Findings: Initiatives to improve rates of living kidney donation
The search identified four broad categories for improving living kidney donation rates. These are:

- Broadening the pool of potential living donors through:
  - Performing HLA (Human Leukocyte Antigens) antibody-incompatible (HLAi) transplantation
  - Expanding donor criteria, i.e. accepting donors considered to be more ‘marginal’ in terms of some health conditions (e.g. people with obesity or proteinuria)
  - Paired kidney donation exchange programs (these enable a donor in an incompatible donor/recipient pair to be ‘matched’ with a recipient in another donor/recipient pair)
  - Increasing altruistic non-directed donation (ANDD) (where an individual donates to an anonymous stranger)
  - Financial reimbursement programs
  - Addressing cultural and socioeconomic disparities in donation rates
  - Education and awareness raising, including:
    - Donor education
    - Recipient education
    - Education and awareness-raising among health care professionals.
4 Findings – Literature Review

4.4 Discussion and implications

The literature review found that while there is a significant body of literature relating to the observed or theoretical barriers to living kidney donation, there is little information available describing effective interventions to overcome these barriers. A number of initiatives that would appear to logically lead to increased LDKTx rates have not necessarily been shown to do so. Key examples include financial reimbursement schemes and paired kidney exchange programs. The review also noted that there is no clear pattern in terms of the relationship between rates of living and deceased kidney donation in the international experience.
5. Findings – Consultations with organisational stakeholders

5 FINDINGS – CONSULTATIONS WITH ORGANISATIONAL STAKEHOLDERS

In this chapter, the key themes emerging from the organisational stakeholder consultations are presented. Organisational stakeholders included:

- Health professionals from hospitals where transplants take place (including transplant coordinators, nephrologists and allied health staff)
- Nephrologists from non-transplanting centres
- International experts in living organ donation
- State/territory government representatives responsible for overseeing living organ donation
- Representatives from support/advocacy organisations and professional groups.

See Chapter 3 for details.

These discussions were wide-ranging and complex. While the interview questions served as a guide and starting point, they did not limit the breadth of the conversations that took place. The key findings are described in the following sections.

5.1 Living organ donation in context

Most stakeholders agreed that LDKTx (and pre-emptive LDKTx in particular) is the ‘gold standard’ treatment for ESCKD, in terms of patient outcomes compared with dialysis or deceased donor kidney transplantation (DDKTx). However, they varied in the extent to which they felt that living donation should be encouraged or promoted, because of concerns that efforts to lift rates of living donation could have the unintended consequence of lowering the safeguards for donors. Further, several respondents took issue with the use of the word ‘barriers’ (to living organ donation) which was used in some of the interview questions, as they felt that many of the reasons why living organ donation may not take place are not barriers that can or should be overcome.

Whilst most respondents spoke of a need for balancing potential risks and benefits to both donors and recipients, some were very passionate about lifting rates, while others were more circumspect. This latter view was largely due to ethical concerns about exposing otherwise healthy individuals to the risks inherent in living kidney donation, and unease that the long term ramifications of living organ donation are inadequately understood.

A number of stakeholders also stressed that living organ donation needs to be considered as but one aspect of the broader goal of improving outcomes for Australians with ESCKD. Other elements highlighted included:

- Maximising rates of deceased donation.
- Optimising care and quality of life for patients on dialysis.
- Ensuring optimal follow-up care for patients following transplantation, in order to reduce the risk of graft failure and extend the life of the transplanted organ, thus reducing the demand for subsequent transplants.

In addition, stakeholders emphasised the importance of public health or preventative approaches to reducing the burden of CKD on the Australian population.
5. Findings – Consultations with organisational stakeholders

5.2 Explanations for the recent decline in rates of living organ donation

Stakeholders were invited to comment on the possible reasons for the recent decline in rates of living organ donation in Australia. While a wide range of possible limiting factors were raised, two key hypotheses emerged that accounted for factors that had changed over the last five to six years and could therefore explain the reduction in numbers. These are described below.

5.2.1 Artificial increase in LDKTx rates in 2008

A number of stakeholders suggested that the apparent decline in rates of living donation may be partially explained by a sharp increase around 2008. Proposed reasons for this spike included:

- Blood group incompatible (ABOi) transplants began to be performed more widely in Australia. This meant that transplantation could go ahead for a number of patients who were on dialysis but who had a potential donor who was ABO-incompatible.
- Resource limitations within some centres (e.g. difficulties securing theatre time) were overcome, enabling a backlog of patients to be cleared.
- The introduction of donor coordinators in hospitals in some jurisdictions facilitated the living donation process, which increased the capacity of these hospitals to perform LDKTx and possibly improved awareness of LDKTx as a possible treatment option for some patients on dialysis.

Several stakeholders suggested that the subsequent reduction in rates represented a return to underlying levels of demand. During the period of increased activity, the ‘low hanging fruit’ was collected (i.e. straightforward transplants were performed), thus the remaining candidates for LDKTx are more marginal and therefore more complex and time-consuming to work up – ‘A lot of younger, fitter, healthier patients have come to transplantation quickly and tend to keep the transplant a lot longer’.

5.2.2 Decline in living donation as a consequence of increased deceased donation

Respondents frequently cited the increase in rates of deceased donation that has occurred since 2008 as an explanation for the decline in living donation during the same period. Respondents considered that the rise in deceased donation (as outlined in Chapter 2) created the impression amongst the public that the waiting list for a kidney from a deceased donor was relatively short. This perception effectively ‘took the pressure off’ both potential donors and recipients, leading both parties to feel that the need to go through with living donation (and the risk it entailed) was less pressing.

The average time on dialysis awaiting transplantation has demonstrably fallen since 2008 (from 4.1 years in 2008 to 3.6 years in 2012) as a direct consequence of the increased availability of deceased donor organs. However, the extent to which the increase in deceased donation rates has actually led to a reduction in the waiting time for a deceased kidney was still questioned by some stakeholders who felt that it varied between jurisdictions and blood groups, and was still unacceptably high for many patients. Many respondents felt there was a mismatch between perceptions and reality, and that this

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5. Findings – Consultations with organisational stakeholders

was in part due to the positive messages from the OTA, which they felt unduly highlighted the success of the deceased donation program rather than stressing the need for more donors.

While the majority of stakeholders noted the relationship between living and deceased donation as outlined above, they varied in the extent to which they viewed this as problematic. Several stakeholders pointed out that a decline in living donation has accompanied an increase in deceased donation in other countries, and that this is in many ways unavoidable. Others viewed it as a failing of the organ donation system: ‘in some ways we are victims of our own success with deceased donor transplants’. Others felt that it indicated that demand was being met and that the reduction in living donation was an entirely appropriate and rational response on the part of potential living donors and recipients who may feel concerned about the risk that LDKTx entails and would prefer to avoid it if possible.

5.2.3 Suggestions for better understanding the data

Stakeholders suggested a number of ways for better understanding the changes in rates and for testing the two hypotheses outlined above. A number of respondents felt that a detailed review and analysis of changes occurring within all major transplanting centres (which was beyond the scope of this project) would be useful. It was suggested that changes in funding, staffing and hospital protocols within these centres may affect the national rates, since a small number of centres in Australia account for the bulk of the LDKTx performed. A large change within a single centre may have a significant impact on the national figures. Further it was suggested that individual clinicians can have a strong influence on rates within particular hospitals. The departure in 2010 of a nephrologist who was described as a passionate and charismatic advocate of LDKTx, reportedly led to a slump in rates within the hospital and state in which he worked.

Closer scrutiny of the data available through the ANZDATA Registry would enable a more granular analysis of the changes in rates of LDKTx within jurisdictions and within individual transplanting centres. If rates have gone down consistently across all hospitals and jurisdictions this may point to systemic factors (for example, a response to the increase in deceased donation rates), rather than intra-hospital issues. A number of respondents expressed concern about what they saw as delays in publication of information provided to ANZDATA as they felt this hampered timely responses to fluctuations in rates of living donation. This was contrasted with the situation for deceased donation, for which ANZOD registry data is required to be reported on a monthly basis.

5.3 The living organ donation process – key steps and critical factors

In the following sections, the living organ donation process is described in more detail in order to identify the key steps and critical issues and highlight opportunities to improve the process.

Living organ donation is a complex logistical process overlaid with an intricate array of social beliefs and motivations. Figure 4 provides a simplified overview of the process in order to provide a framework for discussing the factors influencing living donation. There may be a number of variations or exceptions to this process (e.g. cases of Altruistic Non-Directed Donation (ANDD)).
5. Findings – Consultations with organisational stakeholders

Figure 4: Simplified framework and key issues in the LDKTx process

- Patient with ESCKD considers LDKTx as a treatment option
  - Health professional discusses treatment options including LDKTx
  - Patient and family awareness of living donation

- Donor(s) and patient agree to proceed with living donation workup
  - Donor availability
  - Views and motivations of patients/potential recipients
  - Views and motivations of potential donors
  - Presenting and understanding information about risk.

- Workup takes place
  - Assessing recipient suitability
  - Assessing donor suitability
  - Education
  - Practicalities and logistics of the workup process

- Donation and transplantation proceed
  - Timing the surgery
  - Hospital capacity issues: staffing and funding

- Post-transplant care of the donor and recipient
  - Post-operative support
  - Longer term follow-up
5. Findings – Consultations with organisational stakeholders

5.3.1 *Patient with ESCKD considers LDKTx as a treatment option*

Health professional discusses treatment options including LDKTx

Most interviewees firmly believed that LDKTx should be raised with all patients with ESCKD as one of the options for renal replacement therapy, along with dialysis and DDKTx. The depth in which LDKTx was discussed would then depend on the clinician's assessment of the patient's suitability for this treatment option: if the patient was not considered a candidate for transplantation then it would only be mentioned in passing.

Some interviewees felt that there were some deficiencies in the extent to which LDKTx was discussed with patients, particularly in hospitals that had large dialysis units but no transplant unit, and suggested that this related to the clinicians' awareness of and comfort with LDKTx as a treatment option. While most felt that the majority of clinicians are, in principle, ethically comfortable with the concept of LDKTx, some respondents did feel that 'clinician bias' was an issue. For example, one interviewee suggested that nephrologists in some centres automatically excluded marginal recipients who more experienced clinicians may have been prepared to consider. One respondent suggested that some doctors had 'old fashioned' views about pre-emptive LDKTx, which included the idea that a recipient may not fully appreciate the gift of a donated kidney unless they had spent time on dialysis. There was also the suggestion that some health professionals made value judgments about who 'deserved' a donor kidney – for example, patients who were considered un-motivated to make the necessary lifestyle changes were deemed inappropriate.

Other suggested reasons why health professionals may not raise the issue of living donation included:

- overseas trained and culturally and linguistically diverse (CALD) health professionals may be less inclined to discuss living donation with their patients due to cultural and religious beliefs
- nephrologists in busy clinics may not have time to discuss LDKTx in any level of detail with their patients or answer questions that patients may have
- some younger nephrology registrars have a 'knowledge deficit' in relation to living donation
- within some privately run dialysis units, financial incentives may exist that deter clinicians to refer patients for LDKTx assessment.

When discussing living donation with their patients, health professionals generally reported taking a relatively cautious approach, suggesting that the patients ‘speak to their loved ones about living donation’ rather than ‘sending them off to find a donor’. This was considered important to avoid putting pressure on either the patient or the potential donor. This approach was contrasted with the approach taken in other countries such as the UK and the USA which respondents felt was more strongly focused on procuring a donor and was described by one as 'like a sales pitch'.

**Patient and family awareness of living donation**

A number of respondents reported having patients who proactively raised the issue of living donation, and in some cases had a family member who had volunteered to donate. They observed that these patients generally were from higher socioeconomic status areas, were better educated and more health literate than those who didn’t raise the issue. Many respondents reflected that there appeared to be greater awareness of deceased donation compared with living donation amongst their patients and amongst the community more generally. This was attributed in part to the public awareness and media efforts to promote deceased donation that have been undertaken by the OTA and other organisations.
5. Findings – Consultations with organisational stakeholders

Respondents also felt that there is a general lack of awareness in the community about what living kidney donation involves, and a tendency to underestimate the complexity of the process. They pointed to ‘myths’ about living kidney donation including the notion that ‘you only need one kidney’, which clearly is not true for everyone, as well as limited awareness of the AKX Program.

5.3.2 Donor(s) and patient agree to proceed with living donation workup

In order for a patient to progress down the pathway of living donation, he/she first needs to have a potential donor available, and secondly, both the patient and donor must agree to consider living donation as a treatment option. These key requirements are described below.

Donor availability

Respondents reported that for many patients, LDKTx using a kidney donated from a relative or friend is not an option because they do not have a willing donor. This was a particular problem for people who have immigrated to Australia from other countries (with family members remaining in the country of origin) and people who were unmarried. (Note that the more complex issue of donor suitability is discussed in Section 5.3.3).

Conversely, some respondents reported that some patients have as many as five family members offer to donate. This was often the case for young children requiring a transplant.

Views and motivations of patients/potential recipients

A clear theme emerging from the consultations was that the improved rates of deceased organ donation, and the publicity surrounding this, had led to a perception amongst potential recipients that the waiting times to receive a deceased organ have shortened. This is considered to have led many patients to opt to ‘sit it out’ on dialysis and wait for a deceased organ, rather than deal with the risks and complications inherent in living donation.

Consistent with the literature review (Appendix A) the stakeholders consulted pointed to a diverse and complex range of views held by patients/potential recipients. These included:

- A reluctance to expose a loved one to the risks involved with donating a kidney (this appears to be a particular concern in cases where an adult child offers to donate to a parent)
- Concern about possible changes in family dynamics (including issues of guilt and debt, particularly if the graft failed)
- A preference to wait on dialysis for a deceased donor kidney to avoid these medical and psychosocial risks. It was suggested that in some Asian cultures people are reluctant to accept donations from family members because of issues relating to gift giving and obligation
- Some respondents reported experiences with (a minority of) patients whose overwhelming ‘horror and terror’ of going on dialysis could over-ride concerns for the potential donors’ welfare: ‘Sometimes it is frightening how little they think about the donors’
- Some patients are compelled to accept a donation because of a desire to free their loved ones from having to care for them while on dialysis
- Some patients appear to have unrealistic, ‘magical thinking’ about the extent to which a transplant will restore their health.
5. Findings – Consultations with organisational stakeholders

Views and motivations of potential donors

Health professionals discussed a similarly wide range of potential donor views, as outlined below:

- Most donors were considered to be motivated by a desire to improve the quality of life of a loved one. This included enabling a loved one to stop dialysis or avoid it entirely.

- Some donors preferred the idea of donating a kidney to their loved one rather than have them receive a kidney of (in their view) inferior quality from an unknown deceased donor. This view was echoed by one nephrologist who commented that ‘people don’t usually die healthy...if my son needed a kidney I’d prefer to give him mine’.

- Donors were motivated by the idea that living donation could happen sooner and in a more controlled and planned manner, than deceased donation.

- Altruism was raised as a motivating factor, but several respondents suggested that in many cases altruism is overlaid with other motives, including self interest (e.g. freedom from looking after a sick person, and not having the lifestyle restrictions imposed by dialysis such as limitations on travel).

- Some donors felt compelled to donate because of sense of expectation from the patient. In some cases, this was in spite of their fear about the risks and consequences of donation.

- Practical issues were considered to impact on decisions to donate in some cases. These issues included concerns about taking time off work, financial impacts, pain and disability after surgery, and needle phobia.

As was the case for patients, health professionals believed that the shortening of the waiting list for deceased organs is influencing donors' decisions. It was suggested that the prospect of a shorter time spent on dialysis awaiting a deceased donor kidney could lessen the sense of pressure and urgency felt by living donors. It was suggested that some donors opted to have their loved one wait for a deceased organ and ‘save their kidney for later’ (i.e. for the patient's second or subsequent transplant).

Importantly, several respondents pointed out that it is likely that the views of the health professionals may influence the decisions of their patients or potential donors, but that many working in the sector are reluctant to acknowledge this. For example, one respondent thought it unlikely that patients would be receiving information about shorter waiting times for deceased kidneys through the general media, but rather, felt that this information is more likely to be conveyed via health professionals. Indeed, several health professionals reported that providing their patients with information about the likely waiting time for a deceased organ is essential as they considered it a key factor for donors and patients to consider before proceeding with LDKTx.

Presenting and understanding information about risk

All of the health professionals interviewed reported feeling comfortable discussing the risks of donation with donors and recipients. They noted that this was a mandatory part of their role, and vital from an ethical standpoint. As one nephrologist commented, ‘I would not be comfortable not having the conversation’. The discussions generally covered peri-operative risks as well as longer term health risks and lifestyle limitations. The possibility of donor death was raised: ‘there have been two donor deaths in Australia’; and, bluntly, ‘there is a chance you could die from surgery you don’t need’. Health professionals reported that there were some challenges in discussing longer term health effects, particularly for more marginal donors, due to a lack of longer-term outcome data. While the ANZDATA Living Kidney Donor Registry was considered useful, a number of respondents noted that it had not
5. Findings – Consultations with organisational stakeholders

It has been running for sufficient time to provide robust information about longer-term outcomes, and that it was not adequately resourced to prevent loss to follow-up.

Donor coordinators frequently reported discussing psychosocial risks and implications of donation with donors, including the possibility of changes in relationships and family dynamics which often cannot be foreseen. They recounted cases where marriages had broken down following the failure of a donated kidney, and a situation where a mother, having donated a kidney to her son, became unreasonably demanding and controlling of his life decisions. One respondent cautioned that 'the psychosocial and interpersonal issues are more complicated than we realise'.

In addition, psychological risk arising from the possibility that someone who was very keen to donate may proceed with workup and then be turned down for medical reasons, was also mentioned. This may be particularly profound for a parent hoping to donate to a child. Stakeholders spoke of the importance of upholding a donor’s right to a second opinion by a different nephrologist/transplanting centre if they were deemed an unsuitable candidate for donation, in order to mitigate this risk.

All respondents indicated that the majority of donors, having come forward to donate, were relatively fixed in their views and determined to donate - ‘the seed’ had grown in their minds from the time that their loved one was diagnosed with kidney failure. As such, they believed that the presentation of risk information was unlikely to affect the donors’ decision. In rare instances, donors may decline to proceed once they realise how complex the workup process and the surgery itself is.

In all dealings with donors during initial assessment and workup, all health professionals reported taking care to ensure that the donors felt free to opt out of donating, and reported providing donors with a non-specific medical reason for the donation not going ahead in order to make it easier for the donor to explain to the recipient that they would no longer be donating. They were also alert for any signs that the donor had been coerced into offering to donate either by the patient or other family members. Donor coordinators also recounted instances where it had emerged donors had been offered money to donate, or had been coerced to donate by others in positions of power (e.g. employers).

All respondents reported that discussions about living donation usually occur over the course of a number of sessions and that this was appropriate in order to address feelings or concerns that emerge over time.

5.3.3 Workup takes place

Organising a LDKTx has been described as ‘a huge job with 1000 different steps that need to be done one after another’. Key to this is the assessment and workup process which is undertaken to ensure that the process is appropriate and as safe as possible. Critical steps during this stage are:

- Assessing recipient suitability
- Assessing donor suitability
- Education

These factors are considered in the next sections, followed by a discussion of the logistical and practical challenges of workup identified by stakeholders.
5. Findings – Consultations with organisational stakeholders

Assessing recipient suitability
Stakeholders reported that comorbidities among potential recipients appear to be on the rise, and that this may be affecting rates of LDKTx. At the same time, however, staff from some centres reported being increasingly comfortable undertaking transplantation with more marginal recipients. Some interviewees felt that doctors whose awareness of the LDKTx process was more limited tended to dismiss patients that they deemed inappropriate on medical grounds, and that these patients were not referred to a transplanting centre for a second opinion unless the patient pushed for it. Other respondents reported referring recipients (and donors) that they considered unsuitable to other centres for a second opinion as a matter of course.

A key theme emerging from the interviews was that the adherence to clinical guidelines could be affected by the nature of the relationship between donor and recipient or other factors. For example, while the likely health benefit to the patient arising from transplantation is a critical factor in the decision to transplant, in some cases this may be overridden by a preference for maximising quality, rather than quantity, of life. An example was of a man who wished to donate to his spouse, who had a limited life expectancy due to cancer as well as comorbid ESCKD. In this case, death due to cancer but with a functioning kidney was considered a good outcome from the perspective of the transplant team and the family. This example illustrates that in the living organ donation process, judgements relating to the value of life, quality of relationships and other ethical issues are superimposed on the clinical decision making process.

Assessing donor suitability
Assessment of donor suitability can be a lengthy process. It includes cross-matching, assessment of renal function and general health, a renal angiogram and referrals to other medical specialists or allied health professionals as required. Different centres reported different arrangements in relation to how much workup can be coordinated by the GP, and how much takes place at the transplanting centre. Respondents consistently reported that donor coordinators were vital to the smooth running of the process.

In relation to the potential pool of donors (and the extent to which this may be impacting rates of donation) interviewees spoke of two opposing forces at play. On one hand, the increasing prevalence of health conditions such as hypertension and obesity were seen to be limiting the numbers of appropriate donors. This is considered to be a particular problem in Aboriginal and Torres Strait Islander (ATSI) populations amongst whom the risk of diabetic nephropathy is considerable and makes the identification of a suitable donor immensely difficult. Similar issues were noted for Maori and Pacific Islander populations. The increased propensity to consider more marginal recipients has also increased the number of more marginal donors presenting. For example, older patients may have spouses offering to donate, and these spouses are usually of a similar age to the patient.

On the other hand, therapeutic advances have made it possible to consider donors who once would have been excluded. While there are guidelines to support decision making, stakeholders indicated that these can vary markedly between centres, with some centres being more comfortable accepting older donors for example (conversely, some centres are more likely than others to accept donors at the younger end of the spectrum). Respondents suggested that this variation occurs between centres rather than within them, with staff within transplant units tending towards a unified view.

A key therapeutic advance increasing the potential for living donation to occur was the advent of ABOi incompatible transplants and growing knowledge and effective regimens to prevent antibody mediated
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rejection. Some centres were more comfortable with taking on this more ‘cutting edge’ work than others.

Another key aspect of the donor assessment process is establishing psychosocial suitability for donation. Stakeholders agreed that this should be assessed by a social worker, psychologist or psychiatrist with an in-depth knowledge of the organ donation process. In cases where a donor wished to donate altruistically to a stranger (reported as relatively rare in Australia) most stakeholders noted that the psychological assessment was more rigorous to ensure that the donor is psychologically stable and the motivation to donate is sound.

On the whole, interviewees felt that there were no fewer potential donors presenting for donation but that a smaller proportion of these donors were successfully making it through the workup process, most often for medical reasons (e.g. immunological issues or clinical contraindications). Reported rates of attrition or ‘drop off’ varied markedly between centres, but most respondents felt that the donors presenting had become more medically complex, which had the effect of both increasing the duration of the workup and increasing the rates of attrition. For example, it is not uncommon for the workup to be put on hold while donors attempt to lose excess weight (some have successfully lost 20-30 kilograms). Amongst the donors who were considered to be ‘genuine’ (i.e. who had sounds motivations for donation) it was rare for them to back down due to concerns about risk, or due to the inconvenience of the workup process. This suggests that the decision to donate is usually made before the donor presents to the transplant unit.

Education

Education of both the donor and recipient is a central aspect of living organ donation that begins in the early discussions with health professionals and is an ongoing focus of the workup process. Stakeholders agreed that education (which includes information about risks discussed in Section 5.3.2) is vital from an ethical standpoint. Whilst health professionals from different centres reported varied approaches to providing information (including group sessions, written resources and DVDs), they suggested that provision of a nationally consistent set of educational materials that were up-to-date, practical, appropriate for a range of audiences and available in languages other than English, would be helpful.

5.3.4 Practicalities and challenges of the workup process

The workup process for living donation was viewed by almost all respondents as a necessarily complex process, in order to ensure (as far as is possible) that donation would be safe for the donor and beneficial for the recipient. When asked about specific concerns, the following issues were raised.

Time

Stakeholders indicated that the time taken to complete workup can vary from six weeks to several months. While it was considered important not to rush the process in order to avoid any sense of coercion and to enable the donor and recipient to deal with any issues or concerns that arise, timely access to some services (e.g. angiography, tissue-typing, or cardiology consultations) was identified as a problem by a minority of respondents. Once workup is complete, the scheduled surgery may still be delayed if the donor or recipient becomes unwell, or due to resourcing issues within the transplanting hospital. Stakeholders suggested that these delays may be frustrating for patients and donors but would rarely be an impediment to a donation taking place.
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Costs
Stakeholders indicated that the majority of costs of the medical assessments are covered by Medicare, but donors may be left out of pocket due to travel costs, parking and time off work. For people living in rural or regional areas, travel costs are often higher, and they often have the additional cost of paying for accommodation. While financial support is provided to cover travel costs in some jurisdictions, this was described by some as inconsistent and inadequate. Several respondents suggested that access to allied health services to assist with smoking cessation or weight loss is not always freely available.

For patients whose potential donors live overseas, the workup process is particularly challenging. Some of the workup may be done overseas (depending on the health system in that country) but donors are required to come to Australia to complete the workup process. While in most cases these donors are not charged for the workup and hospital costs of admission, operation or follow-up, they may be left substantially out of pocket because of travel and accommodation costs and time off work. If the transplant cannot be scheduled in the same visit as the workup this can be particularly costly.

Coordination
Since the onus is on the donor to make the necessary appointments and arrangements for the workup (in order to avoid any sense of coercion or pressure from health professionals) there is a small chance that donors may not be able to navigate the process and ‘slip through the cracks’. However, as previously indicated, given the level of motivation of donors who reach this stage of the process, this is relatively uncommon. Respondents indicated that relatively few donors/recipients were from non-English speaking backgrounds, and in those cases interpreters were available and additional assistance provided to make appointments.

Most respondents felt that the increased numbers of donor coordinators or transplant coordinators within transplanting centres was a positive development, as this could assist donors to navigate the process, and also enabled better coordination with other health professionals involved in the workup process who were not based within the transplanting centres (this included nephrologists at smaller/regional hospitals or GPs).

5.3.5 Donation and transplant proceed
It was suggested that the ‘stars need to align’ in order for the donation and transplantation to occur on the scheduled date. Following completion of the workup process there may sometimes be delays to surgery taking place. These may be due to changes in health of the donor or recipient, or hospital-related factors.

Various opinions were voiced regarding the extent to which constraints within hospitals that limited the ability for donation and transplantation to proceed as planned. Not surprisingly, this varied between the jurisdictions and transplanting centres consulted. These factors are discussed below.

Timing of surgery
Some respondents reported that because living donation is an elective procedure (compared with DDKTx which is considered an emergency procedure) it can be bumped off theatre lists. This is compounded by the fact that the hospitals which undertake LDKTx are tertiary centres that are often busy with emergency cases.
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Some respondents reported that the theatre sessions allocated to LDKTx had been reduced (in one case halved), while others reported that additional theatre sessions had been opened up to enable more LDKTx procedures to take place. It was noted that laparoscopic donation required special surgical equipment and that this could at times impact theatre availability.

Staffing
Views regarding the impact of staffing on the ability for timely LDKTx to take place was similarly mixed, with some hospitals experiencing concerns and some not. Several respondents noted that the surgical skills required to undertake laparoscopic retrieval of living donor kidneys are highly specialised. With few surgeons having the necessary skills, if one surgeon is unavailable this can limit surgery taking place. One respondent described the case of a donor who had planned her donation to take place while she was on annual leave, but because the only surgeon who could perform laparoscopic nephrectomy was on sick leave she opted for an open nephrectomy instead, rather than reschedule the surgery. It was also suggested that a shortage of surgeons has resulted in the need for interstate short term recruitment ('fly in/fly out' arrangements) in some areas, which was considered unsatisfactory.

Hospital funding
Many respondents pointed out the savings to the health system that flow from LDKTx, compared with dialysis. They felt that funding arrangements should recognise this in order to encourage hospitals to perform LDKTx. Some respondents felt that the current funding arrangements did not adequately account for the additional costs associated with more complex procedures such as ABOi transplantations. It was also suggested that there are too many transplanting hospitals within some major cities and that it may be more cost effective to concentrate expertise and resources at one centre.

5.3.6 Post-transplant care of the donor and recipient
Respondents were unanimously of the view that the most important indicator for a successful living organ donation program is the quality of the outcomes for both the recipient and the donor. Furthermore, if the experience of living organ donation was a positive one (supportive, streamlined and free from undue financial burden) then this would serve as a powerful motivator for others to seriously consider living organ donation – ‘Australia has a good process. We need to ensure that we’re doing live donation well, and offering support to both sides of the family. There needs to be a positive experience and outcome for everyone in order for others to want to do it.’

Post-operative support
In general, few concerns were raised about the care provided to the donor and recipient in the post-operative period. Several respondents remarked that donors and recipients can find the recuperation period difficult on a practical level due to being unable to drive, needing to take time off work, and struggling to care for children (particularly in the case of spousal donations). These demands are exacerbated for those who have to travel some distance for the surgery or remain in a capital city for an extended time.

Longer term follow up of donor and recipients
Several respondents argued that optimising care of the recipient post-transplant is an area that requires further attention. Maximising the life of the transplanted kidney would in turn reduce the demand for
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more donor kidneys, and may encourage more people to consider donating because they can see the positive outcomes.

Similarly, a number of respondents felt that clinicians could be better supported to collect the outcome data required for submission to the ANZDATA Living Kidney Donor Registry. Loss to follow-up (which has been reported to be more than 70% 34) was a particular issue, particularly for those donors for whom follow-up is undertaken by a GP in a busy rural practice who has more pressing demands than collecting data from (generally not unwell) past donors.

5.4 Opportunities for improving the living organ donation process – suggestions from stakeholders

This section outlines opportunities to improve the living donation process which were identified by stakeholders. The consultation process identified two broad areas where concerns existed: structural barriers to living donation, and the views and motivation of donors and recipients. Most of the suggested strategies address both of these areas.

In addition to the initiatives identified in the literature review (broadening the pool of potential living donors, financial reimbursement programs, education and awareness-raising), respondents identified two further areas for improvement: increasing capacity/funding and resources and governance. All six are discussed in detail below.

It is important to point out that these suggestions are broadly aimed at optimising the process for living donation rather than at lifting donation rates per se. However, it has been suggested that if the living donation experience is positive, streamlined and rewarding, and that the donor is respected for the gift they are giving, then people may be more inclined to donate. Many respondents emphasised that ensuring donor safety and wellbeing must remain paramount.

Broadening the pool of potential living donors

A number of respondents noted that the pool of potential living donors had already expanded significantly in the last ten years, mostly thanks to the initiatives identified in the literature review:

- Development of ABOi/ transplantation
- Implementation of the paired kidney donation exchange (AKX) program
- Accepting more marginal donors (although this can complicate and slow down the transplantation process).

While the literature review also identified increasing ANDD as a way of broadening the pool of potential living donors, responses to the idea of increasing altruistic donation were mixed. Some respondents noted that altruistic donation rates were higher in other countries (such as the USA and the UK) compared with Australia, and felt that increasing rates of ANDD could be helpful, while most were cautious about altruistic donation and emphasised the need to carefully consider donor motivation.

Recommendations from stakeholders included:

- Continue to support and develop the AKX Program

34 P Clayton. ANZDATA: Update from the living kidney donor registry, 2011.
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- Support innovation in procedures and techniques which will continue to expand options and improve outcomes for donors and recipients
- Consider accepting more marginal donors on a case-by-case basis, where appropriate. For example, one respondent noted that ‘donors older than the Australian average are suitable for living transplants because the older donors’ likely future disease pattern is more predictable than younger donors’
- Increase support for potential/marginal donors who are excluded due to contraindications which may be able to be addressed through lifestyle interventions, e.g. smoking, blood pressure, BMI.

Financial reimbursement programs

Respondents unanimously welcomed the introduction of the Supporting Leave for Living Organ Donors Scheme introduced in July 2013. While several respondents identified socioeconomic status (SES) as a major factor in accessing live organ donation (‘It’s very clear that SES drives access to living donations, but not necessarily to deceased donation’), most believed that the introduction of the scheme would not make a substantial impact on donation rates, but all agreed that it was ‘the right thing to do’. A number of interviewees suggested the scheme did not go far enough, and should be extended to compensate all donors, regardless of their employment status. Suggestions for improving financial reimbursement are discussed below.

Supporting Leave for Living Organ Donors Scheme

- Extend the Supporting Leave for Living Organ Donors Scheme beyond the two-year trial – ‘depending on the donor/recipient situation, some live donations can take up to two years to proceed to transplant’
- Expand the Supporting Leave for Living Organ Donors Scheme to include people not currently in paid employment. This was particularly important since women are more likely than men to be living donors, and also more likely to not be in paid employment, meaning that the scheme does not cover a substantial portion of potential (female) donors.

Medicare

- Implement a Medicare code to enable bulk billing of all medical costs incurred by donors in the course of pursuing donation (GP appointments, specialists, pathology, radiology, cardiology, consultants, etc)
- Medical costs incurred in Australia by donors who live overseas but are donating to a recipient who is eligible for Medicare could be bulk billed through the recipient’s Medicare account.

Direct reimbursement

- Directly reimburse 100% of out-of-pocket costs for all donors, including parking, travel and accommodation costs at all stages
- Consider making reimbursements available to pay upfront costs to minimise the need for donors to outlay funds.

Travel and accommodation

Travel and accommodation were identified as a particular area for improvement, especially for rural/regional and interstate donors. Suggestions included:
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- Implement consistent policies regarding travel and accommodation reimbursements across jurisdictions, including making reimbursements available to donors from interstate. Consider setting up a central ‘clearing house’ to administer travel funding across jurisdictions – ‘Current travel and accommodation subsidy schemes are state-based and most do not extend to cover donor/recipients who may live/travel interstate to donate’

- Consider implementing transport schemes for rural/regional donors to attend clinics/test/appointments during the workup phase, and to travel to transplant centres for surgery.

- Reduce travel costs for rural and regional donors, especially during the workup phase, by increasing the accessibility of local clinical resources (GPs, hospitals, etc).

Education and awareness-raising

A number of respondents identified a need for greater education and awareness regarding living organ donation. This included increasing the general public’s awareness and understanding of LDKTx, educating potential recipients and donors about the benefits and risks of LDKTx, and educating healthcare practitioners.

Two points which were raised as important to the success of education and awareness-raising across all three areas were:

- Ensure information is available in a range of languages, including translating written materials into community languages, and ensuring interpreters are available where necessary

- Fund personnel dedicated to dissemination of information and education regarding LDKTx at all levels (general public, recipients and donors, healthcare professionals).

Suggestions for increasing the general public’s awareness and understanding of LDKTx:

- Publicity campaigns across a range of media (digital, print, television, radio, etc), similar to recent promotion for deceased donation to:
  - Increase awareness of LDKTx in general, and the range of options available, i.e. ABOi and AKX
  - Promote living donation as ‘a gift’ with ‘living donors promoting good outcomes/highlighting successes’
  - Celebrate success of deceased donation but be careful not to give the impression that living donation is no longer required.

Stakeholders emphasised that it is important to provide accurate and realistic information to minimise or counter sensationalist stories in the media.

Suggestions for improving recipient and donor education:

- Produce a standardised set of educational materials which ensure consistent, reliable information is easily accessible:
  - Distribute information via pamphlets in GP offices, Medicare offices, hospitals, and other healthcare settings
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- Ensure information is available on the Department of Health website, with links to relevant personnel at hospitals and other bodies
- Make sure policies on LDKTx (including ANDD) are clearly defined and easily available.
  - Fund education and outreach, particularly to rural and regional areas, Aboriginal communities, and Culturally and Linguistically Diverse communities:
    - ‘Fund staff to run education seminars in rural and regional areas rather than using a centralised approach’
    - ‘Educate Aboriginal Liaison Officers in hospitals on LDKTx and involve them in working with Aboriginal families’.

Respondents noted that increased information about the risks and benefits of living donation will not necessarily lead to an increase in donation rates; however, recipient and donor education is vital from an ethical perspective.

Suggestions for improving knowledge of health professionals:

- Ensure access to good quality, consistent information and resources
- Improve training on living donation through the curriculum for health professional training (including nephrologists, GPs and nurses)
- Enhance opportunities for health professionals to do rotations through hospital transplant units.

Increasing capacity

A number of comments related to increasing the capacity of hospitals and transplant centres to coordinate and perform LDKTx. These fell into four main areas: funding, staffing and training, theatre access, and accessibility/outreach, and are related to a number of key suggestions as discussed above.

Funding

Suggestions for improving funding included:

- Linking funding of transplant centres to per-patient costs
- Implementing direct reimbursement to hospitals to cover the costs of LDKTx – ‘this is a critical incentive’
- Funding transplant units as stand-alone units.

Staffing

One of the key means of increasing capacity identified in the consultations was to increase the number of personnel in key roles at each stage of the LDKTx process, and by ensuring those personnel have appropriate skills and expertise. The following recommendations were made:

- Skilled surgeons – living donor transplantation is a highly specialised area, and there is only a small number of appropriately skilled surgeons in Australia. Respondents emphasised the need to provide opportunities for specialised surgical training, and to consider succession planning in transplant units
- Donor coordinators were identified as key to enabling the living donation process – ‘The most critical resource is the living donor coordinator. The most significant change to capacity was
5. Findings – Consultations with organisational stakeholders

	having one person dedicated to coordinating donations.’ Several interviewees suggested additional funding be allocated to enable the creation of new donor coordination positions.

- Tissue typing specialists – some respondents noted that long wait times for test results could delay the workup process, and recommended increased funding for the ARCBS tissue typing lab ‘to employ staff to provide/increase service required’

- GP training was identified as a potential issue during the workup phase. In addition to educating health professionals about LDKTx discussed earlier, respondents also suggested that additional training could enable GPs to better facilitate the workup process – ‘Many doctors don’t know how to do the work-up. This could be addressed through the training college’

Theatre availability

Some stakeholders suggested that theatre availability could be improved by:

- Increasing targeted funding for transplantation to allow for extra theatre sessions
- Increasing funding to hospitals to alleviate overall pressure on theatre times – ‘Hospitals have to juggle the time they allocate to each priority area – all of the pressures on hospitals contribute’
- Prioritising living donation procedures at a hospital level.

Access to medical professionals and facilities in rural/regional areas

Access to medical professionals and facilities was identified as a key concern in rural and regional areas. Increasing access to these resources would help to reduce the burden on potential donors, particularly during the workup stage where they may need to repeatedly travel long distances to attend clinics and undergo testing.

- Increasing the capacity of rural and regional GPs and hospital staff to conduct aspects of workup and follow-up may reduce the burden of travel on potential donors.
- Increasing the ability of metropolitan-based specialist staff to run clinics in rural and regional areas, by increasing flights and availability of seats with the Royal Flying Doctor Service.

Governance

The need for improved governance in relation to living donation emerged in a number of stakeholder interviews. Areas highlighted for attention included:

- Standardised clinical protocols and guidelines
- Improved communication and collaboration between transplant units
- Standardised funding arrangements (including reimbursement schemes)
- Improved capacity for data collection through ANZDATA, including long-term follow-up of donors
- More timely reporting of data and establishment of minimum performance criteria
- A consistent approach and resources to assist with educating the general public, donors, recipients and health professionals.

There was a lack of consensus among respondents about who could take on this role. Some felt that the remit of the OTA should be expanded to include oversight of living donation, so that living and
5. Findings – Consultations with organisational stakeholders

deceased donations could be treated as part of a ‘holistic and coordinated system’ and not as competing paradigms. Others felt that since the processes involved in coordinating and promoting deceased donation (in particular, those designed to facilitate rapid organ retrieval and transplantation) are very different from those required for living donation, it was not appropriate for the OTA to take on this role.
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6 FINDINGS – CONSULTATIONS WITH PATIENTS, DONORS AND RECIPIENTS

This section presents the findings from consultations held with a sample of living donors, recipients, and patients who are on the waiting list for a deceased donor kidney. These interviews provided a personal and often very intimate perspective on the perceptions, emotions and experiences of living organ donation and transplantation. As such, these findings provide an important contrast to the more detailed analysis of the processes and practicalities of living organ donation presented in Chapter 5.

6.1 Donors

Of the five donors interviewed, all had donated to a close relative (a child, spouse or sibling). One donor had donated to his son via the AKX Program. The donations occurred between 2005 and 2013.

6.1.1 Views and motivations

In all cases, the dominant motivation to donate was a desire to see a loved one who was sick, and struggling on dialysis, become well. Most donors had contemplated donation for as long as their loved one had had kidney problems, so the decision was rarely sudden or rash. That said, some didn't think twice about it:

‘When you love someone it's just what you do - you don't have to think about it.’

‘As a mother you do anything you can for your children.’

‘It wouldn’t have mattered what I heard about being a donor – nothing was going to change my mind’.

Others offered to donate after other family members were ruled out as medically unsuitable.

Most donors reported that the recipient had been reluctant to accept the donation because of fear of putting them at risk. In some cases they had to persuade the recipient to accept the donation. One donor took the initial steps of compatibility testing without the recipient's knowledge, to demonstrate that it was a viable option.

On the whole, donors were happy with the amount of information they received through the hospital about risks and complications. One reported doing a lot of his own research including speaking to experts and scouring the internet. He felt that ‘there is a lot of misinformation out there’ (particularly in relation to complications for donors). While some knew other people who’d donated, none had close personal experience with the process.

In general, the donors’ family members were supportive. A mother who donated to her child reported that her husband (the child’s father) was reluctant because he was ‘terrified that I would become unwell’ as a result of the donation and then he would be responsible for looking after two sick people as well as being the family's sole breadwinner. Others reported that some family members felt ‘squeamish’ about the idea, but in general, respected the courage they had shown in offering to donate.

6.1.2 The workup and donation process

Most donors felt that the workup process was managed well, and that they received a high level of care throughout the donation process. The one exception was a donor who felt that the follow-up care was
6. Findings – Consultations with patients, donors and recipients

suboptimal and explained he had been discharged with inadequate pain relief medication. He commented that 'they really look after the recipient post-op, but for the donor, it's like they've got what they need and they don't really follow up'.

Most of the donors reported being in a fortunate financial position which meant that the decision to donate did not result in significant financial burden. However, most felt that the Supporting Leave for Living Organ Donors Scheme is a positive initiative which may encourage people who are tentatively considering donating to ‘put their hand up’. One donor hypothesised that financial reimbursement may influence a person’s decision to donate to a more distant (rather than a close) relative. She considered that the decision to donate to a close relative (such as a spouse or a child) was a ‘no-brainer’ and that any financial barriers would be overcome.

Regardless of whether or not they felt that the Supporting Leave for Living Organ Donors Scheme would encourage more to donate, they felt that financial support for donors was important. Two interviewees made comparisons with paid maternity leave, arguing that in the case of maternity leave the government provides payment for something that is a common, and generally uncomplicated, personal choice. They felt that since donors are financially disadvantaged in the process of enabling a potentially life-saving transplant (which can also save the government money through cessation of dialysis), they should be entitled to more government support.

6.1.3 Outcomes

All donors reported positive outcomes for themselves and for the recipients. Most reported being physically well and feeling gratified at seeing the improvement in their loved ones’ health:

‘The gains are obvious – you have this life that is waning and you give it vitality.’

‘For us, it's been like a “get out of jail free” card.’

Most donors reported making positive lifestyle changes (e.g. improved diet, reduced alcohol consumption) since donating.

The donors reported that they were encouraged to have annual check-ups following donation, and in most cases the hospital had helped to arrange appointments. One donor admitted that he was overdue for his first annual follow-up appointment: ‘It’s human nature; you feel fine so it’s easy to put it off – it doesn’t seem like a high priority’.

6.2 Recipients

All but one of the five recipients interviewed had been on dialysis before having the transplant. In two cases the donor was a spouse; for the others it was a father, niece and aunt. The recipients felt extremely grateful and fortunate to have found a willing and suitable donor. One explained that he didn’t really think about living donation until there was an ‘active offer’: ‘You don’t ring someone up and say ‘can I have a kidney?’

6.2.1 Views and motivations

Two strong themes emerged through the interviews with recipients. Firstly, recipients spoke of how difficult life was on dialysis (particularly haemodialysis), including the imposition on lifestyle, the ability to
6. Findings – Consultations with patients, donors and recipients

work, the pain and discomfort, and the feeling of dependence on the system. Freedom from dialysis – in particular the ability to live a normal life, and ‘be productive and a taxpayer again’ - were powerful motivators. The second, somewhat opposing theme, was concern for the physical wellbeing of the donor, which in several cases led them to initially decline the donor’s offer:

‘There isn’t anyone I could put through that.’
‘You go in sick and come out well, while the donor goes in well and comes out sick.’

6.2.2 The LDKTx process

The recipients described feelings of anxiety as the donor went through the workup process, desperately hoping that they would be accepted. At the same time, the rigour of the assessment process reassured them that kidney donation would be safe for the donor. The transplant operation was described as a turning point in their lives: ‘The 3rd of August is tattooed on my brain’.

6.2.3 Outcomes

Some of the recipients reported having some ongoing health concerns following the transplant (including infections and medication side-effects) and one was aware that his transplanted kidney ‘would not last forever’. However, all were resoundingly positive about the impact that the surgery had had on their lives:

‘It gave me my life back – we were free to live again.’
‘I feel healthy - I am embracing life.’

6.3 People on the deceased donor waiting list

Interviews were conducted with six patients who were currently on dialysis, awaiting a deceased donor kidney. These individuals provided an important contrast from the donors and recipients interviewed, as they were those for whom LDKTx was a less straightforward decision, either because a living donor was not available, or because they did not wish to ask someone to donate.

6.3.1 Views and motivations

Similar to the recipients, these interviewees described the hardships associated with life on dialysis. The outlined a range of reasons why they did not have a suitable live donor, including:

- The possible donors had occupations that, in their view, would be difficult to maintain with only one kidney (e.g. heavily physical labour; an employment requirement for regular ‘medicals’)
- A reluctance to have a spouse donate due to concern that if they too were to become ill it would be difficult to care for their young children
- A family history of medical problems that reduced the pool of possible donors. One patient had made the decision not to have children for fear of passing on the gene for polycystic kidney disease (PKD) (which he suffered) to them, and several of his relatives also had PKD
- In the case of a patient with PKD, whose son also had the disease, a reluctance to take a kidney from her other (healthy) son in case the son with PKD needed it in the future.
6. Findings – Consultations with patients, donors and recipients

One patient reported having a son who was willing to donate, but said had been informed that he would not have to wait much longer for a deceased kidney so he had told his son to ‘hold on, I might need you later on’. Another explained that he had ‘received the call that a deceased kidney had come in, and to be at the hospital at 5pm’. Later, the hospital phoned him to tell him that the kidney was unsuitable. Despite this disappointment, he was confident that a deceased kidney would come in soon. These perspectives suggest that patients do factor information about the deceased donor waiting list into the decision making process about living donation. Indeed, a number of donors, recipients and patients interviewed felt strongly that more should be done to lift deceased donation rates.

Most of these patients reported having spoken with their doctors about living donation: one reported that ‘the discussions happened to a degree – It was a bit like, “If you know anyone who would like to donate, send them in”, but no-one has put up their hand to donate’. Another reported that her nephrologist had suggested that she ask people to donate, but that she was not comfortable with this approach: ‘people need to have the room to make the offer’. Two patients indicated that they had been inadequately informed of LDKTx as a treatment option: one assumed (incorrectly) that he was too old and therefore ineligible, and another was not informed that he could simultaneously be on the deceased donor waiting list and pursue LDKTx.

Interviewees expressed a range of views about the desirability of going through with LDKTx. At one end of the spectrum patients explained that they would take it up in an instant, with two patients volunteering that they’d offer a cash incentive to a donor: ‘desperate people are prepared to do desperate things’. In contrast, other patients were less comfortable with the idea of living donation:

‘There would be feelings of guilt – my greatest fear would be to accept a kidney and have it reject.’

‘It's my illness and I have to deal with it – I would never blame anyone for not offering.’

Similar to the donors and recipients interviewed, these patients saw value in the Supporting Leave for Living Organ Donors Scheme, although they did not necessarily feel that reimbursement would help them to secure a donor. Indeed, several indicated that they would be prepared to personally compensate a potential donor for any financial burden. Two patients felt that the key financial constraint faced by potential donors was not the time off work required for workup, surgery and recovery, but rather, the perceived potential impact on their ability to keep working in their former occupation with one kidney, particularly if their health was compromised as a result of donating.

6.4 Suggestions for improving the LDKTx process in Australia

Through the consultations with donors, recipients and patients, a number of suggestions were made about ways to improve the LDKTx process in Australia. These largely reflect those raised by the organisational stakeholders (Chapter 5), and include:

- Ensuring that health professionals raise the issue of living organ donation with all patients with ESKD (even those for whom LDKTx may not be a viable option)
- As part of the hospitals’ education and workup process, facilitate access to donors and recipients ‘who’ve been through it and come out the other side’, to reduce the ‘fear of the unknown’. A number of interviewees reported that they had volunteered to take on this role at their transplanting hospital
6. Findings – Consultations with patients, donors and recipients

- Ensuring quality care and follow up of donors, both in the immediate post-operative period and ongoing
- Improving levels of financial compensation for donors (the Supporting Leave for Living Organ Donors Scheme was seen as a good starting point)
- Improving public recognition for those who have donated, in order to increase visibility of living donation.

In addition, many individuals stressed the need to increase rates of deceased donation. Suggestions included having an ‘opt-out’ system for deceased organ donation, removing the ability of a deceased person’s next of kin to override their decision to donate, and boosting public awareness campaigns. For the majority of patients and recipients interviewed, their goal was a kidney transplant, and they did not express a preference for a living rather than deceased kidney donation. Indeed, a number of those interviewed indicated a preference for a deceased kidney because it would mean they could avoid subjecting a loved one to the risk of donation.
7 Synthesis of key findings and opportunities

7 SYNTHESES OF KEY FINDINGS AND OPPORTUNITIES

7.1 Key findings

7.1.1 Living organ donation rates

The decline in rates of living organ donation in Australia since 2008 was the impetus for this review. This decline commenced at about the time that the Australian Government, through the OTA, boosted efforts to increase deceased donation. As outlined in Chapter 2, Australia is doing relatively well by world standards, particularly when kidney transplantation rates are considered in relation to the prevalence of ESRF. Furthermore, as discussed in Chapter 4, there is no clear pattern in terms of the relationship between rates of living and deceased kidney donation in the international experience.

Importantly, stakeholder opinions varied regarding the extent to which they considered the decline in living donation to be problematic. While some strongly felt that living donation had been sidelined due to the OTA's focus on improving deceased organ donation rates, others felt that a reduction in living donation in response to an increase in deceased donation reflected a rational response on the part of donors and recipients. This latter group was also eager to caution that any efforts to improve rates of living donation or overcome 'barriers' may have the unintended effect of lowering safeguards for donors. In light of these concerns, the primary focus of this analysis has been on 'optimising' or 'improving' the process of living organ donation, rather than on strategies to 'improve rates'.

In addition, a number of stakeholders stressed that living organ donation should not be considered in isolation from other approaches to reducing the burden of renal disease in Australia. These include population health interventions to prevent CKD, optimising care for patients on dialysis, and improving rates of deceased donation. Interviews with patients on dialysis (as well as those who had received a living donor transplant) revealed that the key goal for these individuals is to procure a kidney (and whether it is from a living or deceased donor is a secondary consideration). Indeed, most of those interviewed suggested that receiving a deceased donor kidney would be preferable as it would eliminate the need for a living donor to be subjected to any risk. Whilst optimising deceased donation was considered an important goal, there was general acknowledgment that 'there will never be enough deceased donors' to cater for the demand for kidney transplantation.

7.1.2 The kidney donation process

The interviews conducted through this review have reinforced the notion that in terms of the LDKTx process, Australia is doing well by world standards. Australia has very strong donor and recipient outcomes, and achieves high standards of clinical care. Nevertheless, it was felt more could be done to:

- Raise awareness of LDKTx as a treatment option for patients with ESCKD
- Support both donors and recipients through the workup process (including education, coordination and financial assistance)
- Overcoming any resource constraints (staffing, funding etc) that may impact on the transplant surgery taking place in a timely manner
- Improve post-operative support for donors and recipients
- Encourage a stronger commitment to ongoing follow-up of donors to strengthen the evidence base in terms of long-term donor outcomes.
7 Synthesis of key findings and opportunities

7.2 Opportunities

The Literature Review (Chapter 4) uncovered a range of possible barriers to living organ donation, as well as a number of strategies that may have the potential to improve rates of living organ donation. At this stage there is a lack of conclusive evidence for effective interventions to improve living donation rates.

The stakeholders interviewed identified a range of opportunities for optimising living donation in Australia, and these are largely consistent with the issues and themes discussed in the Literature Review. These are summarised in the following sections.

7.2.1 Suggestions for policy and practice

Key recommendations for improving policy and practice in relation to living organ donation include.

- Continuing to support and develop the AKX program
- Supporting clinical innovation to expand options and improve outcomes for donors and recipients (including those considered more marginal)
- Expanding financial reimbursement and support for live donors (the Supporting Leave for Living Organ Donors Scheme was viewed as a positive first step in this regard)
- Developing and ensuring consistent delivery of education and awareness-raising strategies around living donation, targeting:
  - the general public
  - potential donors and recipients (including having access to 'mentors' who are past kidney donors or recipients)
  - health professionals (including nephrologists, GPs and dialysis nurses)
- Increasing health system capacity to undertake LDKTx by addressing funding, staffing and theatre access issues.
- At a national level, improving governance and leadership in relation to living organ donation. This includes:
  - Developing standardised clinical protocols and guidelines
  - Improving communication and collaboration between transplant units
  - Standardising funding arrangements (including reimbursement schemes)
  - Improving capacity for data collection through ANZDATA, including long-term follow-up of donors
  - Ensuring more timely reporting of data and establishment of minimum performance criteria
  - Facilitating a consistent approach to education.

7.2.2 Suggestions for research

In addition to suggestions for improving policy and practice relating to living organ donation in Australia, a number of suggestions for further research have arisen from this review. These include:
7 Synthesis of key findings and opportunities

- Conducting a more granular analysis of LDKTx at the level of jurisdictions/transplant centres to identify variations in funding, policies and clinical practice that may impact on rates of living organ donation
- Supporting the ANZDATA live donor registry in order to build the evidence base around long term outcomes (particularly for donors who are considered marginal)
- Sociological and social biology research into the reasons why people consider living kidney donation (from both the donor and recipient perspectives), and the short- and longer-term psychosocial impacts of these choices
- Developing a better understanding of the characteristics of the potential donor pool, including the numbers who present for donation and the attrition rate during the workup process
- Understanding local public opinion regarding non-directed donation may be useful in determining whether consideration of strategies to increase this potential donor pool is warranted
- Further investigation into variations in access to and rates of LDKTx between population subgroups (particularly Aboriginal and Torres Strait Islander people and socioeconomically disadvantaged groups).

In addition, the planned review of the Supporting Leave for Living Organ Donors Scheme may provide some insight to the extent to which financial considerations act as a barrier to living donation in the Australian context.
8 Conclusions

8 CONCLUSIONS

Chronic Kidney Disease is a significant public health concern in Australia, and the number of people requiring Renal Replacement Therapy is set to increase markedly over the next decade. For ESCKD patients who are suitable candidates for kidney transplantation, LDKTx provides an alternative to DDKTx, provided that a suitable living donor is available. Compared with dialysis, LDKTx has proven highly cost effective.

This project has explored the practice of living organ donation in Australia through a comparative literature review and interviews with a range of stakeholders, including health professionals, academics, representatives from government agencies, advocacy/awareness groups as well as donors, recipients and patients on dialysis. These stakeholders shed light on some of the possible reasons for the decline in rates of living organ donation since 2008, and also provided a rich description of the prevailing attitudes towards living donation in Australia. A clear theme emerging was that in all efforts to optimise living donation rates, the safety and welfare of donors must always be paramount. The review pointed to a number of opportunities to improve the practice of living donation. In many cases, these focused on improving awareness and reducing some of the costs and inconvenience that many donors endure. While most respondents believed that addressing these issues may not substantially lift the rates of living donation, the majority believed that they should be addressed ‘because it is the right thing to do.’

Living organ donation is an ethically complex concept that evokes strong emotional reactions. In conducting this project, we spoke with a diverse range of passionate individuals and heard stories about how living donation can transform lives. We also heard from people who were at pains to point out that there is much that we still don’t know about the longer term impacts, both physical and psychosocial, of LDKTx and that living donation must always be approached with due caution. AHA is grateful to all those who gave generously of their time to contribute to this review.